Carers: provision of support for adult carers

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Age UK	Guideline	General	General	Age UK welcomes the opportunity to comment on the draft NICE guideline on the provision of support for adult carers. There are currently 7.6 million carers in the United Kingdom over the age of 16 and a quarter of those who provide family care are aged 65 or over (Social Market Foundation 2017). Carers make a substantial contribution to the care of their loved ones and society as a whole; the Office for National Statistics (2016) estimate that unpaid carers provided support worth £59.5 billion in 2016 and Carers UK (2015) estimate that the total economic value of contribution made by carers in this country is £132 billion. Carers must not be expected to sacrifice their health and quality of life, yet they are under increasing pressure due to the lack of support available through social services. The latest data shows that within the last year 360,310 carers were either supported or assessed by their local authority (NHS Digital 2018). This represents a decrease of 7 per cent from the 386,600 carers supported in 2015/16 (NHS Digital 2018). More than one in seven carers report that they or those they support received fewer care or support services during the previous year (Carers UK 2018). Since 2014/15, there has been a 24 per cent fall in expenditure on supporting carers from £192 million (NHS Digital 2014-15) to £145m (NHS Digital 2018). Improving practical and emotional support for carers is essential if we are to safeguard the health and wellbeing of individual carers, the people they support and ensuring families and friends can continue to make a sustainable contribution towards the care and support of a loved one.	Thank you for your comment. We are grateful for this information outlining the need for these recommendations. This is useful context for supporting the implementation of the guideline.
Age UK	Guideline	General	General	As we highlighted in Age UK's 2017 response to the scope and initial draft guidelines, we continue to recommend that the guideline should explicitly recognise that many carers are older people themselves, facing their own mix of health and care issues and emphasise the importance of supporting carers to maintain good health and wellbeing.	Thank you for your comment. We are grateful for this information outlining the need for these recommendations. The committee agreed that the guideline had considered the needs of older carers and that the recommendations, though inclusive to all carers, already reflected this throughout. However the committee agreed to add further information into the rationale and impact sections

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				Just under 2 million older people are carers in the UK (Social Market Foundation 2017) and an ageing population combined with reduced access to public services has meant that more and more older people are finding themselves providing care for friends and family. Between 2010/11 and 2015/16, there was a 16.6 per cent increase in the number of older people who provided care to family and friends (Age UK 2017). Nearly two thirds of older carers have a health condition or disability of their own and they are often caring at quite high levels of intensity, particularly those over the age of 80 who are likely to be caring for a co-resident partner. Despite this, many carers are often unable to find a time to rest or look after their own health and care needs. Older carers are more likely to provide longer hours of care than other age groups, with half of carers aged 85 and over providing 50 or more hours per week (Age UK and Carers UK 2015). Carers UK (2017) found that 40% of carers say they haven't had a day off for more than year, despite the detrimental impact on later life, in terms of physical and mental health. In fact, nearly half of carers aged 85 and over providing 20 hours a week or more say they feel anxious or depressed (Age UK and Carers UK 2015), 69% of carers say caring has had an adverse effect on their mental health (Carers Trust), and nearly a third of carers experience feelings of loneliness (Age UK 2017). Maintenance of good health and wellbeing is vital both for the carer themselves and the person they care for and supporting older carers to engage with their own health needs is an important step in supporting their overall wellbeing and preventing it from deteriorating. Age UK have published *Advice for Carers: practical and emotional help when you are looking after someone*, which provides some steps to achieve this, encouraging people to be proactive in managing their own health while also recognising the crucial role GPs can play. It is important to ensure the guideline covers recommendations to support carers to maintain good health and includes measures for promoting resources like the *practical guide*	and to add an example to one of the recommendations about additional support that carers might need as they become older and less able to care. The context section explicitly refers to the high and growing numbers of older carers.

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				which can help carers, particularly when they are starting their new role.	
Age UK	Guideline	General	General	Alongside specific offers for health and wellbeing, many carers face challenging financial situations due to their caring responsibilities. In a recent Carers UK report (Carers UK 2019), they show that just under half of all carers they surveyed cannot afford their bills without struggling financially. Moreover, it is estimated that hundreds of thousands of carers are missing out each year on benefits they are entitled to. When it was last counted, it was estimated that 360,000 carers are missing out on over a billion pounds of Carer's Allowance (Carers UK 2015). The impact of having to worry about finances can be extremely detrimental to a carer's wellbeing and therefore we recommend making sure the document reflects this and strongly states the necessity for adequate financial information and the same time as discussions about being a carer.	Thank you for your suggestion, in response to which the committee agreed to strengthen a recommendation to say that specialist benefits, financial and legal advice should be included in support, advice and information provided by the local authority
Age UK	Guideline	004	010	We recommend the guideline provides advice on caring for someone with dementia. Looking after someone with dementia can bring specific challenges to a carer for which they may need tailored advice and support. Age UK provides some examples of what information may be useful for a carer of someone with dementia here: https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/caring-dementia/	Thank you for your suggestion. The scope of the guideline focussed on adult carers in general, not carers supporting people with specific conditions. The NICE guideline on dementia [NG97] includes recommendations covering the issues you highlight, namely in the section on 'supporting carers'.
Age UK	Guideline	005	012	We would suggest adding in more detail to the guideline to recognise the importance of empowering and involving carers, including through specific recommendations to promote better communication between health and care professionals, carers and the person they care for. Age UK consistently hears about cases where carers are being excluded by health professionals from conversations about a person's care needs, even in the context of carers being central to meeting those needs. On the other hand, we also hear of cases where older people are excluded from conversations, with carers or family members being prioritised.	Thank you for your suggestion, which the committee discussed. However they agreed that the proposed wording was too lengthy and repetitive compared with the version in the draft guideline. They also felt that the principles reflected in your suggested wording are reflected throughout the guideline, especially in terms of the provision of information and advice, promoting the wellbeing of carers and ensuring they are treated as valued members of the team surrounding the cared for person.

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				Promoting formal processes for genuine shared decision-making and training and supporting staff to carry this out would make an important difference to all parties being valued and involved in care, and we feel this is something that should be explicitly addressed in this guideline. We would therefore recommend amending point 1.16 so that the first bullet point reads: *'Provide information and advice for carers (for example about planning and coordinating care) in a way that empowers carers and values their contribution, following formal processes for shared decision-making' while respecting confidentiality'.*	
Age UK	Guideline	007	014	The scope of the guideline should also consider more specifically those carers who care at a distance or do not live with the person they care for because that person lives in a care home. Estimates suggest that around half of carers do not live with the person they care for (NHS Information Centre for Health and Social Care, 2010) and carers in this situation are often overlooked and may not be included in the person's Carer's Assessment or have access to support services. Carers at a distance provide fewer hours of care than co-resident carers and are less likely to provide personal care. However, they are more likely to be combining care with work, childcare and other responsibilities (Carers UK, 2015), and therefore more likely to experience carer stress than co-resident carers. Similarly, carers of individuals living in care homes largely continue in a caring role, contrary to the assumption that once someone has moved into a care home, their family or friend's role as a 'carer' has come to an end. For example, 57 per cent provide support with managing finances and 35 per cent continue to provide personal care. For those carers who care at a distance or for a loved one in a care home, caring commitments can be particularly unpredictable. In addition, carers in this situation are more likely than co-resident carers to report reduced time available for parenting and other caring roles, leisure or holidays, as well as adverse impact on finances and	Thank you for your suggestion and for the information provided. In light of yours and other stakeholder comments, the committee agreed to edit the final version of this recommendation to explain the fact that carers might not always live with the cared for person, for example because they may have moved away or into long term care.

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				increased isolation due to reduced opportunity to stay socially connected. It is therefore crucial that the scope and guideline acknowledge these groups, take their needs into consideration, and do not rely on assumptions about co-resident carers, particularly when it comes to identifying who is playing a caring role. As such, we would recommend adding a sentence to this section '*consideration should be given to those caring at a distance or supporting a loved one who has moved into residential care, given the pressure that continuing caring responsibilities can put on their lives'.*	
Age UK	Guideline	008	021	Caring can have a significant impact on health and we know that carers are not only likely to be living with a long term condition or disability themselves, but are likely to report being in poorer health due to their caring responsibilities. In the most recent Carers UK report (2019), carers who care for 50 hours or more reported poorer health, with 25% reporting bad or very bad physical health and carers who have been caring for 15 years or more also reported poorer health, with 28% describing their physical health as bad or very bad. We recommend the guideline states the importance of reminding a carer of their rights to a needs assessment by reading: *'Offer carers the opportunity to have conversations about their own need as carers separately from the person they are supporting and remind them of their right to a carers needs assessment and how they can access this'.*	Thank you for your suggestion. The committee agreed that you raise an important issue. However they did not make the suggested change because they felt that both points are already covered by the recommendations. For example, at the start of the section on identifying carers, the recommendations reads 'Actively seek to identify carers (in line with the Care Act) and ensure they know about their right to a carers assessment, what it is and the benefits of having one'. In the same section there is a separate recommendation about offering carers the opportunity for confidential conversations about their own needs as carers separately from the person they are supporting. The committee agreed that since these recommendations are made separately this arguably gives them greater emphasis.
Age UK	Guideline	013	019	Recent research by Carers UK (2019) found that the number of carers who were also in paid work is around one is seven - 4.87 million - far higher than previously thought. Given so many carers are also juggling employment, we recommend the guideline states explicitly that most people have the statutory right to request flexible working arrangements to help them fulfil their caring responsibility and the right to time off in an emergency. Age UK provides detailed information on this topic here - https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/im-juggling-work-and-caring/	Thank you for your comment. The committee acknowledge the point being made. These recommendations are in line with existing NICE guidelines on workplace health. The focus of these recommendations is on the flexibilities that workplaces should offer working carers. There is no legal obligation to provide these flexibilities so the committee were unable to draft this as a 'must' recommendation. However, prompted by discussion about your comment, the committee agreed to strengthen the recommendation that 'workplaces 'must' ensure that staff with caring responsibilities have equal access to career development (in line with the Equality Act 2010)'

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Age UK	Guideline	021	019	We fully support the guideline's intention to make clear the importance of continuity of professional care staff to support carers when caring for someone at the end of life, but emphasis should also be placed on access to professional care staff, particularly in the community. Good end of life care for people being cared for in their own home or in a residential care setting requires the input from a wide range of professional care staff in the community, yet the workforce pressures in community based health are clearly visible with the number of district nurses declining sharply (CQC 2018) and the GP workforce unable to keep pace with rising patient demand (NHS Digital 2018). NHS Providers (2018) highlighted that nearly two thirds of trusts providing community services were worried or very worried about maintaining adequate staffing. As a carer of someone nearing the end of their life, the greatest impact can often come from being given a quick response to questions or concerns about changing needs of the person being cared for – particularly if the person deteriorates quickly or is in an unmanageable amount of pain. By being provided with quick advice, a carer has the ability to support the person themselves or arrange support within the community, rather than relying on emergency care. In a recent Carers UK report (2019) 13% of carers felt access to a district nurse would have stopped their loved one having an unplanned emergency admission.	Thank you for your comment. We are grateful for this information and this is useful context for supporting the implementation of the guideline.
Age UK	Guideline	022	007	As is suggested in the guideline already it is really important that any responsibilities attributed to a carer within an individual's advance care plan for the end of their life is discussed with a carer. There is potential for this guideline to be more specific about the need for health and care professionals to ensure a carer feels equipped with the right knowledge and skills to adequately support their loved one at the end of their life. Ensuring this can aide a much better end of life experience for the carer and the individual and reduce the likelihood of a carer feeling overwhelmed or panicked and an unnecessary	Thank you for your comment. Although the committee did not make a specific change to this recommendation in response to your comment they did feel that your important point is adequately addressed by the guideline. For example, the recommendation about giving carers of people at the end of life up to date information about financial, legal and logistical issues and also recommendations about providing support and advice to carers which reflects the stage they are at in their caring experience. Also, that their information needs are revisited as their caring experiences progress.

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				emergency admission for the individual who is dying. In a recent Carers UK report (2019), half of carers said they felt an emergency hospital admission could have been prevented if they'd had more care and support.	
Alzheimer's Society	General	General	General	We are pleased to be able to provide input to the consultation on provision of support for adult carers. Alzheimer's Society welcomes the new NICE guideline on the provision of support for adult carers. We support the recommendations for further action in the areas identified. We believe, based on the experiences of carers we have encountered in our work, that this will help improve the lives of carers of people with dementia. We believe there are additional areas the guideline could consider. These include; ▪ Recognising that improved support for carers can also benefit the health and wellbeing of the person they care for (1.2.2, and other applicable parts of the guideline). ▪ Training in dementia, and the specific challenges faced by carers of people with dementia, should be provided to the role of 'carer champion' (1.1.14; 1.2.11 – 1.2.14; 1.4.2), health and care practitioners (1.3.4) and practitioners (1.3.15). ▪ Flexibility in timing and location of carers assessments should extend to all carers. For those who do not work, challenges such as the needs of the person they care for, a lack of available respite, limited transport options and rurality make attendance at carers assessments more difficult (1.3.9). ▪ Health and social care organisations should explore the use of technology when arranging appointments for carers, assisting those unable to make appointments in person. Challenges noted for section 1.3.9 also apply here (1.4.8). Whilst we are aware that NICE have acknowledged some of the above issues, such as the need to tailor information to carers individual needs and preferences, including accessibility considerations (1.19), we	Thank you for your comment and your support for this guideline. The committee agreed that the benefits of recognising and supporting carers often extends to the person who they are caring for so they edited this recommendation accordingly. The committee also considered your point about a greater emphasis on the needs of carers of people living with dementia. Given the scope of the guideline - on adult carers of people generally - and the focus of the evidence reviews it was not possible for the committee to draft more specific recommendations. However as you highlight, the committee ensured that the guideline promoted the provision of support for carers in such a way that responds to individual needs and circumstances and in a number of places they listed specific examples of reasons carers might require support by certain means and in particular ways. Examples included the condition of the cared for person and the intensity of support provided by the carer. Your point about exploring the use of technology was similarly made by a number of stakeholders and as a result the committee agreed to place greater emphasis on the use of digital technology and social media in the provision of information, support and advice to carers. Finally, although committee members recognise your point about funding for local services and social care more generally, it is beyond the remit of NICE guidelines to comment on health or social care funding. However, the committee did formally reflect on the potential resource implications for this guideline. The committee considered that their recommendations could lead to more carers seeking advice and support, which could lead to a higher demand for carers' support services. However, they also thought their recommendations could

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				believe the guideline could include more specific recommendations in consideration of the areas noted above. Furthermore, Alzheimer's Society welcomes the rationale and recognition of impact of the recommendations in the guideline. In particular, it is encouraging that the elements of the STrAtegies for RelaTives (START) training programme were used to inform recommendation 1.6.4, and that the recommendation for psychological support for carers from the NICE dementia guideline was used to inform, and adapted to shape, recommendations for psychosocial and psychoeducational interventions (1.7.1 - 1.7.4). At the same time, we believe there is a need for recognition in the guideline, or from NICE separately, that realisation of specific recommendations (1.2.11 - 1.2.14; 1.3.14 - 1.3.16; 1.4.1 – 1.4.4), in relation to the guideline's recognition of the potential affect on practice, will require more funding for local support services and social care. Higher demand for carers support services, greater demand for services such as replacement care and carers work-related support services in each area will likely require short and long-term investment in support services and social care. We would also encourage recognition of the need for more investment in support services and social care, to enable carers to undertake opportunities such as training or work-related support.	improve coordination between local authorities and local health and social care organisations in identifying and supporting carers. The committee recognised that providing replacement care could have a resource impact in some areas, dependent on the current availability of services. However, they considered that their recommendations on replacement care were supported by evidence on cost-effectiveness and consistent with the Care Act and a duty for local authorities to promote individual wellbeing, which includes participation in work, education and training. The recommendations do not stipulate the amount of replacement care that should be provided nor that the local authority should necessarily fund this. The committee anticipated that their recommendations would encourage commissioners to develop local markets so that replacement care was available to purchase, whether that be through local authority or self-funding
Alzheimer's Society	Specific Question	Comment Form	N/A	***Q2. What is the effectiveness of personal health and social care budgets in supporting carers to return to work, education or training?*** Alzheimer's Society recognises the potential of personal budgets to provide carers with greater control, flexibility and choice to support them to organise care and support in ways that can help reduce pressure on them, by helping support the person they care for[1], and help them access work, education and/or training opportunities. Direct payments provide greatest flexibility and choice. As these can	Thank you for your comments in support of this research question and which also provide helpful information for implementation of the guideline.

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[1] NHS England (2017) Personal health budgets and Integrated Personalised Commissioning: National expansion plan.

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				be used to employ family members, friends or neighbours, provided they do not reside with the person requiring care and support, they have potential to provide employment for a carer who may otherwise have difficulty balancing work and caring responsibilities. However, we recognise nominal budgets may be more appropriate for some carers. With this in mind, we recommend further work to develop the evidence base for carers using personal health and social care budgets of different forms, and personalised planning, to help them return to work, education and/or training. We consider this to be a valuable step to improving support for carers.	
Alzheimer's Society	Specific Question	Comment Form	N/A	***Q3. What training, support or interventions help to reduce caring-related accidents or incidents?*** Alzheimer's Society is aware of training, support and interventions that help carers feel more supported to provide care. These include; START, developed by University College London; Empowered Conversations training course, developed by University of Salford and Alive Conversations Cards, developed by Alive. Presentations providing more information have been sent alongside this response. We can also facilitate contact between NICE and the respective researchers if requested.	Thank you for your comments in response to this research question and which also provide helpful information for implementation of the guideline.
Alzheimer's Society	Specific Question	Comment Form	N/A	***Q4. What is the effectiveness, cost effectiveness and acceptability of carer passport schemes?*** Alzheimer's Society has worked closely with BT for several work areas relating to helping BT become more dementia-friendly. As identified in our Dementia-friendly Business Guide, BT has a 'carer's passport' scheme. The passport can be completed by any BT employee with caring responsibilities that could impact on their ability to work, now or in the future. The passport describes the form of caring responsibilities and adjustments the individual may need to make, and outlines action to take if they need to leave work suddenly, with agreed communication between the carer and BT should they be unable to attend work. We can facilitate contact between NICE and relevant contacts at BT if required to discuss evidence of effectiveness, cost	Thank you for your comments in support of this research question and which also provide helpful information for implementation of the guideline.

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				effectiveness and acceptability which BT may have collected. Around 40% of family carers of people with dementia have clinically significant depression or anxiety.[2] Activities associated with social prescribing, including arts, nature and physical activities, can help carers connect with others and have the potential to help alleviate symptoms of conditions carers can experience, such as those noted above. Provision of a link worker through social prescribing can also help, facilitating a person-centred conversation which can signpost carers to services to address other needs they may have.[3] Carers can also benefit from the use of social prescribing to support the person they care for. This can provide opportunities to enjoy activities together and/or for carers to have time to undertake their own activities and connect with others, knowing the person they care for is engaged in an activity of their own. We believe the earlier carers access social prescribing, the greater the chance of cost-effective outcomes, due to the prevention or help for illnesses and/or conditions carers can experience. Consequently, we recommend wider provision of social prescribing for carers. The Dementia Choices Action Network (DCAN), a joint initiative between NHS England and Alzheimer's Society, can help explore areas with less evidence, and is conducting an initial review of social prescribing and dementia, including evidence and impact. This review will report findings in November 2019. Next steps may include consideration of areas in which gaps in evidence exist. We welcome engagement with NICE as part of the activity of DCAN, and we can provide an update on this work if it would be of interest.	

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[2] Livingston, G. et al. (2013) 'Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomised controlled trial'.
[3] NHS England (2019) Social prescribing and community-based support: Summary guide.

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Bolton Carers Support	Guideline	001	009	We are concerned that only including adult carers who care for someone over the age of 16 will exclude those people caring for a child eg) parent carers who also require and should be entitled to the same amount of support.	Thank you for your comment. The scope of the guideline was informed by the original referral from the Department of Health and Social Care and agreed through consultation. It cannot be changed at this stage. Carers of people under 16 are likely to have additional specific needs that would be better covered in a more specific guideline.
Bournemouth, Christchurch and Poole Council	Guideline	006	019	We are concerned that due to competing demands within the workplace, having enough time to discuss information is not always possible.	Thank you for your comment. The committee decided not to make any changes to this recommendation because the emphasis is on practitioners whose responsibility it is to provide information. As the provision of information to carers is a statutory duty on the part of local authorities (Care Act 2014) then this recommendation should not have a significant resource impact.
Bournemouth, Christchurch and Poole Council	Guideline	008	006	Local carers are clear they expect GP's to understand they are carers and signpost them to support	Thank you for this information. It is encouraging to hear that carers in your local area already see GPs as a source of support. However evidence reviewed for this guideline demonstrated that this isn't the case throughout the country and the committee therefore drafted a recommendation to address this issue.
Bournemouth, Christchurch and Poole Council	Guideline	008	008	This will only be possible if the person remembers and recognises they need support.	Thank you for your comment. The committee accept the point you make but feel it is addressed by the guideline because there are a number of other recommendations in this section about the range of ways in which carers might be identified and be supported to identify themselves as carers. For example, one of the opening recommendations on 'identifying carers' states that every opportunity should be taken to identify carers, including GP appointments, flu jab appointments, social care and other needs assessments and home visits.
Bournemouth, Christchurch and Poole Council	Guideline	009	004	Our strategic partnership invested in a six-month marketing campaign. This approach demonstrated how hard it was to identify carers, and other investment methods have been more successful.	Thank you for this information. The committee hopes that this guideline will support the identification of carers and in turn the provision of information and support.
Bournemouth, Christchurch and Poole Council	Guideline	009	011	There needs to be further clarity on the size of the organisations cited as having a 'carers champion' and the operational level of the champion. Our experience of carers leads in GP surgeries is that the role is allocated to them, often on top of their usual duties. They may be working at different levels from receptionist to district nurse. This can impact on their effectiveness within the organisation.	Thank you for your comment. Partly in view of the complications you identify, this recommendation was only drafted as a 'consider' recommendation, which in NICE terms has less strength than other recommendations using language such as 'should' or 'must'. In the final version of this recommendation, the committee edited it slightly to say that carers champions would 'help' implement the recommendations in

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					this guideline, reflecting the fact that no one individual should be solely expected to implement the Care Act in relation to carers and the recommendations in this guideline. Finally, the committee edited another related recommendation which in part addresses your point. Instead of recommending that GP surgeries nominate a surgery-based champion, the committee agreed to say that nominating carer champions was one way that primary care providers and primary care networks could promote services to carers.
Bournemouth, Christchurch and Poole Council	Guideline	012	012	The capacity of the current care market workforce makes this provision challenging.	Thank you for your comment. The Rationale and Impact section notes that there may be a need to develop local markets so that replacement care is available to purchase, through either local authority or self-funding.
Bournemouth, Christchurch and Poole Council	Guideline	013	024	Flexible working arrangements may be more of a challenge for SME's and may need incentivising.	Thank you for your comment. Whilst the committee accept the point being made it is not within the remit of a NICE guideline to incentivise firms. Furthermore, there are statutory rights with respect to flexible working arrangements which exist independently of the recommendations of this NICE guideline.
Bournemouth, Christchurch and Poole Council	Guideline	014	005	Flexible appointments may need to be considered for the cared for person, so the carer does not need to use annual leave to support them to attend appointments.	Thank you for this suggestion. We have amended the recommendation to include the cared for person.
Bournemouth, Christchurch and Poole Council	Guideline	014	016	The capacity of the care market workforce needs to be able to support this.	Thank you for your comment. The Rationale and Impact section of the guideline notes that there may be a need to develop local markets so that replacement care is available to purchase through either local authority or self-funding.
Bournemouth, Christchurch and Poole Council	Guideline	017	019	There is evidence that digital and assistive technology is underused. There needs to be wider promotion and availability at no cost to carers, in order to encourage take-up to help carers remain in work or to have a break.	Thank you for your comment. We agree about the importance of promoting this technology. This recommendation reflects the evidence we found, and we hope that our recommendation will promote more uptake.
Bournemouth, Christchurch and Poole Council	Guideline	019	003	Local evidence suggests that carers can be reluctant to think ahead and may interpret advice as being more directive than is intended. They need to be encouraged to explore options and prepare, so they are ready to implement them before the point of crisis.	Thank you for your comment. We hope the recommendations in the guideline will help practitioners support carers in thinking ahead, focusing on their own needs and preparing for changes in their caring role.

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Bournemouth, Christchurch and Poole Council	Guideline	030	017	Assessing and supporting carers needs to be built into professional qualification training. The focus of the training is predominantly on the vulnerable person or patient and they are not well prepared for interaction, assessment or support for the family around them.	Thank you for your comment. Your points are supported by the evidence we identified. As a result the recommendations in the section on 'assessing carers needs' now state that health and social care organisations should ensure the relevant staff have the training, skills and goals to do this.
Bournemouth, Christchurch and Poole Council	Guideline	031	021	Local carers tell us that assessment should always lead to an improvement in their situation, this does not necessarily mean allocation of resources, but may be recognition of their value.	Thank you for your comment. The committee agreed with this, and we have added more details on what carers should be able to expect following a carers assessment.
Bournemouth, Christchurch and Poole Council	Guideline	032	029	Whilst there may be economic benefits to increased levels of carers support these are longer term. The immediate costs of this would need to be offset with the organisation or individual before the benefits would be realised.	Thank you for your comment. The point about immediate costs is a fair one although applies to many NICE recommendations which depend on resources being available for their implementation.
Bournemouth, Christchurch and Poole Council	Guideline	035	017	To release the economic gains from increased labour market participation there needs to be investment in making the care available before this is realised. This would require front loaded investment and care workforce availability.	Thank you for your comment. We agree that the gains from increased labour market participation are contingent on replacement care being provided (through front loaded investment and care workforce availability) It is not within the remit of NICE guidelines to address workforce capacity directly but we would anticipate that implementation of the guideline would have a positive impact on workforce capacity over time.
Bournemouth, Christchurch and Poole Council	Guideline	036	005	Developing local markets for replacement care will only be possible with workforce capacity. This may be feasible through a range of options for this being explored. Workforce capacity for traditional replacement care is a national challenge, so there needs to be other means explored nationally.	Thank you for your comment. It is not within the remit of NICE guidelines to directly to address workforce capacity directly but we would anticipate that implementation of the guideline would have a positive impact on workforce capacity over time.
Bournemouth, Christchurch and Poole Council	Guideline	037	016	We note the committee prioritised carers' passports for future research. We launched a Carers Card four years ago, it is featured on Carers UK Carers Passport website. We would be happy to participate in any future research.	Thank you for your comment and bringing this project to our attention.
Bournemouth, Christchurch and Poole Council	Guideline	037	019	Local evidence suggests that many carers are unable, or do not want, to leave the person they care for, so in order for them to have a break, the cared for person needs to be present, or their needs accommodated in a way they and the carer find acceptable.	Thank you for your comment. Your points compliment the views and experiences of the guideline committee - and this should be covered by the recommendation specifying that the form a break should take will 'meet the specific needs of each carer'

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Bournemouth, Christchurch and Poole Council	Specific Question	Comment Form	N/A	***Q. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why?*** A. Enabling carers to return to, start, or remain in work, education and training. This requires resources, which practitioners have limited access to as a result of the financial pressures facing Local Authorities. It also requires the availability of replacement care in the quantity, and at the time, to make the aspiration possible.	Thank you for your response to this question which is helpful for implementation of the guideline. The committee recognised that providing replacement care could have a resource impact in some areas, dependent on the current availability of services. However, they considered that their recommendations on replacement care were supported by evidence on cost-effectiveness and consistent with the Care Act and a duty for local authorities to promote individual wellbeing, which includes participation in work, education and training. The recommendations do not stipulate the amount of replacement care that should be provided nor that the local authority should necessarily fund this. The committee anticipated that their recommendations would encourage commissioners to develop local markets so that replacement care was available to purchase, whether that be through local authority or self-funding
Bournemouth, Christchurch and Poole Council	Specific Question	Comment Form	N/A	***Q. Would implementation of any of the draft recommendations have significant cost implications?*** A. The provision of replacement care as there is not the capacity in the market. Due to this, a vulnerable person without a carer will be prioritised over a vulnerable person with a carer. In addition to this, the person in receipt of the replacement care, or other family members, can be unwilling to pay the cost of the when they would prefer to receive, or have provided, the care from the unpaid carer, thus preventing the carer from having the support.	Thank you for your response to this question which is helpful for implementation of the guideline. The committee considered that their recommendations would encourage commissioners to develop local markets so that replacement care is available to purchase, through either local authority or self-funding.
Bournemouth, Christchurch and Poole Council	Specific Question	Comment Form	N/A	***Q. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)*** A. An improved range of options such as residential homes having day care/replacement care facilities away from traditional times. Staffing	Thank you for your response to this question which is helpful for implementation of the guideline.

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				and cost would still need addressing for carers to use this to remain in, or return to work.	
British Association of Social Workers	Guideline	General	General	BASW England welcomes the NICE draft guideline on Carers: provision of support for adult carers consultation. After consultation with our membership (and dialogue with service-users and other key stakeholders), our full response is as follows: The 'Supporting Adult Carers' draft guideline is a comprehensive and informative document. However, it has a limited of recognition of the key decisions about whether and how local authorities meet needs, and also the role that social workers play in the decision-making process. There is no reference to eligibility criteria, nor the critical decisions made within the support planning process about the sufficiency of the personal budget. This partial representation of the process of identifying and meeting needs is exemplified in the statement on page 47: "The Care Act 2014 gives unpaid carers specific rights to personal budgets, direct payments, information and advice, assessment and support to maintain their health and wellbeing". But this needs to more accurately detailed for the following reasons: 1. Carers do have a right to assessment in most circumstances. 2. They do not have a right to support unless the carers have eligible needs that the local authority has a duty to meet. 3. The right to individual information and advice mostly only applies to support needs that do not meet the eligibility criteria. 4. The local authority must set out a personal budget for carers whose needs meet the eligibility criteria. This may or may not be wholly or partly funded by the local authority. 5. A direct payment must be offered to individuals unless their circumstances are such that it cannot be offered. An individual cannot	Thank you for your support for this guideline and for your detailed consideration of the recommendations and other guideline documents. We have been clearer in the guideline that not all carers might want or need a formal assessment and have also noted that some support will be means tested and is subject to eligibility criteria. We have also added a covering note to the guideline that it should be read alongside the Care Act 2014 statutory guidance which provide the level of detail you describe. The scope of the guideline did not cover detailed guidance about local authority administration arrangements for personal budgets and direct payments.

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				receive a direct payment unless a) a personal budget has been determined and b) this will be funded wholly or partly by a local authority.	
British Association of Social Workers	Guideline	General	General	Other general comments from our members were: • This guideline is needed, but it requires considerable revision. • The role of social workers is not mentioned, and it is not clear that the understanding of who 'health and social care practitioners' are is accurate or defined. Do the writers of the paper understand the difference between a social care worker (not on a register, not a 'professional practitioner') and a social worker (a registered professional practitioner)? I think not! It is important that this distinction is made. • The most importance aspect for supporting carers is to ensure that they receive information about what can help them, and that it is made clear where they can go to receive this information. The paper does not state this. • Age UK and the CAB, could be designated as providers of information. • The paper does not make it clear who will do assessments of needs. • The recommendations need a clear summary at the beginning and end. • The paper is too long and detailed with endless lists and so it lacks clarity. • Greater prominence should be given to consulting the 'cared-for' about involving any carer and certainly sharing any information with them. • There appears to be no mention of considering the mental capacity of the carer.	Thank you for your comments. • Please be assured that the guideline committee is clear about the difference between care workers and social workers. Where reference is made in the guideline to 'health and social care practitioners', this is deliberately designed to apply broadly, so that any practitioner working with the carer ensures the recommendation is implemented. It reflects the fact that services are configured differently across the country and that people working with carers in the same circumstances might have different roles or different job titles depending on geographical location. • The provision of information to carers is acknowledged in the guideline as critically important and the recommendations are drafted in such a way as to reflect that while it may not be a social workers' responsibility to provide that information, their role is in signposting to relevant services, for instance for advice and information on welfare and benefits or on education and employment. • In terms of who conducts carers assessment, the recommendations are clear that the statutory responsibility lies with the local authority but that they might delegate the conduct of the assessment to social care organisations. It is therefore social care and health practitioners who will be carrying them out either as part of, or on behalf of the local authority. • Some recommendations do include lists of examples in order to support the implementation of the recommendation, helping practitioners to consider a range of possibilities or options. Nevertheless, in light of yours and other stakeholder comments, some of those lists have been removed from the final guideline, which is intended to make the recommendations more succinct.

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				• There appears to be no reference to managing any conflict of views between two carers. • There appears to be no reference to managing a conflict of views between the cared-for and the carer. • There appears to be no reference to the right of the carer to have an independent advocate.	• Although there is no specific reference to the mental capacity of the carer - since relevant data were not located in the evidence reviews - the recommendations do emphasise the importance of assessing and reviewing the carers' willingness and ability to support the carer for person. • There are no recommendations specifically relating to conflict resolution because this was not an area of focus for any of the evidence reviews and not a key area of the scope. Nevertheless, in the section of the guideline about psychological support for carers, your point is, to some extent, addressed by the recommendation that this kind of support should include training in communication skills, training to help carers understand and respond to changes in mood and behaviour and the development of personalised strategies. • In relation to advocacy, the recommendations specify that carers must be given information about accessing advocacy support services and a new recommendation has been included in the final guideline about the duty to provide an advocate.
British Association of Social Workers	Guideline	033-035	General	We would also like to make the point that waiting times for Carers' Assessments can vary. In many cases, a hospital social worker's referral for a Carers' Assessment to community teams can often elicit a response of "we will put them on our waiting list, unless it is an emergency situation." Emergencies may include a request for care for someone going home from hospital, but support for a carer may be just as vital as a patient's direct care. Any referral that is generated because someone having been in hospital now needs care, thereby turning a family member into a carer (a role they may not have had before) if not an emergency, can very often be urgent. There are implications for organisations around advising on factors with which they are not familiar e.g. and especially, work, education and training. This is not really pursued in the guidelines in terms of	Thank you for your comments. We intend that our recommendations will encourage better practice regarding carers assessments. With our recommendations the committee aimed to encourage services to do them in a timely fashion while outlining the benefits of this to all parties. With regards to education and training, our guidelines are a reflection of the what the evidence suggests is needed by carers. We have made the strongest recommendations we can based on the evidence available, with the intention that it will encourage services to find better modes of practice.

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				how it might be achieved. There are training implications in this respect as well as generally, and also for training trainers to provide training to carers. There is also the issue of convincing workplaces and education institutions of the importance of helping carers to fit in their caring responsibilities with their employment/education role. This refers to both carers' current work/education and their adaptability. This is partly acknowledged in principle on pages 33, 34 & 35. Although we agree with the principle, the idea of the cost of replacement care etc for the person being cared for being offset by the value of employers retaining workforce is a concern. There appears to a gulf between the needs of private enterprise and social care needs.	
British Association of Social Workers	Guideline	044-045	General	In reference to pages 44 & 45, it is important to recognise the caring role is just as vital in the community, as it is in care home settings. Therefore, recognition of the importance of Carer's Assessments is essential. They may not always be viewed as a top priority, but it is undeniable they have needs and we have a moral duty to assess and support them. We hope this feedback is helpful and received in the constructive spirit with which it is intended.	Thank you for your comment. The committee agree with the point raised. In response to similar comments from other stakeholders we have increased the emphasis in the opening section of this guideline on valuing the contribution of carers wherever they are.
British Association of Social Workers	Guideline	011	026-027	The support plan appears to be only one of a range of options for meeting needs, as follows: "1.3.13 Ensure there are clearly identified outcomes for the carer following assessment, for example: • arrangements for replacement care to allow the carer to work or attend to education or training. • a carer's break. • a one-off direct payment. • a carer's support plan. • carer training. • further information and advice."	Thank you for your comment. As a result of a number of stakeholder comments this recommendation has been substantially revised and new recommendations added. The recommendations no longer list examples of clearly identified outcomes for the carer assessment but a new recommendation notes that a carers support plan might be an outcome of a carers assessment and, if so, that it should be monitored and reviewed on an on-going basis. This is in its own section now called 'after an assessment'.

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				Of course, each of these outcomes would be included within the support plan. Also, direct payments can be ongoing. As a consequence of these inaccuracies and the way the process is referred to, no reference is made to the important role of practitioners in making professional judgements and how this impacts on how needs are met. Also, the way that the process is framed results in little attention being given to prevention, and under met and unmet need.	
Cambridgeshire and Peterborough NHS Foundation Trust	Guideline	007	008-013	Should also include supporting carers enables them to provide the best possible support to their loved one	Thank you for your suggestion. The committee revised this recommendation to emphasise that the benefits of identifying and recognising carers include ensuring their own needs can be addressed and sharing valuable knowledge so that the right care and support can be delivered to the cared for person.
Cambridgeshire and Peterborough NHS Foundation Trust	Guideline	016	014	I would suggest it being retitled 'Carer training AND SUPPORT programmes', which better reflects the needs of carers.	Thank you for your comment. This section specifically addresses training and other sections address support for carers and therefore we have not amended the heading in line with your suggestion.
Cambridgeshire and Peterborough NHS Foundation Trust	Guideline	016	022	Add an additional bullet point 'enable carers to support entire loved one's recovery and/or health needs'	Thanks for your comment, we agree this is important but the committee felt it was sufficiently covered by the bullet point about "carers' circumstances, including the health condition, disability or needs of the person they care for".
Cambridgeshire and Peterborough NHS Foundation Trust	Guideline	018	001-003	This ss a bit weak for me - I really think there should be a responsibility to enable support groups, so I would suggest an additional bullet 1.6.10 'enable support groups facilitated by an appropriately qualified person'	Thank you for your comment. The committee did not feel there was enough evidence to make a strong recommendation that service providers put resources into a facilitator for ongoing groups. However the committee do feel it is important to enable the development of support groups, and feel that it is covered by this recommendation.
Carers First	Guideline	General	General	Carers FIRST has coproduced this feedback with Carers and our staff. Overall Carers and staff thought the document was excellent and covered everything to support the carer in their caring role and support staff to get Carers recognised and valued by health and social care professional. All comments received were positive about the document and it intentions, "the impact upon carers is finally being recognised across all areas",	Thank you for your comments and your support for the guideline. Thanks also for your efforts in collating and reporting feedback from colleagues and from carers. You raise one area which you believe could be strengthened and the committee agreed with this point. In response they edited a recommendation to say that information and emotional and practical support should be provided to carers when their circumstances change, for example when they transition from being a young carer. Finally, thank you for letting us know that some carers

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				"It will make it easier for carers to deal with health professional and get the support they need". There was some concern about how it would be implemented and would budgets allow for it to be implemented particularly with the replacement care offer. Mental health carers feedback that that being signposted early in their caring role to support networks reduced the impact on their own mental health. They were pleased that carers mental health had been thought about and best practice in dealing with this had been considered. Staff working with end of life Carers said, this section sums it up completely. It supports the carer in their caring role and acknowledges the guilt they may feel for thinking about themselves. Staff had confidence that the document is best practice due to the amount of research that had taken place and re- enforces our current work and partnership working with health. Carers First staff member working on the Employment for Carers project feedback that it will support carers in their caring role because it is laying out guidelines that we would potentially have to deliver and be accountable for. We are running a pilot employment project already and so are working with some organisations like Carers UK, EfC and EveryOne (local Lincolnshire organisation) and providing information and support to carers already. It is reinforcing the need for closer team working to ensure there is a better understanding of all a service has to offer. It is pleasing to see that the unique offer we have given through the Employment project about Carers understanding their transferrable skills is reflected in this document multiple times. Having now had the opportunity to work through a workshop and 1:1s with the handbook I have developed I can say I see a difference in carers when they feel	found the guideline difficult to read. This is important feedback and will be passed on to the editorial team.

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				that their role is recognised and provides them with good CV / Interview opportunities. What is missing from this section is not enough emphasis on the YAC offer, including transition into adult services, structure, processes that are easy to work with, preventing duplication and allowing engagement to continue Carers found the guidance difficult to read but staff said they found it easy to read and commented it relies on the reader having a computer and the skills to know to open and close additional information in links. If it was in a paper format, it would be enormous. The wording is clear, and once completed, a summary could be made which was carer friendly	
Carers in Hertfordshire	Guideline	General	General	Carers in Hertfordshire supports the recommendations contained within the draft Guideline document as they reflect what carers of adults tell us is important to them and indeed what they expect from the Care Act 2014. We have some detailed comments which we will include below but as general comments note that (a) there is no reference to carers who are managing more than one caring role, e.g. caring for a parent with dementia and a disabled adult spouse/adult son or daughter – an issue here is to ensure clarity about which social care team/agency leads on undertaking the Carer Assessment and commissioning any support required to avoid the carer being referred backwards and forwards between agencies (a not uncommon experience); (b) there is no reference to carers who have a caring role for an adult who lives outside their own social services local authority area – this may, for example, be a elderly parent living in their own home. Present practice requires the local authority where the cared for person lives to undertake any Carers Assessment. We consider that it would be more	Thank you for your support for the guideline. We have made some amendments to the recommendations to include reference to carers who are caring for more than one person. We have also included reference to carers who do not live with the person they care for but we were unable to go into the specific detail about how assessment and support is arranged and coordinated when the carer and the cared for person live in different local authority areas. We understand that local authorities will deal with this in different ways depending on local arrangements. In terms of where the carers assessment is conducted, the committee did not review any evidence about this and therefore felt unable to draft a recommendation specifically on the point you make. The committee included a recommendation for local authorities (and social care organisations delegated by local authorities) to conduct carers assessments in accordance with the Care Act and associated statutory guidance, which in reality allows for the current local variation according to structures and preferences. Although the Care Act itself is clear that carers assessments should take place where the carer is ordinarily resident, the statutory guidance allows greater flexibility in

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				practical for the carer's local social services authority to undertake the assessment as they will be better placed to refer to local support and services across all sectors. We also note that different social services authorities use different carers assessment forms and have different approaches to undertaking an assessment. (c) this Guidance is aimed at adults caring for adults and young people aged 16 years or older, it would be helpful to know whether NICE will prepare similar Guidelines for adults caring for a child/young person under 16 years and for young carers. one barrier to carer identification is the ongoing confusion between unpaid carer and professional care worker and the term carer is used interchangeably. It would be helpful if more emphasis could be placed on using the term care worker where appropriate.	terms of which authority (the carer's or the cared for person's) conducts the assessment and has responsibility for providing any resulting support – or indeed they may decide to share that responsibility. The important point and the one which the committee felt they had the basis to make was the carer's entitlement to an assessment of their own support needs. At present there is no guideline referral for adults caring for a child/ young person under 16 years of age or for young carers. Finally, the committee were aware that there is sometimes confusion between the terms 'carer' (for unpaid carer) and care worker. For this reason they were careful never to use the two interchangeably. The term care worker was not used at all in the guideline because it was not relevant to the recommendations. The term 'carer' is specifically defined in the 'terms used in this guideline'.
Carers in Hertfordshire	Guideline	004 005	005-009 006-009	We support these recommendations but note that this will require regular and ongoing carer awareness training – particularly for healthcare professionals – together with opportunities for networking so that practitioners are fully aware of the range of support/services provided by the all sectors. Carers in Hertfordshire has a 'Carer Trainer Unit' which recruits and trains carers to deliver carer awareness training to professionals in health and social care services and to support other training programmes. We would be pleased to share our experiences with NICE – contact roma.mills@carersinherts.org.uk. We further note that collating and maintaining a local authority wide information library is challenging , Carers in Hertfordshire supports 16 Carer Hubs (support groups) across Hertfordshire, these and similar Hubs in other areas could provide such a library service (online and hard copy) on a more local level. Again we would be pleased to share our experiences of setting up and sustaining this groups with NICE – contact roma.mills@carersinherts.org.uk.	Thank you for your support for these recommendations. The committee were in agreement with you about the importance of practitioners having skills and awareness about carers and their potential support and information needs. There was not a specific review question about training for practitioners but the committee were nevertheless able to recommend that practitioners responsible for providing and discussing information with carers should have the knowledge, time and communication skills to do so. They also recommended that practitioners carrying out carers assessments have the necessary skills, knowledge and understanding of potential opportunities for returning to, or remaining in work, education and training. These things are likely to require ongoing or refresher training, including through continuing professional development but the committee did not feel they had the basis on which to stipulate how practitioners acquire or maintain necessary skills, allowing local, organisational discretion about how this should be achieved.

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					Thank you also for your offer of information to support the implementation of this guideline. We would encourage you to share your experiences by submitting them via a case study to the NICE shared learning database https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies
Carers in Hertfordshire	Guideline	005	014	This should also include specific information that carers need to enable them to remain safe in their caring role. Being safe is an issue that carers are raising in relation to a number of different caring circumstances – where someone with dementia or autism is behaving in a challenging or aggressive way, where someone with mental health issues is becoming unwell, where someone with drug and/or alcohol issues is behaving in a threatening manner towards family members. Carers in Hertfordshire is c urrently working with Hertfordshire County Council and health colleagues on developing a training session and resources to help carers keep safe.	Thank you for your suggestion. The committee recognised the importance of your point and added a new bullet to the recommendation, stating that carers should be given specific information to enable them to remain safe in their caring role.
Carers in Hertfordshire	Guideline	006	017	In addition to being consistent and coherent, the information also needs to be up-to-date.	Thank you for your suggestion. The importance of information being up to date is actually emphasised in one of the earliest recommendations in the guideline so the committee are content that point is made.
Carers in Hertfordshire	Guideline	007	009-010	A further benefit for the carer is that they can be provided with information, training and support to enable them to continue with their caring role (if they so wish) safely and effectively and maintain their own well-being.	Thank you for your comment. As a result of yours and other stakeholder comments this recommendation has been edited to emphasise that one of the benefits of identifying and recognising carers is that their own support needs can be addressed.
Carers in Hertfordshire	Guideline	008	018-020	Practitioners should actively seek to identify carers and involve them in the assessments and planning that is being undertaken – particularly discharge planning. Carers have often raised issues about a relative or friend being discharged from hospital without their involvement in agreeing a care plan or any assessment of the suitability of the home environment. Carers have also suggested that an assessment of a person's entitlement to Continuing Healthcare Funding should take place as part of the discharge planning process.	Thank you for your comment. The committee did not make any specific changes in light of your suggestions because they felt that the point about involving carers as key members of the team supporting the cared for person is already adequately made in the guideline. Recommendations also emphasise the benefits of identifying carers so that they can share valuable knowledge about the cared for person, helping practitioners to provide the right care and support. Specifically in relation to involvement in discharge planning, the committee felt this

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					was addressed through signposting to the NICE guideline with transitions between hospital and home as its specific remit [NG27].
Carers in Hertfordshire	Guideline	009	002-008	Social media should be included in the list of tools/services that Health and Social Care organisations can use to encourage people to identify as carers. Facebook, Twitter, Instagram etc. are becoming increasing used for sharing information and communicating within groups.	Thank you for your comment. In response to yours and other stakeholder comments the committee agreed to place a greater emphasis on the use of digital technology and communication. For example, the recommendation that health and social care organisations should encourage people to recognise their role and rights as carers through (a number of means including) digital communications, social media and online forums that engage with carers. There are other relevant reference including a recommendation to making information available to carers in a range formats now includes as examples 'links to online and digital resources (including local and national websites and forums and social media)'.
Carers in Hertfordshire	Guideline	009	017-019	This has workforce training implications.	Thank you for your comment. The committee did not make any changes because the recommendation simply states a statutory obligation on the part of the local authority. Therefore training in this area should not have any additional resource implications.
Carers in Hertfordshire	Guideline	010	011-012	We have not seen any evidence of health and social care practitioners working together or contributing individually to Carers Assessments – we are only aware of this being carried out by a social care practitioner. Clearly this would have implications for health care practitioners' workloads.	Thank you for your comment. The committee hope that their recommendations will promote this working together
Carers in Hertfordshire	Guideline	011	001-003	The default position should be that the carer is offered a separate assessment and that this should only be linked to the assessment of the person cared for where there are good reasons to do so.	Thank you for your comment. We have amended this recommendation to reflect that the carers assessment should be jointly produced with the carer and to recognise that there may be occasions when this should be linked to the assessment of the cared for person (with the consent of both parties).
Carers in Hertfordshire	Guideline	011	016	Carers' assessments should be carer-centred – the carer may need support and guidance in considering their own needs and possible solutions to challenges and problems. There is some concern that 'carer-led' may be less effective where a carer has not considered their own needs or what they might do to meet them.	Thank you for your comment. The guideline has recommendations about practitioners being skilled in assessments, covering all health and social care needs. A carer-centred assessment does not require any expertise but acknowledges they may have valuable expertise from experience and that the assessment is intended to promote carer wellbeing.

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Carers in Hertfordshire	Guideline	012	009-012	See comment 12 above.	Thank you for your comment. Unfortunately we were unable to respond to this as we were unsure what issue you were raising.
Carers in Hertfordshire	Guideline	013	011-014	While organisations employing less than 10 workers are unlikely to have the resource to appoint a Carer Champion, it would be useful to promote this as good practice to organisations with a workforce above a minimum defined level.	Thank you for this suggestion. We have amended the recommendation to refer to "nominating" rather than "appointing" a carer champion to make it clearer that this need not be a funded position.
Carers in Hertfordshire	Guideline	013 014	019-025 001-004	Very welcome recommendations but how can employers be required to offer supportive and flexible working arrangements and equality in terms of career development – this may be considered good practice, but it is not enforceable.	Thank you for your comment. Whilst NICE guidance does not require employers to offer supportive and flexible working arrangements and equality in terms of career development, it is hoped that the recommendations will promote good practice.
Carers in Hertfordshire	Guideline	014	011-026	See comment 12 above.	Thank you for your comment. Unfortunately we were unable to respond as the comment was unclear.
Carers in Hertfordshire	Guideline	015	003-010	The last census recorded 114,000 carers living in Hertfordshire – currently Carers in Hertfordshire is in touch with approximately 30,000 so there is a real concern that current capacity in both the voluntary and statutory sector is insufficient to meet the needs of all or even 50% of those living in the county. More investment in the voluntary/community sector would reduce pressure on statutory services and enable more carers to be supported.	Thank you for your comment and information, we recognise that there are capacity constraints. Sectoral funding and allocation of budgets is not the remit of NICE guidelines, rather our guidelines set out good practice, however we do outline all of the committee's considerations about this in the rational and impact section of this guideline.
Carers in Hertfordshire	Guideline	015	012	Regularly needs to be a bit more specific, would this be at least annually?	Thank you for your comment. The committee did not wish to be more specific with respect to the frequency as it would to some extent depend on the individual circumstances of the carer.
Carers in Hertfordshire	Guideline	015	017-019	This really depends upon the availability of flexible residential respite care and a well-resourced care support workforce. The levels of	Thank you for your comment. The committee hope that implementation of this guideline will promote carers' breaks that are arranged in a way

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				payment and terms and conditions of employment in domiciliary and residential care do not currently deliver a robust and diverse workforce.	that provides reliable and consistent support to the carer. The committee is aware that practice may vary geographically but did not consider that this recommendation would have a significant impact on practice or resource implications. They hope that their recommendation would promote best and cost-effective practice.
Carers in Hertfordshire	Guideline	016	General	The issuing of appropriate equipment in a timely manner is also essential.	Thank you for your comment. The evidence reviewed in this section related to training and therefore we were not able to make evidence-based recommendations on the issuing of equipment.
Carers in Hertfordshire	Guideline	016	002-004	Carers in Hertfordshire provides a 1:1 peer mentoring scheme where volunteer carers are provided with training and ongoing support to enable them to mentor another carer over a specified timescale. This cost-effective service receives good feedback and is valued by those receiving it. We would be pleased to share our experiences with NICE – contact roma.mills@carersinherts.org.uk.	Thank you for your comment. We are pleased to hear of this scheme and it may be useful for you to submit to the shared learning database on the NICE website (https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies).
Carers in Hertfordshire	Guideline	016	018-020	One to one guidance would be particularly useful when someone is discharged from hospital and equipment, e.g. hoists, are provided to enable this. Too often equipment is delivered without any training or support to the family carer who will be required to use it.	Thank you for this comment in support of the guideline.
Carers in Hertfordshire	Guideline	017	017-019	Carer training programmes should also include keeping safe and looking after the carer's own health and well being.	Thank you for your comment. We agree this is important and have now added a point about 'remaining safe' to the recommendation.
Carers in Hertfordshire	Guideline	017	026-027	Carers in Hertfordshire had a Carers Development and Learning service that offers a range of courses and single sessions including learning (Willls and Trusts, Moving and Handling), enjoyment (Digital photography, Footgolf,) and building resilience (Caring with Confidence, Mindfulness, Resilience). We would be pleased to share our experiences with NICE – contact roma.mills@carersinherts.org.uk.	No response needed - non-registered individual.
Carers in Hertfordshire	Guideline	018	004-008	It is essential that carers are involved in any assessments for equipment and/or adaptations as they are likely to be using the equipment and be impacted by an adaptation to the home. Timely training is the use of all equipment is also essential.	Thank you for your comment. The committee felt this was addressed by the recommendation that practitioners should involve carers in assessments for equipment and adaptations.
Carers in Hertfordshire	Guideline	018 019	011-024 001-019	We agree that the range of information, advice and training opportunities should routinely be offered to carers – we were uncertain why these are termed 'psycho-social or psycho-educational'	No response needed - non-registered individual.

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				as whilst there may be a therapeutic benefit from feeling more in control of a caring situation (with the right information and tools to manage) this does not feel like therapy.	
Carers Northumberland	Evidence Review D	032	General	Where the carers assessment identifies a need to provide replacement care if the carer wants to remain in or return to work or training there may be unintended consequence on the local authority (depending on the carers financial situation) to provide replacement care.	Thank you for this comment. The committee recognised that providing replacement care could have a resource impact in some areas, dependent on the current availability of services. However, they considered that their recommendations on replacement care were supported by evidence on cost-effectiveness and consistent with the Care Act and a duty for local authorities to promote individual wellbeing, which includes participation in work, education and training. They anticipated that their recommendations would encourage commissioners to develop local markets so that replacement care was available to purchase, whether that be through local authority or self-funding.
Carers Northumberland	Guideline	009	General	Concern that while health and social care professionals should be routinely identifying carers and encouraging carers to self-identify this may lead to a significant increase in demand on community and voluntary organisations and services which may impact on their ability to meet that demand.	Thank you for your comment. Whilst we appreciate that local authorities operate under funding constraints it is a statutory duty for them to identify carers.
Carers Northumberland	Guideline	010	General	Local authorities often differ greatly in how they provide and carry out carers' assessments across the country. Where the local authority carries out the assessment it is difficult to see how independent this can be and if the carer will get the support they need as a result of the assessment due to lack of resources.	Thank you for your comment. While we understand the point you make, it is not within the remit of NICE guidelines to address a perceived lack of resources at a sector level. However, the committee were very much aware of this context, and they took account of the practicalities of implementing the guideline in the careful deliberations.
Carers Northumberland	Guideline	015	012	Discussing with carers their options for having a break will be inconsistent and heavily dependent on the resources available in specific areas.	Thank you for your comment. The committee agreed with your comment and felt the recommendations do not preclude a discussion of the options reflecting what is available locally. The remit of guidelines is to establish best practice. Sectoral funding and allocation of budgets is not the remit of NICE guidelines, however we do outline all of the committee's considerations about this in the rational and impact section of this guideline.
Carers Northumberland	Guideline	015	014	The guideline supports the theory that carers' breaks and respite should be arranged in a way that provides reliable and consistent	Thank you for your comment, we recognise the point you are raising. The remit of NICE guidelines is to establish best practice, while sectoral

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				support to the carer – this would depend on the availability of local respite provision and consistent home care services. In Northumberland respite beds which are pre-bookable are practically non-existent.	funding and allocation of budgets is not the remit of NICE guidelines. However we do outline all of the committee's considerations about this in the rational and impact section of this guideline – especially with respect to Carers Breaks and being consistent with the Care Act (2014)
Carers Trust	General	General	General	Commissioners and providers should be encouraged to co-produce and co-design carer support services with carers and former carers. This will enable commissioners and providers to better ensure services meet the needs of service users.	Thank you for your comment. The guideline is very clear about involving carers as equal partners in discussions and decision making about their own information and support needs as well as the care and support needed by the person their care caring for (always with the persons consent). We have also included recommendations about involving carers in the design and delivery of training.
Carers Trust	General	General	General	Overall the guidelines are positive in referencing the Care Act and the duties contained within it. However, NICE should also highlight one key aspect of the Care Act which is currently not in the draft guidelines. The final guidelines should highlight that the Care Act Guidance outlines carers should be able to choose the intensity of and which aspects of care they are willing to provide.	Thank you for your comment. We have now added more references to the fact that carers need to be 'willing and able' to provide care and support and that this needs to be taken account of in the assessments of the person being cared for and when assessing the needs of the carer. It is also included when considering advance care planning.
Carers Trust	General	General	General	Following NICE's advice on your website, the Triangle of Care Steering Group contacted Carers Trust as the Registered Stakeholder which most closely represent their interests. Members of the Triangle of Care Steering Group are experts by profession or experience in supporting carers of people with mental health issues and have supported the development and implementation of Carers Trust's Triangle of Care programme. Carers Trust invited members of the Triangle of Care network to feed in their views on the draft guidelines. The comments below are from the Triangle of Care Steering Group and endorsed by Carers Trust.	Thank you for capturing comments from the network and feeding them in to this consultation. In finalising the guideline, the committee included a new section about the importance of practitioners working with and involving carers and the importance of carers being seen as equal partners in the planning and provision of care, alongside practitioners. This has also been emphasised more clearly in a number of other areas in the guideline, including assessment and in responding to changes in the caring role. In light of yours and other stakeholder comments, the committee also agreed to place a greater emphasis on ensuring carers are 'willing and able' to deliver care both now and in relation to advance care planning

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				• Triangle of Care was originally developed for carers of people with mental health issues. However, since its inception and developments, its influence has spread more widely to be applied to other services. • The principles contained within the Triangle of Care can be used as a basis for good support for carers of people with a broad range of conditions. In particular, the final guidelines should ensure: • Staff receive Carer Awareness Training which is developed and delivered jointly with carers. • Services and professionals should recognise carers and their role, and use the carer's knowledge of the service user's "history" to provide treatment and support. • Staff receive training in managing confidentiality and information sharing • Service providers should involved carers when the service user has their care transferred and services should provide carers with a Care Plan and Crisis Action Plan. The final guidelines should also: • Emphasise the importance to providers of conversations with carers about the aspects and intensity of caring which happen at key stages in the caring journey – for example, transfer of care. • Remind service providers that Carer's Assessments should be reviewed whenever there is a change in circumstance for the person with care and support needs, at a minimum annually	and emphasised the importance of not making assumptions about who is willing and able to provide care when undertaking assessments. The committee agreed about the importance of ensuring staff have the requisite skills to support carers and this is reflected, for example in a recommendation that health and social care organisations should ensure practitioners conducting or contributing to carers assessments have training and skills in the role as well as access to specialist advice. The committee also agreed about the importance of reviewing carers needs, with a recommendation that if a carers support plan results from an assessment then this is monitored and regularly reviewed. There is also a recommendation in the first main section of the guideline that practitioners should take account of the fact that carers information needs will change over time, for example when their circumstances or caring role change. With regard to issues around information sharing and confidentiality, this is addressed in a recommendation about discussing with carers the health condition, disability or needs of the cared for person. The recommendation emphasises that these discussions should take account of the wishes of the cared for person in terms of confidentiality. Also that through these discussions, information should be shared with carers which helps them provide care effectively and safely, while respecting confidentiality (and that the constraints of confidentiality should be explained to them). By the same token, the committee agreed to recommend that carers be given the opportunity to have confidential conversations with practitioners, separately from the person they are supporting. The point made by the network about the importance of primary care workers in identifying carers certainly resonated with the committee and was reflected in the evidence. On this basis there is a

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				• Recceomnd that services (which should be co-designed with carers) should also be reviewed at least every two years by carers to ensure they are still achieving support for carers • Recognise the importance of staff receiving information from carers (even when they cannot yet share information), respecting carers' rights to confidentiality (information or feelings they may have shared with staff), not using confidentiality as a barrier to involving carers, resources such as "Common Sense Confidentiality" (already used by a number of NHS Trusts and other services), and the 6 principles of Triangle of Care. • Highlight the importance of primary care workers in identifying and supporting carers. Primary care is a service that almost all carers are likely to pass through. • Emphasise the importance of support for carers within hospital settings. • Highlight the importance of having good links and developing a shared approach with local voluntary organisations who provide specialised support for carers. • Providers should also be reminded to make clear to carers that the carer's assessment is about their own needs, and not their abilities.	recommendation in the final guideline that every opportunity to identify carers should be taken, for example including GP appointments, flu jab appointments and home visits. There is also a recommendation to ask people with care and support needs whether anyone gives them help or support, apart from paid practitioners. The committee felt that a key opportunity for this would be presented through GP consultations. Finally, there is a recommendation specifically aimed at primary care providers and primary care networks, which states that they should explore ways of offering and promoting services to carers. The guideline also reflects the committee's view that hospitals and transfer between hospitals and between hospital and home provides an opportunity for identifying and working closely with carers. For example, the recommendation about taking every opportunity to identify carers also suggests hospital admissions and discharge assessments and planning meetings as further examples. Another recommendation signposts to the NICE guideline on transitions between inpatient hospital settings and community or care home settings for advice on supporting and training carers during transitions between hospital and home. The same transitions guideline is also signposted in an earlier recommendation about the importance of involving carers in planning for transition between hospital and home. Finally, in relation to the importance of voluntary sector organisations, the committee did originally draft a recommendation that information for carers should be up to date and cover how to access local services, for example from community voluntary sector organisations. However, through discussing final revisions to the guideline the committee agreed to broaden this, now referring to 'social and community support for carers', which includes but is not exclusively limited to community support provided through the voluntary sector. In addition there is a recommendation in the final guideline stating that primary care providers and primary care networks should explore ways of offering

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					and promoting services to carers, including through working with local support services.
Carers Trust	General	General	General	**1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.** The guidelines make it clear that the provisions in the Care Act are vital to ensuring carers are supported. Carers Trust are supportive of the legislative framework for supporting adult carers, and carers in transition, under the Care Act. However, the evidence shows that local authorities do not currently have sufficient funding to enable them to fulfil their duties. Whilst NICE are unlikely to be able to comment on local authority funding, the latest ADASS Budget survey makes it clear that councils are already facing challenges in fulfilling their duties. The latest ADASS survey revealed that: • Planned savings for 2019/20 are £700 million. Since 2010, social care spending in England has decreased by £7 billion. • In 2019/20, only 35% of directors of adult social care are fully confident that budgets will be sufficient to meet key statutory duties in the year, 59% being partially confident and 6% having no confidence. • For future years only 5% of directors are fully confident of their ability to meet all statutory duties with 20% having no confidence. ○ 31% said they were less than confident that they would meet the prevention and wellbeing duty in 2019/2020, and 49% were less than confident that they would meet this duty in 2020/21. The draft guidelines currently repeatedly refer to the Care Act. This is welcome and should be maintained in the final guidelines. It is the	Thank you for responding to these consultation questions and for making the suggestions for useful resources. As you correctly note, a NICE guideline is unable to comment on the level of local authority funding, which you identify as the biggest challenge in implementing this guideline. However, the committee did formally reflect on the context for implementation and the potential resource implications of their recommendations. The recommendations did not introduce any new practices that are not current practice already in a number of local authority areas known to the committee. However not all local authorities will currently be doing all these things. The recommendations were kept non-specific where the evidence was weak and where practice was thought to be disparate across different local authorities. Recommendations were carefully worded to allow local area partnerships between health and social care especially to be able to organise services in a way that best meets local demands and the committee was very mindful of this. The recommendations on replacement care are based on cost-effectiveness evidence and supports your view that supporting carers can result in an increased economic contribution from carers.

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				implementation of the Care Act, as set out in these guidelines and the statutory Care Act Guidance that would make a significant positive impact on the lives of carers. The challenge remains the funding made available to local authorities and the services they commission. **Would implementation of any of the draft recommendations have significant cost implications?** Evidence shows that supporting carers can save money in adult social care services whilst improving the life of the carer and the person with care needs. It can also provide savings for the NHS and benefit the wider economy with an increased economic contribution from carers. The Impact Assessment published by the then Department of Health in October 2014 makes an estimate of the monetised health benefits of additional support for carers. This estimates that an anticipated extra spend on carers for England of just under £293 million would save councils just over £430 million in replacement care costs and result in monetised health benefits of £2.3 billion. This suggests, as a ratio, that each pound spent on supporting carers would save councils £1.47 on replacement care costs and benefit the wider health system by £7.88. http://www.legislation.gov.uk/ukia/2014/407/pdfs/ukia_20140407_en.pdf **What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)**	

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				Carers Trust and others have produced a number of guides and models that will help providers overcome challenges they face when supporting carers. **Carers Trust Triangle of Care model(s)** **The Triangle of Care, Carers Included: A Guide to Best Practice in Mental Health Care in England** can be used across all mental health services, not only inpatient, and includes a universal self-assessment tool as well as guidance notes. In addition, the guide now includes good practice examples from across the mental health care pathway. https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health **The Triangle of Care for Young Carers and Young Adult Carers, A Guide for Mental Health Professionals** The Triangle of Care programme has identified that many frontline staff are unaware of who young carers are and what their needs are. Thanks to the support of NHS England, Carers Trust has produced a supplementary resource to support staff to understand the needs of young and young adult carers, what the challenges are to identifying them and how to overcome them. The resource supports the wider implementation of the Triangle of Care and works to ensure that all carers are included and supported by mental health services. https://professionals.carers.org/sites/default/files/toc_ycyac-proof4.pdf **Triangle of Care for Dementia**	

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				The Triangle of Care for Dementia was developed in partnership with the Royal College of Nursing and in consultation with carers, people with dementia and professionals. It is based on the original Triangle of Care and is aimed at acute care hospitals. https://professionals.carers.org/triangle-care-dementia **NHS England Carers Toolkit** NHS England and partners, including Carers Trust, developed a toolkit to help health and social care organisations work together in identifying, assessing and supporting the wellbeing of carers and their families. This toolkit covers duties on NHS organisations brought about by the Care Act 2014 and the Children and Families Act 2014 and includes numerous examples of positive practice that are already making a difference to Carers and their families. The toolkit also includes a template Memorandum Of Understanding (MOU) that local partners can use to help them work together in supporting Carers of all ages and their families. https://www.england.nhs.uk/commitment-to-carers/carers-toolkit/ **NHS England Supporting Carers in Primary Care** This document offers a series of practical ideas that have been developed in partnership with carers, primary care teams and other key stakeholders. Collectively, these provide a framework for improving how general practice can better identify and support carers of all ages. https://www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/	

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				Carers Trust and Carers UK's Carer Passports. A Carer Passport is essentially a record which identifies a carer in some way and leads to the provision of support, services or other benefits in response. Funded by the DHSC Carers Trust and Carers UK developed carer passport materials for different settings including employment, hospital, community, mental health and education. https://carerspassports.uk/	
Carers Trust	Guideline	General	General	Carers Trust are concerned about the repeated mention of "self-care" throughout the guidance – for example, page 4, line 15; page 15, line 8; and page 17, line 9. Carers may only be able to "self-care" if the wider system of support for themselves, and for the person they care for, works well. The expectation should be on providers to ensure this before carers are able to take part in "self-care" activities if they want to. Carers being enabled to "self-care" depends on carers getting the assessment and support they are entitled to. Whilst "self-care" may be one aspect of enabling carers to maintain their own health and wellbeing, it should be part of a range of choices that the carer can take part in, and it is also important for carers to have support for their own health, statutory assessment and support of their own needs, including a break or respite. For example, current NHS England advice is that healthy adults should do at least 150 minutes of moderate exercise per week. Given that 1.3 million carers provide more than 50 hours of care per week and another 700,000 provide over 20 hours of care per week it is more difficult for many carers to fit in this time for "self-care". The State of	Thank you for your comment. It was not the intention of the committee to suggest that carers should be left alone to look after themselves. They believe that the recommendations they drafted - on the basis of research evidence and their own expertise - are strongly focussed on the need (and where relevant 'duty') of health and social care practitioners to identify carers, assess their needs and provide advice, support and information. The recommendations reflect an emphasis on the importance of the wellbeing of carers. However, in light of some stakeholder comments, the committee agreed to make more explicit reference to the importance of ensuring - and then reviewing - carers' willingness and ability to provide support and they believe this also helps to address the point you make.

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				Caring survey highlighted that 81% of carers said they are not able to do as much physical exercise as they would like to, for example. The onus for a carers' health and wellbeing should not be shifted onto carers and health and social care providers should take responsibility for ensuring carer needs do not deteriorate and ensure there is appropriate support available for carers.	
Carers Trust	Guideline	005-006	General	Carers Trust welcome the guidelines set out under "How to set out information and advice"	Thank you for your support for this particular section of the guideline.
Carers Trust	Guideline	004	003	Carers Trust welcome the clear highlighting of local authorities' duties under the Care Act 2014.	Thank you for your comment. We are reassured that the recommendations address issues that you perceive to be important.
Carers Trust	Guideline	004	014	Carers Trust are pleased to see "support for the carers' own health and wellbeing" included in examples of information that local authorities should be giving to carers, in line with the Care Act. However, we are less convinced of the usefulness of the inclusion of "self-care" in the same sentence. Whilst the importance of carers' own health and wellbeing is clear in Care Act Guidance, "self-care" is only mentioned once in the Care Act Guidance, and even that is in the context of a link to an external source. Whilst Carers Trust agree that carers can be given the tools, advice and information to enable them to maintain their own health and wellbeing, the onus should be on the local authority to ensure unpaid carers have the resources to do this, and that a carer's assessment is still offered. The wider context of a lack of social care for the person with care and support needs, a lack of funding for carer support, a lack of time and other pressures mean carers are often unable to "self-care". Carers Trust would recommend not including this in line 14 and keeping it to "support for the carer's own health and wellbeing"	Thank you for your comment and for highlighting this. The list in the recommendation to which you refer has actually been removed from the final guideline because the committee felt it was problematic to list some issues and not others running the risk that information that was not listed here, would not be provided. On a more general but related point, the committee wanted to highlight that the recommendations, as a whole, reflect an emphasis on the importance of the wellbeing of carers. However in light of some stakeholder comments, the committee agreed to make more explicit reference to the importance of ensuring - and then reviewing - carers' willingness and ability to provide support and they believe this also helps to address the point you make.

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Carers Trust	Guideline	005	006-009	Carers Trust welcome the guidance to "tell carers where they can find local carers services….". Carers Trust would like lines 6 to 9 (page 5) to remain in the final guidance.	Thank you for your support for this recommendation, which appears in the final version of the guideline. Only one small edit was made, where the word 'find' was replaced with the word 'access'.
Carers Trust	Guideline	005	010-011	Carers Trust are pleased to see the guidance to "Work closely with carers and treat them as a valued member of the care team for the person they care for." Carers Trust would like lines 10 to 11 (page 5) to remain in the final guidance.	Thank you for your comment, on the basis of which the committee agreed to place even greater emphasis on the importance of the carer as a critical part of the team around the cared for person. They edited the recommendation to which you refer to underline that as a valued team member, the carer should be involved in decision making and care planning and be kept up to date.
Carers Trust	Guideline	005	016	Carers Trust suggest NICE should point front line staff to more information about confidentiality here as we know that many front line staff do not always have confidence in using confidentiality procedures. It is important that staff recognise the importance of receiving information from carers (even when the staff member cannot yet share information), and respect carers' rights to confidentiality (information or feelings carers may have shared with staff). Staff should not be using confidentiality as a barrier to involving carers NICE could point professionals to resources such as "Common Sense Confidentiality" and the 6 principles of Triangle of Care. Many NHS Trusts use "Common Sense Confidentiality". Here is one example from Northumberland, Tyne and Wear NHSFT https://www.ntw.nhs.uk/content/uploads/2016/08/Commonsense-confidentiality-1.pdf The Triangle of Care can be accessed here: https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health	Thank you for your suggestion. The committee believes that the recommendations as a whole already emphasise the importance of recognising carers and involving them as a key member of the team around the cared for person. The recommendations also emphasise the importance of giving carers the opportunity to have confidential conversations, separate from the cared for person. Given the scope of the evidence reviews and therefore the data on which recommendations are based, the committee agree that this is as far as the guideline can go in terms of 'training' practitioners about the nuances of confidentiality procedures.

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Carers Trust	Guideline	006	011-017	Carers Trust would recommend NICE signpost to the NHS England Accessible Information Standard as an additional bullet point to the list already provided.	Thank you for your suggestion. The Accessible Information Standard is already referenced via the direct link from this guideline to the NICE guideline on people's experiences in adult social care. In addition, a reference is now made to the Accessible Information Standard in a redrafted recommendation about the provision of information in a range of formats, to meet carers' needs and preferences.
Carers Trust	Guideline	006	024-028	Carers Trust would recommend signposting to NHS England's Supporting carers in general practice: a framework of quality markers (https://www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/) to help primary care providers better support unpaid carers.	Thank you for your comment. The committee agreed to make specific reference to Carer Quality Markers in the context section of the final guideline.
Carers Trust	Guideline	006	026	When setting out the example for partnership working NICE should include the word "local" so the example reads: for example with **local** carer support services". This would better align this with the guidance contained on page 5 line 6.	Thank you for your suggestion. The committee agreed to refer to 'local' carer support service' in the final version of this recommendation.
Carers Trust	Guideline	007	001-007	Carers Trust welcome the guidelines set out to identify carers and their alignment with the Care Act.	Thank you for your comment and your support for this particular section of the guideline.
Carers Trust	Guideline	007	008-013	Carers Trust would recommend that the "benefits of identifying carers" should be slightly amended and added to. The first bullet point should add "…and carers' support needs are addressed" so it will read "the carer because their role can be recognised and their contribution acknowledged, and carers' support needs are addressed" A third bullet point should be added which reads: "The service itself because carers will have valuable knowledge which can be vital in ensuring the person with care and support needs get the support they need.	Thank you for your suggestions, which the committee have incorporated in the final version of this recommendation.

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				This should be linked back to the above guideline above (page 5, line 10 – 11) about including carers as a valuable member of the care giving team.	
Carers Trust	Guideline	008	003-004	Carers Trust recommend NICE add "free flu jab" to the list of "opportunities" that an identified and supported carer could access.	Thank you for your suggested addition, which the committee agreed to make to the final version of this recommendation.
Carers Trust	Guideline	008	008-012	Carers Trust are pleased to see that NICE is encouraging professionals to think broadly about possible caring relationships and to encourage professionals to identify carers. However, professionals should also be reminded that children under 18 can also be providing care and professionals have a duty to identify young carers. A guideline should be added making it clear that those in a caring role may be under 18 and professionals should be identifying them. In particular, for these guidelines, professionals and services should be guided to identify 16 and 17 year olds in a caring role. This would be more in line with the Care Act which sets outs the duty for young carers to have a transition assessment. At a minimum, the guidelines must make reference to young adult carers who are aged 16 and 17 as they transition into adult services (and therefore within the remit of these guidelines). One step NICE could take is to make reference to NICE's Guidelines on Transition and highlight the sections which highlight young carers.	Thank you for your comment. The scope of this guideline covers carers aged 18 years and above. Carers aged under 18 years are likely to have many additional specific needs that would be better addressed in a more specific guideline.
Carers Trust	Guideline	008	021-022	The current guidelines read: "Offer carers the opportunity to have conversations about their own needs as carers separately from the person they are supporting."	Thank you for your comment. The committee discussed the points you made and agreed to edit the recommendation so there is now an emphasis on 'confidential' conversations with carers. In terms of your point about carers having the right to decide how much caring they

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				Carers Trust welcome the inclusion of this. To strengthen this guideline, Carers Trust recommends NICE add a line setting out the need for professionals to highlight to carers that confidentiality rules also apply to information shared by carers and that the professional will not share any information without the carer's permission. Carers often tell Carers Trust that they have feelings of guilt about the fact that their caring role causes them to be stressed and that they would not want the person they care for to know the impact it is having. Therefore, reassuring carers that they can have a separate conversation and secondly, the conversation about their own needs is confidential, may encourage more carers to seek support and be fully open about their own health and wellbeing needs. During this conversation, professionals should also highlight to carers that the Care Act gives them the right to decide how much caring they want to do.	want to do, the committee were in agreement with this and have introduced a greater emphasis in the guideline on the importance of ascertaining and reviewing carers' willingness and ability to provide care.
Carers Trust	Guideline	009	004-008	Carers Trust would strongly recommend adding "partnerships with local carer support organisations" to the list of what health and social care organisations can do to encourage people to recognise their role as carers. The importance of local carer support organisations are already recognised within the guidelines, and this is another opportunity for NICE to highlight their importance to providers.	Thank you for your suggestion, on the basis of which the committee agreed to make this change to the recommendation.
Carers Trust	Guideline	009	004-008	Carers Trust would also recommend NICE add "Digital Communications, for example, social media" as another way that health and social care organisations can do to encourage people to recognise their role as carers.	Thank you for your comment. In finalising the guideline, the committee have placed greater emphasis on the use of digital technology and online communication, particular as a means of providing information and advice.

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Carers Trust	Guideline	010	General	Carers Trust broadly welcome the guidelines set out under "assessing a carer's needs" and its signposting to the Care Act 2014.	Thank you for your support for this particular section of the guideline.
Carers Trust	Guideline	011	011-012	It is good that NICE has set out the need to "Provide flexibility in the timing and location of carers' assessments for carers who work" • However, Carers Trust strongly believes that this should apply to **all** carers regardless of their employment status. Carers' assessments should always be at a time and place that suits carers whether or not they are in work. This includes young adult carers (aged 16 to 24) who may be in college, university or in a job. This is more in line with the Care Act Guidance and will ensure all carers are offered the same flexibility.	Thank you for your comment. We have amended this recommendation so that the focus is no longer just carers who work.
Carers Trust	Guideline	012	001-007	Referral to a local carer organisation should be added as possible examples of a clearly identified outcome for carers following an assessment.	Thank you for your comment. This list of examples has been removed from the recommendation as the committee, on reflection, considered that it could be misleading. The recommendation emphasises the importance of identified outcomes without providing examples as to what those outcomes might be. We have however included reference to the important role of local carer organisations in other parts of the guideline.
Carers Trust	Guideline	012	001-007	Carers Trust are pleased to see arrangements for replacement care included as an example of an identified outcome for carers.	Thank you for your support for this particular section of the guideline.
Carers Trust	Guideline	013	General	The section "Helping carers stay in, enter or return to work, education and training" is generally strong on how services and workplaces can support carers in this respect. However, the guidelines should acknowledge the particular challenges faced by young adult carers who may be entering the workplace for the first time.	Thank you for your support for this particular section of the guideline. The evidence review identified only one study relating to the disadvantages experienced by young carers in attempting to balance work or education with a caring role. The committee added to this from their own expertise noting that carers often lack confidence about their suitability for employment, especially if they have spent many years in a caring role instead of in education or training. The committee therefore drafted a recommendation to overcome this, through providing help to

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				We know that young adult carers are more likely to be not in education, employment or training than peers not in a caring role, and that their education is often impacted negatively because of their caring responsibilities. Carers Trust have produced a guide for young adult carers about getting into work https://carers.org/sites/default/files/media/employment_booklet_a5_leaflet_version_4_final.pdf NICE should encourage providers to be aware of this guide and refer young adult carers to it. The Statutory Care Act guidance also sets out Care Act duty to help young adult carers find employment or a place at university or college There is a duty for the local authority to discuss plans for further and higher education with the young carer. The Care Act guidance is clear that where a young carer wishes to attend higher or further education, the transition assessment should help them identify suitable institutions for them to apply to, as well as put support in place to enable young adult carers to attend university. The final NICE guidelines should highlight this.	carers to convey transferable skills to potential employers. They also drafted a recommendation about the provision of access to tailored advice, including about education. The committee deliberately drafted recommendations that would apply to all carers, regardless of age, in order to improve outcomes as widely as possible and avoiding carers being overlooked for this support on the basis of their age. Finally, we are unable to provide direct links to guidance which has not been produced or accredited by NICE.
Carers Trust	Guideline	013	General	The section "Helping carers stay in, enter or return to work, education and training" should encourage providers to refer carers to specialist back-to-work programmes in the area.	Thank you for your comment. The committee felt that this was too specific especially as such programmes may not be available in all areas. Furthermore, no evidence on such programmes was reviewed.
Carers Trust	Guideline	014	General	It is good to see NICE set out the benefits of replacement care for carers who want to stay in, enter or return to work, education or training.	Thank you for your support. We agree that the guideline acknowledges the wider importance of replacement care elsewhere. The recommendations in this particular section were based on the scope and evidence about remaining in, entering or returning to work, education and training, which explains the particular focus.

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				It should be made clear that replacement care **is beneficial for all carers**, whether they are in or want to return to work, training or education, or if they are retired older carers, or if they have chosen not to work and focus on caring. We know, and NICE recognises elsewhere in the document, the importance of breaks and respite to enable carers to maintain their own health and wellbeing.	
Carers Trust	Guideline	015	General	Under "Social and community support for carers" NICE should make it clear to providers that information about community services and other sources of support of advice should be tailored to the carers' needs and profile, based the outcomes of the carers' assessment of their needs as a carer and conversations with the carer. For example, an older carer may want support from a group that specialises in support for older carers or older people more generally. Or they may want support based on an interest they have such reading, gardening, or walking. Likewise, a young adult carer may want to be informed about a service which has specialist services for young people who are carers or may want to access support based on their interests.	Thank you for your comment. We have a number of recommendations that stress the importance of tailored advice and support for their individual preferences in the section on information. We also suggest conditions specific support in the sections on carer training and on emotional support.
Carers Trust	Guideline	015	General	Carers Trust welcome the guidelines around carers' breaks.	Thank you for your support for this particular section of the guideline.
Carers Trust	Guideline	015	005	Carers Trust welcome the inclusion of "local carer support services" in the examples of sources of advice and support.	Thank you for your support for this particular section of the guideline.
Carers Trust	Guideline	016	014-020	In the "training in providing care and support" section, NICE should highlight to providers that one way of ensuring carer training meets local needs is to co-commission and co-produce training with carers and former carers. They have expertise by experience and will be well placed to help commissioners develop training that meets local needs.	Thank you for your comment. We have added a new recommendation stating that carers should be involved in the planning and delivery of carer training to ensure it reflects their skills and expertise.

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Carers Trust	Guideline	020	001-023	NICE need to draw attention to carers aged between 16 and 17 in this section. The final guidelines should highlight to providers that they should be providing transition planning and assessments for young adult carers aged 16 and 17. - Whilst these are guidelines for adult carers (those aged over 18), we strongly believe these guidelines should also apply to carers aged 16 and 17 making a transition into adult services so that providers ensure this transition is a success. Carers aged 16 and 17 are approaching the age where they will be covered within the remit of these guidelines. However given the importance of transition, this should be included in the final guidelines. Many of the same providers who will be using this guide to ensure they provide effective support for adult carers are also responsible for ensuring good transitions for young adult carers between children's and adult's services, and implementing their legal duties as the Care Act covers transition for young carers from children's to adult's services. Carers Trust believes it makes sense for this group of carers to be included within these guidelines to ensure that they get the effective transition planning and assessment that they are entitled to. By including carers aged 16 and 17 who are coming up to important transition points, the final guidelines will be even more closely aligned to the Care Act and ensure providers are reminded of and are able to fulfil their duties under it. At a minimum, the guidelines must make reference to young adult carers who are aged 16 and 17 as they transition into adult services (and therefore within the remit of these guidelines). One step NICE	Thank you for your comment. The scope for this guideline is adults carers aged 18 and over, and consequently evidence for 16/17 year olds was not appraised. There is a recommendation with a cross-reference to NICE's guideline on transitions from children's to adults' services albeit in the context of the cared for person. We have also included reference to the need for services to take account of changes to the caring role when a young carer turns 18 and becomes an adult carer.

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				could take is to make reference to NICE's Guidelines on Transition and highlight the sections which highlight young carers. NICE could go further than this minimum step to ensure carers who are aged 16 and 17 experience a good transition into adult services. The Care Act places a duty on local authorities to conduct transition assessments for young carers where it is likely they will need support. By including the importance of transition in the final guidelines, NICE will ensure they are better aligned with the Care Act. The importance and benefits of a good transition between children's and adult's services are widely recognised. Young adult carers are already more likely to face poor health, additional barriers to education and employment, as well as facing social isolation than their peers not in a caring role, so it is vital that a good transition happens for young adult carers.	
Carers Trust	Guideline	020	002-004	Carers Trust welcome the inclusion of the guidelines that providers should be "aware that caring responsibilities may not end when the person being cared for moves away from home, for example into a residential care home"	Thank you for your comment. We are glad our recommendations cover topics that are considered important by stakeholders.
Carers Trust	Guideline	020	013-016	Carers getting older should be added as an example of a change in circumstances that providers should be aware of. As carers get older, they may become physically less able to care, they might want to make changes to their caring role (as is their right under the Care Act at any stage), and those on Carer's Allowance are no longer entitled to it once they reach pension age so many will face changes to their finances.	Thank you for your comment. This recommendation has been amended in line with your suggestion.

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Carers Trust	Guideline	021	General	In addition to the guidelines set out currently, NICE should also encourage providers to have conversations about the aspects of care that the carers wish to take part in during end of life care. Some carers may want to increase their involvement, others may wish to curtail it to spend the last period of time with the person they care for without undertaking caring tasks.	Thank you for your comment. We have added more emphasis across the guideline that carers should only be expected to give as much care as they feel willing and able. This value applies to the end of life period and all other times.
Carers Trust	Guideline	021	022-024	In addition to encouraging carers to get support from family, friends and wider social network, it should be pointed out that carer services will support carers during and after end of life care – this is especially common if the carer is already known to the support service.	Thank you for your comment. The committee agreed but considered that the recommendation to "Help carers who are providing end of life care at home to access local services that could support them" (with examples) addressed this.
Carers UK	General	General	General	Carers UK feels that the approach taken to sourcing evidence needs to be tailored for social care. Randomised Control Trials, for example, are rare within the social care world. They are often inappropriate and the funding for outcomes-based work tends to be very small within the sector and even smaller for economics-based work. The investment in social care research is tiny in comparison with that in health. Social care research, interventions and outcomes are often informed by a culture of lived experience and self-defined outcomes and this does not fit well with a health-based methodology and approach that NICE tends to take. The research into lived experience and the effectiveness of interventions is often influenced by a wider range of factors than those found in health research. It may often be the case that a variety of interventions are needed to deliver an outcome, and this may vary between different people. Social care has also been subject to significant cuts over the past few years, unlike health, which impact on any studies looking the effectiveness of services. This is in the context of rising charges, services being cut or not being delivered, benefits are being cut, and more people having to give up work to care. We would strongly suggest that you review your methodology and acceptance of evidence in the development of future guidelines on social care.	Thank you for your comment. The methods manual for the development of NICE guidelines was last updated in November 2018 reflecting ongoing lessons learned from the commissioning and development of social care guidelines. NICE is aware of the fundamental contribution that lived experiences make to the social care evidence base. This is reflected in the fact that NICE social care guidelines are generally underpinned by a number of qualitative evidence reviews seeking data on the views and experiences of people using services, carers and practitioners for example about the acceptability of certain approaches or barriers and facilitators to achieving outcomes. However evidence reviews of quantitative data also play an important role in the development of NICE social care guidelines, depending on the type of question being addressed by the review. If the question seeks to establish the effectiveness of an intervention or approach then the most appropriate type of study is usually a randomised controlled trial - just as it would be in the context of clinical guideline - since it provides data in which the committee can have the greatest confidence. However, a range of other non-randomised evidence, such as observational evidence, experimental and qualitative evidence, may also be used to inform assessments of effectiveness, or aspects of effectiveness. Sometimes in social care (and indeed clinical) topics, there is little

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					evidence from scientific studies, or the evidence is weak or contradictory. In these cases, we look for evidence from other sources to see if it agrees or differs ('triangulation'). When there is little or no evidence, the committee may also use expert testimony, make consensus recommendations using their knowledge and experience, or make recommendations for further research.
Carers UK	Guideline	General	General	The guideline needs to set out the principles at the beginning of the document, before the section on Information and Advice to set out the goal of wellbeing i.e. Section 1 of the Care Act 2014 – the wellbeing principle that covers all carers. This needs to be inserted and referred to throughout as well as a stand-alone section. This is an important principle that either statutory authorities have to abide by, or any commissioning decisions of services, which naturally need to link to. Employers have a duty of care to their employees; therefore the wellbeing principle equally applies in the workplace. There should also be references to the Human Rights Act, the Equality Act, and discrimination by association, as these are the basic rights and responsibilities that have to be abided by.	Thank you for your comment, in response to which the committee agreed a number of changes to the final version of the guideline. For instance, there is now a greater emphasis in the context section on the wellbeing principle of the Care Act and a description of the responsibilities of health and social care practitioners in relation to the identification of carers and provision of information and support. The committee also agreed to introduce a section of the guideline entitled 'working with and involving carers' with recommendations which make explicit how practitioners should do this. In addition there is now greater emphasis on important links with legislation with a note at the start of the guideline to say that it should be read together with statutory guidance for the Care Act and the Children and Families Act 2014. Finally, the recommendations about support from employers have been strengthened, for instance changing one recommendation to the strongest 'must' in order to reflect the duties in the Equality Act, which is described in the rationale and impact section for this set of recommendations. In terms of explicitly listing the Equality or Human Rights Acts in the guideline itself, the committee did not feel this was necessary since the legislation applies across all NICE guidelines, not exclusively or specifically this one. NICE guidelines in general are produced with the aim of reducing health and social care inequalities, as required by the Equality Act and are in compliance with the Human Rights Act 1988.
Carers UK	Guideline	General	General	There needs to be a stronger thread throughout that the carer has to be willing and able to provide care – i.e. a clear element of choice. This is critical in the delivery of all statutory services or commissioned	Thank you for your comment. When they discussed your point, the committee were in agreement about the importance of avoiding assumptions about the willingness and ability of carers to provide support. They therefore made revisions to the final version of the

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				by services as they need to follow the letter of the Care Act 2014. This would also be in keeping with a positive human rights perspective. The current narrative within the guidance is very clearly based on the carer that is currently caring, and needs "replacement care". This is currently not in line with the Care Act and should be amended. This is not a question of whether there is evidence or not, but a legal foundation. We would recommend that this is built into the first section and the wellbeing section, as well as throughout the rest of relevant sections.	guideline, which now includes a separate recommendation that assumptions should not be made about the willingness and ability of carers to carry out tasks when completing assessments for the carer or the cared for person.
Carers UK	Guideline	General	General	The notion that all care is "replacement care" is not in line with the Care Act 2014 and needs to be changed. This places an assumption on the carer already being there and providing care for which they need to be replaced. This is not in line with "willing and able" principles in the Care Act and the notion of choice about caring It is also not in line with a "carer blind" assessment of the person needing care – as is required by the Care Act.	Thank you for your comment. When they discussed your point, the committee were in agreement about the importance of avoiding assumptions about the willingness and ability of carers to provide support. They therefore made revisions to the final version of the guideline, which now includes a separate recommendation that assumptions should not be made about the willingness and ability of carers to carry out tasks when completing assessments for the carer or the cared for person.
Carers UK	Guideline	General	General	There is one section that suggests that employers should ensure that carers have equal access to careers. It should be pointed out that not to do so would be in contravention of the Equality Act 2010 and would constitute discrimination by association. This point needs to be made clearly in the recommendations rather than being seen as "good practice".	Thank you for your suggestion, with which the committee agreed. They therefore changed this particular recommendation to say that 'workplaces must ensure that staff with caring responsibilities have equal access to career development' because this, as you say, is in line with the Equality Act 2010.
Carers UK	Guideline	General	General	Throughout, more could be made of digital, online and technological solutions. The examples given tend to be very traditional and not always looking at the preferred methods of communication, which also include digital.	Thank you for your suggestion, in light of which the committee agreed to make reference to the potential use of digital communications, social media and online forums. For instance, one recommendation now states that information should be made available to carers in a range of formats, including through links to online and digital resources and another highlights that practitioners should encourage carers to recognise their role and rights through a number of means, including digital communications and social media.

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Carers UK	Guideline	General	General	In relation to assessments, very little is mentioned about joint assessments with the person needing care, although covered in the background information.	Thank you for your comment. Although this issue was discussed at length there was very little in the evidence about the effectiveness or acceptability of joint assessments. In view of this the committee drafted a recommendation to make practitioners aware that carers assessments may on occasion be combined or linked with the assessment of the person they care for (with the consent of both parties). The committee were more concerned to promote the conduct of conversations and assessments with carers in a way that focusses on their needs and preferences and the promotion of their own wellbeing, which might mean they choose to have those conversations separately from the cared for person and in confidence.
Carers UK	Guideline	General	General	It would also be beneficial to have more work on different types of multiple caring responsibilities and joint working. People are often caring for two or more people who may or may not be adults and need care.	Thank you for your suggestion. The committee were aware of the particular challenges involved when someone is caring for more than one person but specific evidence relating to these situations was lacking in the reviews underpinning this guideline. Nevertheless the committee drafted two recommendations to highlight these circumstances; one to make practitioners aware that people may be caring for more than one person and the other to ensure replacement care is flexible and provides a choice of options to meet all levels of carers' needs, including for those who care for more than one person and who care for over 20 hours per week.
Carers UK	Guideline	General	General	It would also help to make the point about joint working more forcefully and ensuring that information, records and activity/services are effectively coordinated when assessments are done.	Thank you for your comment. In finalising the guideline, the committee placed greater emphasis on practitioners treating carers as a valued member of the team around the person being cared for and in this sense emphasising joint working and information sharing with carers. The main areas in which the committee considered evidence about the importance of joint working between health and social care practitioners were the identification of carers and assessment of their needs. In finalising the guideline, the committee placed greater emphasis on these aspects, for example, recommending that every opportunity should be used to identify carers, including through GP appointments, outpatient appointments, social care and needs assessments and flu jab appointments. This emphasises that the

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					identification of carers is within the remit of practitioners across health and social care. There is also now a more detailed recommendation in the final guideline stating that health and social care organisations should encourage people to recognise their role and rights as carers, for example through partnerships with community pharmacies or local carer support groups and through partnerships with local community organisations. In terms of assessing carers needs, the opening recommendation of this section has now been strengthened and states that local authorities and social care organisations delegated by local authorities to carry out carers assessments should make arrangements for and carry out assessments in cooperation with other relevant health and social care organisations. The committee were able to further emphasise joint working by recommending that health and social care practitioners work together to carry out or contribute to carers assessments to ensure they cover all relevant aspects of health, wellbeing and social care needs and that details of the assessment should be shared between the other practitioners and organisations involved. In terms of the remit of the guideline and the nature of the evidence located (there were no review questions specifically about joint working) the committee agreed that they had placed as much emphasis in the guideline as possible on the importance of health and social care practitioners working together and taking responsibility for the identification and assessment of carers and ensuring they have the support and information needed to carry out their role and maintain their own health and wellbeing.
Carers UK	Guideline	General	General	The guideline needs to mention the fact that it is not in the interests of carers or services if there is a charge for services. These services should be free at the point of delivery.	Thank you for your comment. The committee were unable to make any changes in light of your suggestion because it is beyond the remit of NICE guidelines to comment on issues around funding or charging for services.

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Carers UK	Guideline	General	General	We would strongly suggest that prevention needs be in the guideline – to be able to maintain health and wellbeing, and section 1 of the Care Act.	Thank you for your comment. The committee agreed to place a greater emphasis on the Care Act principles in the introduction to the guideline. In terms of the recommendations, the committee were content that they were all drafted with the health and wellbeing of carers as their central focus.
Carers UK	Guideline	General	General	It would be helpful to mention loneliness and isolation this could be included in the principles.	Thank you for your comment. The committee agreed to emphasise the Care Act principles in the introduction to the guideline. In terms of loneliness and isolation specifically, the committee recognised this important issue and included a recommendation that carers should be told how to access peer support and that practitioners should explain how these services or groups can help to reduce a sense of isolation and provide social and emotional support.
Carers UK	Guideline	001	General	In the 'Who is it for?" section, 'care providers' need to be explicitly referenced after 'Hospital and community care'	Thank you for your suggestion. The committee felt that the text in bullet points under the 'providers of health and social care services' already provides this level of detail.
Carers UK	Guideline	004	009	This point should also include the need for practitioners to utilise positive digital communications that are community based to engage with carers. 'GPs, pharmacies and voluntary organisations' should also be explicitly listed here.	Thank you for your suggestion, in light of which the committee agreed to make reference to the potential use of digital communications, social media and online forums.
Carers UK	Guideline	005	011	We would like the guideline to include a further point after 1.1.5. Insert, "Carers are also a person in their own right and have a right to choose how much care they provide". This is not currently explicitly stated, and assumptions could be made that carers are willing and able to continue providing care – which may not be the case. Our suggestion is in line with the Care Act and is a very fundamental principle of choice.	Thank you for your comment. Your point about avoiding assumptions about the willingness and ability of carers to provide care and support was similarly made by a number of other stakeholders. As a result the committee agreed to strengthen this message in the final guideline though drafting an additional, separate recommendation that when completing assessments for carers or the cared for person, practitioners should not make assumptions about the willingness and ability of carers to carry out caring tasks.
Carers UK	Guideline	006	008	The default is to mention 'face-to-face' appointments, but there also needs to be recognition that digital or online appointments might be a carer's preference.	Thank you for your comment. In light of yours and other stakeholder comments about the important role of digital technology the committee revised a number of recommendations. This included the one to which you refer, which no longer emphasises face to face meetings but says

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					that information should be made available according to carer's needs and preferences.
Carers UK	Guideline	006	012	Make reference that as well as providing written materials, carers may prefer to receive communications digitally, for example via attachments to emails.	Thank you for your comment. In light of yours and other stakeholder comments about the important role of digital technology the committee revised a number of recommendations. They did not revise the one to which your comment refers because they felt the point could be made more clearly in a revised recommendation about the importance of making information available in a range of formats, including via online and digital resources such as local and national websites and forums and social media..
Carers UK	Guideline	007	General	There is no mention of the importance of carer passports in the section 1.2 ('Identifying carers'). These could be valuable tools to support greater identification and recognition of carers.	Thank you for your suggestion. The committee agrees about the potential role of carers passports but since no related evidence was located in any of the reviews, they agreed to prioritise this as a recommendation for future research.
Carers UK	Guideline	007	010	In the first bullet point after 'acknowledged', insert, *"…and important steps taken to support their own needs."* The statement as in the draft guideline assumes the carer will always be there which might not be the case.	Thank you for your comment. As a result of yours and other stakeholder comments this recommendation has been edited to emphasise that one of the benefits of identifying and recognising carers is that their own support needs can be addressed.
Carers UK	Guideline	007	025	Add additional bullet point stating, *"They may have a specific view about who carers are, which they don't identify with."* People have different perceptions of what it means to be a carer.	Thank you for your comment, which the committee discussed. They concluded that the point you make does not add a great deal to the recommendation, which already highlights that carers may prefer to continue to identify as a husband, wife or daughter rather than as a 'carer'.
Carers UK	Guideline	009	004	Add another bullet point to the list – *'Public health campaign to identify and support carers'*	Thank you for this suggestion. It is beyond the remit of this guideline, aimed as it is at influencing practice in health and social care, to recommend public health campaigns.
Carers UK	Guideline	009	007	Add another bullet point to the list – *'Carers clubs, for example in hospital settings'*	Thank you for your suggestion. The committee did not make this change because the examples listed are designed to encourage people to recognise their role and rights as carers, rather than being means of support, which a carers club would seem to be.

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Carers UK	Guideline	009	016	Add to end of sentence, *"…including any specific policies for supporting carers'.*	Thank you for your comment. This recommendation is specifically about identifying carers and the guideline as a whole is designed to promote support for carers.
Carers UK	Guideline	011	006	Include additional bullet point: *"Where best to hold the assessment to meet the carers needs."*	Thank you for your comment. We have amended a recommendation in the section an assessment of carers to say that flexibility should be offered in the time, location and method of carers assessments in order to reflect the individual circumstances of carers.
Carers UK	Guideline	011	012	Flexibility in the timing and location of carers' assessments should be a principle applied to all carers, not just working carers.	Thank you for your comment. We have amended this recommendation so that the focus is no longer just carers who work.
Carers UK	Guideline	011	012	Be more explicit about how that flexibility could be provided, e.g. telephone/online assessments. It is of paramount importance that the assessment is timely i.e. expedient. There are waiting lists of months before an assessment is done.	Thank you for your suggestion. The committee considered this and agreed not to be too prescriptive in recognition that different approaches will be available across time and in different areas. The point of the recommendation to which you refer (and others in that section) is to encourage practitioners to understand the types of situations in which it will be necessary to think about offering assessments flexibly, particularly in terms of timing and location.
Carers UK	Guideline	011	020	The first bullet point in the list needs to be split into two separate bullet points. This is because a local authority *must* be informed – it is not an either/or situation. This would be correct and in line with the Care Act.	Thank you for your suggestion. We have amended the recommendation to make it clearer that informing any delegated care organisation would be in addition to the local authority. It now states "inform the local authority (and/or any delegated care organisation) that a carer's needs have been identified"
Carers UK	Guideline	011	025	Re. the second bullet point, this is particularly important as the support for the person cared for will impact either positively or negatively on the carer.	Thank you for your comment in support of the guideline.
Carers UK	Guideline	012	002	Insert additional bullet point after 'arrangements for replacement care to allow a carer to work or to attend education and training' – add: *"arrangements for replacement care to allow a carer to attend medical appointments or treatment that the carer has scheduled."*	Thank you for your comment. This list of examples has been removed from the recommendation as the committee, on reflection, considered that it could be misleading. The recommendation emphasises the importance of identified outcomes without providing examples as to what those outcomes might be.
Carers UK	Guideline	013	General	New point under 'Flexibilities to support employment" section – add: *"Flexible working and other employment policies (including carer*	Thank you for your comment. It is beyond the scope of the guideline to make such recommendations.

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				specific policies) should be made available pre-interview for prospective employees when advertising employment opportunities." This is in light of the Good Work consultation from BEIS.	
Carers UK	Guideline	013	006	Insert the phrase *"and welfare"* between "benefits" and "advice" – full sentence to read: *"Local authorities should ensure carers have access to tailored advice about balancing work, education or training with caring, including associated benefits and welfare advice".* This is to ensure that this covers all kinds of financial assistance, not just benefits.	Thank you for this suggestion, which the committee agreed to add to the recommendation.
Carers UK	Guideline	013	017	After "work", include the sentence: *"Specific policies regarding carers and support for carers should be transparent and publically available."*	Thank you for this comment. This goes beyond the remit of NICE guidelines, which make recommendations about the development of local but not national policy. For this reason the committee were unable to make the suggested amendment.
Carers UK	Guideline	013	021	Include *"or fixed hours or shifts"* after "Examples might include flexible hours…" This has been raised by carers as being particularly important in hyper-flexible working environments. These carers rely on routine because alternative care/support has to planned and routine is therefore easier to manage.	Thank you for your comment. We have amended the recommendation in line with your suggestion.
Carers UK	Guideline	014	General	Add new point after 1.4.9. To say: *"Health and social care organisations should ensure that their own employees who are unpaid carers are also similarly supported".*	Thank you for your comment. Health and social care organisations support for own employees are covered by recommendations for workplaces.
Carers UK	Guideline	014	004	Add: *"…and that any skills individuals have gained through caring are recognised and considered".*	Thank you for your comment. The committee considered that the recommendations need to be kept concise and focused. The expertise carers have gained by experience are recognised in other recommendations.
Carers UK	Guideline	014	007	Add at the end: *"…as well as digital access and telephone appointments."*	Thank you for this suggestion. We have amended the recommendation to incorporate this.

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Carers UK	Guideline	014	011	This needs to be broadened beyond "replacement care" to include other sorts of services that may not be "replacement care" in order for the carer to return to work, education or training. The section on advice and support does not adequately cover the service delivery that carers would be able to access.	Thank you for your comment. The recommendations on replacement care reflect the evidence that was reviewed.
Carers UK	Guideline	014	014	It is vital that digital is seen as a core part of delivering services and support. Add to end of sentence: *"…including any digital, tech-related support that would achieve this goal."*	Thank you for this suggestion. Although we have not amended this particular recommendation in line with your suggestion, we have amended other recommendations in the sections on information and on identification to reflect that digital approaches are a part of delivering services and support.
Carers UK	Guideline	014	024	We are questioning why this is for carers who care for more than 20 hours a week? Age UK research suggested an impact takes place from 5 hours of care per week.	Thank you for your comment. Whilst the recommendation does not preclude carers who work less than 20 hours a week, we felt the recommendation was clear and the emphasis was correct and based on the evidence we identified - suggesting that caring for 20 hours or more per week, compared to caring less than 20 hours per week, was a significant factor in causing carers to leave work.
Carers UK	Guideline	014	025	The reference to reviewing replacement care (and other forms of support) regularly to respond to changing working patterns and career development also needs to go hand in hand with reviewing care and support if the caring situation changes with the objective of giving the carer the option of working. Although this appears later more generally, it would be helpful to reinforce this practice here.	Thank you for your comment. Whilst, the committee wanted to keep this recommendation concise and focused they supported the sentiment in the comment. We have added a recommendation to the assessment section to state that any carers support plan should be monitored and reviewed on an ongoing basis.
Carers UK	Guideline	015	004	Add: *"…should also encourage voluntary organisations to share their knowledge of supporting carers".*	Thank you for your comment. This particular recommendation is about the responsibilities of local authorities to keep carers informed about local services. We have added to the guideline in a number of areas to emphasise the importance of carers working as equal partners alongside practitioners and the importance of involving carers directly in the design and delivery of training for example.
Carers UK	Guideline	015	005	Both pharmacies and religious groups need to be added to the list of sources of advice and support.	Thank you for your comment. We have added community and faith groups as additional examples of available community services and other sources of support and advice.

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Carers UK	Guideline	015	005	Add at end: *"The impact of any adaptations should be assessed in relation to the carer and as part of their carer's assessment."*	Thank you for your comment. The committee did not think this addition belonged to this recommendation on keeping carers regularly informed about community services and other sources of support and advice.
Carers UK	Guideline	015	012	Is it possible to clarify "regularly" more with an example or examples?	Thank you for your comment. The committee did not wish to be more specific with respect to the frequency as it would to some extent depend on the individual circumstances of the carer.
Carers UK	Guideline	015	015	Add to first bullet point: *"…as well as information about nutrition and hydration."*	Thank you for your comment. The committee considered that reference in the recommendation to the "health condition, disability or needs" covered this and that an exhaustive list of examples was not necessary.
Carers UK	Guideline	015	016	Add: "Recent research (2019) from Carers UK shows that this is not currently the case".	Thank you for your comment. We have made sure to make reference to context information from Carers UK in the context section of the guideline.
Carers UK	Guideline	018	021	Change 'mental health problem' to 'mental health *condition'*.	Thank you for your comment. The widely accepted term used by NICE for the conditions we are referring to is 'mental health problem' and so we have maintained this here.
Carers UK	Guideline	019	003	Add to the last bullet point: *"…such as, financial planning, and on retirement, pensions, and wills, etc."*	Thank you for your comment. The items covered in this list were based upon what was suggested by our evidence search on content of psychosocial and psychoeducational interventions. However we do cover all of these other topics in other dedicated parts of the guideline.
Carers UK	Guideline	019	009	Add third bullet point; *"Early intervention would be best practice to support carers".*	Thank you for your comment. The committee agreed with this point and has added an additional bullet point within this section to emphasise timeliness.
Carers UK	Guideline	019	012	Include additional bullet point in the list – add; *"Timing of the intervention"*	Thank you for your comment. The committee agreed with this point and has added an additional bullet point within this section to emphasise timeliness.
Carers UK	Guideline	019	017	Add *"…and method."*	Thank you for your comment. In this case the committee felt that method was suitably covered by the term 'format'.
Carers UK	Guideline	020	016	Need to add more examples, including; *"when a carer enters education/employment", "if they become a sandwich carer', "if there is a significant change in their life – e.g. a health condition", "the need for additional support if a sibling moves away and can no longer care", "an additional caring responsibility for a parent or friend".*	Thank you for your comment. The committee has added some additional examples to this recommendation but agreed that the examples are not meant to be an exhaustive list.

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Carers UK	Guideline	023	018	Change "problem" to *"condition"*	Thank you for your comment. The widely accepted term used by NICE for the conditions we are referring to is 'mental health problem' and so we have maintained this here. However, please feel free to contact NICE with feedback on terminology across our publications.
Carers UK	Guideline	024	003	We suggest you use the following definition for carers' breaks as we feel the current definition in the guideline is too narrow: *"Breaks are essential in helping carers to continue a caring role and to maintain their own health and wellbeing. Carers need a wide range of breaks options to meet their needs effectively. There is no one size fits all – either for carers or for the people they care for. A break is something that carers want to use for themselves. It should be planned, meaningful and positive. The arrangements need to work for both the carer and the person they care for in order to be beneficial and improve carer wellbeing. Carers value breaks for a wide range of reasons – practical, emotional, social and psychological. Being able to take time away from the pressures of a caring role is one of the most frequently-voiced carer demands. Breaks are vital to maintaining relationships with many carers using breaks to spend time with family and friends. Despite this, access to breaks can be difficult and many carers just don't get the breaks they need."*	Thank you for your comment. With these definitions we felt it was important to give a short and concise outline of what the concepts are, rather than an explanation of how they are currently being used in practice or their value to different individuals. Consideration of these other points can be found in the evidence reports.
Carers UK	Guideline	024	004	"Respite care" is not disability positive language and should be changed to breaks.	Thank you for your comment. We agree and so 'breaks' is the term we are using throughout this guideline. We have referenced the term 'respite care' in the glossary to recognise that it still holds meaning for some that have used it previously, but to give clarity that 'break' is the term we use presently.
Carers UK	Guideline	024	009	Replace "Replacement care" with *"Care"*	Thank you for your comment. Replacement care refers to the subtype of care we are referring to, and is not interchangeable with all other types of care.
Carers UK	Guideline	024	009-016	The section on replacement care is problematic. It assumes that carers will/do provide care, whereas the primary duty of a Local Authority is	Thank you for your comment. We received several comments calling us to reinforce the message that carers must be willing and able to provide

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				to ensure that the needs of the person needing care are met. Carers have to be both willing and able to care.	care. Although we are keeping the definition for replacement care used here, we have reviewed our recommendations to make sure your point is better reflected through the whole guideline.
Carers UK	Guideline	024	010	Replace the first sentence with the following: *"Replacement care is care that a person with care and support needs has that replaces care normally given by a regular carer".*	Thank you for your comment. We reviewed the wording as well as the sources that we have based our definition on. The committee agreed that our current wording already reflected these points.
Carers UK	Guideline	031	024	After "…community staff" add: *"…with a follow up to check that the carer is coping and the arrangements are working effectively."*	Thank you for your comment. In this section we comment on the evidence, but unfortunately we didn't have evidence to suggest about follow-up checks. However we have added a section about 'after carers assessments' to make sure that those who conduct an assessment follow up about implementation with other organisations.
Carers UK	Guideline	035	005-007	In this section, only negative costs are mentioned, rather than the positive costs of employers retaining key staff. Estimates of savings from employee retention range between 0.5 to 1.5 times the annual salary of a staff member. We are concerned that flexibility is only considered in negative cost terms whereas practice suggests there are potentially also other savings or benefits for employers.	Thank you for this comment. We have amended the Rationale and Impact section to acknowledge this point, which was already made in the committee discussion of evidence and Appendix J of Evidence Review D.
Carers UK	Guideline	037	015-017	We don't agree with this statement about the lack of evidence that carers passports as a means of improving support for carers. This is contained in the background evidence pack on the website that Carers UK hosts. This includes evidence gathered from those having implemented schemes across different settings and the benefits to organisations overall, staff, patients and carers, workers, etc. The evidence gathering phase to inform this work consisted of a few basic questions plus an in-depth interview. Carers UK's evidence is also informed by carers' lived experiences and Carers UK received 1,700 responses from carers calling for evidence and lived experience of a range of different carers' passports. A number of carers were also interviewed as part of the research process based on these responses.	Thank you for your comment and for highlighting the growing evidence around carers passports. The protocol specified that only evidence from peer reviewed studies would be searched and reviewed, as that is used to benchmark more rigorous research. . But through our research recommendation on the topic we hope that further research will produce something we can make future recommendations from, and draw upon the basis of the research you have identified.

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Carers UK	Guideline	038	012	Add: *"Digital support should be available."*	Thank you for your comment. We have now added more emphasis on digital support throughout the guideline after receiving significant feedback from stakeholders that this was important.
Challenging Behaviour Foundation	Guideline	General	General	It should be acknowledged that some adult carers do not live with their loved one e.g. their child might be in an assessment and treatment unit sometimes hundreds of miles away from home, may be at a residential school / college. Our joint report *Keeping in Touch with Home*, 2016[4] found that many families are discouraged from visiting their children, Local Authorities often fail to fund that travel and phone calls and digital forms of keeping in touch are rarely used. Providing families with the support they need to keep in touch with the children, young people and adults they are caring for when they are away from home is important. The actions that should be taken are outlined in *Keeping In Touch With Home, 2016*[5]	Thank you for your suggestion. In the final version of the guideline in the section on identifying carers, the committee agreed to make reference to the fact that carers may not lived with the cared for person
Challenging Behaviour Foundation	Guideline	007	003	**Identifying Carers** Supporting, working and engaging with families and carers is an important consideration in ensuring effective care of people with complex needs. Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs. [6]	Thank you for your comments. We agree with your points, and hope you agree that we address these points with our recommendations about recognising carers and later about ensuring support is accessible to all.

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[4] The Challenging Behaviour Foundation, Mencap, *Keeping in Touch with Home: How to help Children and Young People with Learning Disabilities and Their Families Keep in Touch When They are Living Away From Home,* 2016

[5] The Challenging Behaviour Foundation, Mencap, *Keeping in Touch with Home: How to help Children and Young People with Learning Disabilities and Their Families Keep in Touch When They are Living Away From Home,* 2016

[6] Department for Health, *Valuing People Now:Summary ReportMarch 2009-September 2010,* 2009

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				Families are diverse – their individual circumstances vary, so understanding each family context is essential to offering appropriate support. The family carers of children, young people and adults with severe learning disabilities whose behaviour challenges may be particularly isolated, especially in minority groups. Iriss notes that it is the relative 'invisibility' of BME (Black and Ethnic Minority) carers which means they are not made aware by their local authorities of support which exists for them. [7] Extra efforts need to be taken to reach these hidden groups and this needs to be acknowledged in the standards.	
Challenging Behaviour Foundation	Guideline	007	008	Early identification of carers with lifelong support needs should be a priority –this should be easy to achieve through existing information (e.g. health information regarding children with diagnosed long-term conditions). This will enable planning for long-term support for the family unit (including sibling carers).	Thank you for your comment. We agree, and note that we discuss ways that services can identify carers in the next section.
Challenging Behaviour Foundation	Guideline	7	13	It is important that the right medium is used for identifying carers and sharing information (it is not always going to be through a practitioner). A lot of individuals do not view themselves as family carers and therefore do not always seek out support, as they do not know they are entitled to it.[8] This can make these family carers hard to find through official routes like practitioners. Efforts should be made to ensure information is shared with carers and they are identified on the platforms that they are likely to use and access, regardless of their awareness of support which already exists.	Thank you for your comment. We agree, and note that we discuss these topics in the recommendations that follow.

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[7] Iriss, *Improving Support for BME Carers,* 27th May 2011

[8] Iriss, *Improving Support for BME Carers,* 27th May 2011

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Challenging Behaviour Foundation	Guideline	10	2	**Carers' Assessments** The right to an assessment should lead to a comprehensive assessment of need, followed by a support plan which is implemented and regularly reviewed. There must be a delivery plan with measured outcomes for family carers and identified milestones for local authorities and this needs to be regularly reviewed.	Thank you for your comment. We agree, and hope you feel we have alluded to all of these points in the recommendations that followed within this section.
Challenging Behaviour Foundation	Guideline	15	17	**Carers' Breaks** It can be harder for families of adults with severe learning disabilities whose behaviour challenges to secure short breaks services because of a high level of exclusion from these due to an inability to effectively respond to challenging behaviour. Carers can often receive phone calls in the middle of the night asking them to collect their loved one, cutting their time short, causing plans to be changed at the last minute, and creating disruption and instability for the individual with learning disabilities. [9]	Thank you for your comment. This guideline cannot go into specific detail about different carer support needs or interventions that may be associated with care in relation to a specific condition. The guideline has however tried to be inclusive in its considerations of what works for all adult carers. There are other NICE guidelines that will have more to say about carers role in relation to certain health conditions or social care needs.
Challenging Behaviour Foundation	Guideline	16	21	**Carer training programmes** Individuals with learning disabilities and behaviour which challenges are a significantly marginalised and disadvantaged group. Services which provide support to these individuals are usually specialist and high cost. Staff who support these individuals require specialist and ongoing training and support and where they do not the care is often inadequate. [10]It is essential therefore that their families are provided with targeted and practical information and support which meets their individual needs. Good, early support can prevent future crises. Failure to do this is expensive, both in cost to the individual and their family, and in health and social care costs to respond to the crisis.	Thank you for this comment. This recommendation states that training should be "relevant to carers' circumstances, including the health condition, disability or needs of the person they care for" and the committee considered that this addressed the issues raised in the comment with respect to specialist and ongoing training. Other recommendations address information and support and state that "Health and social care organisations should promote ways of working

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[9] The Challenging Behaviour Foundation, FAQs *My relative has been excluded from his/her local short breaks services because of his/her challenging behaviour- what do I do?*

[10] Healthcare Service Journal, *CQC threatens enforcement action for 'inadequate hospital,* 2019

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				Paving the Way found that the annual cost of intensive support and follow up for seven young people was less than the annual cost of one residential placement[11] (unfortunately residential assessment and treatment units are where individuals are often sent during a crisis). Training for carers needs to complement training received by other professionals supporting their loved one. Stepping Stones in Brighton and Hove[12] highlight good examples of how evidenced based parenting programmes give parents the skills and confidence they need to minimise challenging behaviour. In addition, Bristol Positive Behavioural Support Service[13] highlights how positive behaviour support services can work effectively across school and home. The development and delivery of training should be co-produced with family carers who know the individual and their needs best. [14] Families who are in contact with the Challenging Behaviour Foundation are often not provided with the information or training that they need to support their loved one with severe learning disabilities. Replacement care costs should be considered in the development of carer training programmes.	with carers that acknowledge them as expert partners in care and value their skills and knowledge about the person they care for." There is a section of recommendations on replacement care which are based on the committee's assessment of the evidence and cost-effectiveness.
Challenging Behaviour Foundation	Guideline	18	9	**Psychological and emotional support for carers**	Thank you for your comments. We agree with your points, and hope you agree that we address these points with our recommendations

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[11] The Challenging Behaviour Foundation, Council for Disabled Children, *Paving the Way: How to develop effective local services for children with learning disabilities whose behaviour challenges,* 2014

[12] The Challenging Behaviour Foundation, *Paving the Way,* 2014

[13] The Challenging Behaviour Foundation, *Paving the Way,* 2014

[14] The Challenging Behaviour Foundation, *About Positive Behaviour support, https://www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/positive-behaviour-support.html*

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				There needs to be recognition that families experience trauma too and the impact on them needs to be acknowledged and addressed. When designing psychological and emotional support for carers of people with learning disabilities it is important to recognise that carers are sometimes also providing trauma support to their family member, due to lack of available trauma support for people with severe learning disabilities. There is a lack of appropriate and skilled psychological support for trauma for the individual with learning disabilities and/ autism. If this gap is filled, it is usually by the family members (if they are able to do so). These family members are themselves already traumatised by their experiences. This means that family members, who are often suffering the effects of PTSD, are providing counselling support for their traumatised relatives without any access to support themselves, or any guidance, advice, or coping strategies. Those providing psychological and emotional support need to have a good understanding of the diagnosis and experiences of the person the carer is supporting. Otherwise, family carers can be retraumatised by repeatedly explaining their situation or experiences.	about ensuring that staff are trained and support is accessible and relevant to the individual carer.
Compassion in Dying	Guideline	022	001	Compassion in Dying has supported people to plan ahead and to understand the laws and policies around end-of-life decision-making for over 12 years. Therefore and with reference to the numerous calls we receive on our Information Line from carers who are struggling to have their loved one's care preferences and their own Power Of Attorney understood and respected by health and care professionals, we strongly recommend adding the following point before 1.9.7: "Ask carers if they are aware of and if yes, have copies of, any advance care plans that the person being cared for has already made. These	Thank you for your comment. While this guideline does include recommendations on advance care planning and the involvement of carers, the committee felt that the important points you raise are more appropriately dealt with (and in greater detail) the NICE guideline on decision making and mental capacity.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

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				plans include Advance Decisions to Refuse Treatment, Advance Statements, Lasting Powers of Attorney (LPA) for Health and Welfare and DNAR orders, and treatment decisions must be made accordingly." We hear many examples of carers who have either Power of Attorney for a loved one, or hold copies of other planning documents only to find healthcare professionals don't accept or understand these documents and their legal status. For example: *The caller's husband is dying at home and they have 'hospice at home' support. The caller is her husband's main carer and he has made her his LPA with the authority to make life-sustaining treatment decisions. The hospice at home staff want a DNAR form for her husband but she thinks the LPA is enough. Hospice people are not listening to her and said that if an ambulance is called they will go "gung ho" on him [i.e. insist on resuscitation and other life-sustaining measures] and she really doesn't want that to happen to him."* *"I have Lasting Power of Attorney for Health and Welfare for my father, why are the doctors not listening to me?"* Further information in support of this recommendation can be found in our reports - "I wish I had known…"- https://compassionindying.org.uk/library/i-wish-i-had-known/ the launch of which was attended by NHS England, the British Medical Association (BMA) and the Royal College of Physicians (RCP). - Advance Decisions: uncovering what GPs need https://compassionindying.org.uk/wp-content/uploads/2019/08/CID_ADVANCE-DECISIONS-GP-REPORT.pdf.	
Compassion in Dying	Guideline	022	003	For effective advance care planning to take place it is vital that the tools available for doing so are well understood by patients, carers and healthcare professionals. Not being specific about the legal tools	Thank you for your comment. The focus of our guideline is primarily about the carers, while the focus of your recommendation pertains more to the options which should be offered for the sake of the person

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				available risks denying people the ability to make decisions about their care in a meaningful way. Therefore, for clarity and ease of reference, please add: "Explain the different advance care planning options available (i.e. Advance Decisions to Refuse Treatment, Advance Statements, Lasting Powers of Attorney for Health and Welfare, health and welfare deputyships) depending on whether or not the person cared for has the capacity to make decisions about their own treatment and care." Examples from our services in support of this addition are as follows: From a caller to our Information Line: *"Before he lost capacity, the social care team asked my brother who he would like to make decisions in case he cannot do so himself. He said me and wrote it down on a document, but the care team never mentioned LPAs and now I don't have the necessary legal paperwork [and status] to support my brother."* From our training delivery: *At a recent workshop on advance care planning at a hospital, the Compassion in Dying Training Lead observed that the 'End-of-Life Care Champions' were not aware of the legal tools available for planning ahead.*	being cared for. It was agreed not to make that recommendation within this guideline. However these points are covered in the other NICE guideline which we refer the users to.
Compassion in Dying	Guideline	022	017	With reference again to the isolation felt by some of the carers who contact our Information Line, please add the text in italics to 1.9.11: When managing medication at the end of life, follow the principles of involving carers and the dying person, as described in NICE's guideline on care of dying adults in the last days of life; *ensure that the purpose, pros and cons of the various medications and decisions being made are clearly explained and discussed with the carer; and give them an opportunity to ask questions.*	Thank you for your comment. We considered the addition to the recommendation proposed, but concluded that the principles about explaining clearly and giving opportunities to ask questions are already set out in the section about giving carers information
Dementia UK	General	General	General	Dementia UK is pleased to contribute to this necessary *Carers: provision of support for adult carers guidance GID-NG10046* and we	Thank you for your comment. Our scope establishes that this guidelines only covers England. However we agree that services and policymakers

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				support its development. Our particular focus is on the support of carers of people living with dementia. We welcome this guideline focussed on adult carers and recognise the connection to *Dementia: assessment, management and support for people living with dementia and their carers* *NICE guideline [NG97] (NICE 2018). Whilst we recognise that* the way NICE was established in legislation means that guidance is officially England-only, we highlight the importance of considering the impact and influence of and from Wales, Scotland and Northern Ireland in evidence, experience and practice.	from other nations of the UK may wish to consider it's applicability to their setting.
Dementia UK	General	General	General	We would like to highlight the importance of recognising carers as both clients in their own right as well as caregivers. Whilst the draft guideline suggests actions that would fall into these two categories, we would recommend a stronger emphasis on the systematic assessment and support of carers as *'co-workers'* in supporting patients; to ensure carers have the information, skills and equipment for this role and as '*clients'* in their own right to preserve their own wellbeing and health (Ewing and Grande 2013, 2018), see: ○ *Ewing G, Grande GE (2013). Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice at home: a qualitative study. Palliative Medicine; 27(3): 244-256.* *Ewing G and Grande GE. (2018) Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK.*	Thank you for your comment. The committee agree about the importance of the points you raise and have emphasised this more strongly in the guideline now. We have added a new section in the guideline about the importance of practitioners involving and working with carers and seeing carers as equal partners in the planning and delivery of care (always in the context of the consent of the person being cared for).
Dementia UK	General	General	General	Dementia UK has experience of successfully implementing the Admiral Nurse approach which supports family carers of people living with dementia and would be willing to submit its experiences to the NICE shared learning database. See: ○ *Aldridge, Z., Burns, A. and Harrison Dening, K., 2019. ABC model: A tiered, integrated pathway approach to peri-and*	Thank you for your comment and for sharing this information with us. The NICE shared learning database can be accessed here https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies We would encourage you to submit your examples.

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				post-diagnostic support for families living with dementia (Innovative Practice). Dementia, p.1471301219838086 ○ *Gridley, K., Aspinal, F.J., Parker, G.M., Weatherly, H.L.A., Neves De Faria, R.I., Longo, F. and Van Den Berg, B., 2019. Specialist nursing support for unpaid carers of people with dementia: a mixed-methods feasibility study. Health Services and Delivery Research, pp.1-232.)* *Maio, L., Botsford, J., Harrison Dening, K. and Iliffe, S., 2019. Challenges and Lifelines: What Was Important to Family Carers of People With Dementia Accessing the Admiral Nurse Services, a Specialist Family-Centered Dementia Support?. SAGE Open, 9(2), p.2158244019856947.*	
Dementia UK	General	General	General	Admiral Nursing is the only specialist nursing dementia service in the UK with a specific focus on carers. In addition to providing emotional support and helping people to live positively with the condition, Admiral Nurses seek to join up different parts of the health and social care system so that needs can be addressed in a coordinated way. Dementia UK would be willing to submit its experiences to the NICE shared learning database. See: ○ *Gridley, K., Aspinal, F.J., Parker, G.M., Weatherly, H.L.A., Neves De Faria, R.I., Longo, F. and Van Den Berg, B., 2019. Specialist nursing support for unpaid carers of people with dementia:: a mixed-methods feasibility study. Health Services and Delivery Research, pp.1-232.* ○ *Gridley, K., 2018. Understanding the outcomes of specialist nursing: the continuing importance of relationships for carers of people with dementia. International Journal of Integrated Care, 18(s2).* *Maio, L., Botsford, J., Harrison Dening, K. and Iliffe, S., 2019. Challenges and Lifelines: What Was Important to Family Carers of People With Dementia Accessing the Admiral Nurse Services, a Specialist Family-Centered Dementia Support?. SAGE Open, 9(2), p.2158244019856947.*	Thank you for your comment and for sharing this information with us. The NICE shared learning database can be accessed here https://www.nice.org.uk/about/what-we-do/into-practice/shared-learning-case-studies We would encourage you to submit your examples.

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Dementia UK	Guideline	001	007	We are concerned that the guideline may imply that informal carers who support e.g. family members in the care home setting are not considered to be carers. The guideline states that a carer provides health and social needs. As such the latter maybe provided within a care home still. Page 20, line 2 mentions changes in the caring role when a person is transferred to a care home so we feel it would be helpful to list care homes on this page too, see: ○ *Reid, R.C. and Chappell, N.L., 2017. Family involvement in nursing homes: Are family caregivers getting what they want?. Journal of Applied Gerontology, 36(8), pp.993-1015.* ○ *Mueller, C., Lautenschlaeger, S., Meyer, G. and Stephan, A., 2017. Interventions to support people with dementia and their caregivers during the transition from home care to nursing home care: A systematic review. International journal of nursing studies, 71, pp.139-152.* We would also like to highlight other settings that carers may need support e.g. the workplace, hospice, prisons and carers from a distance, see: ○ *Weatherhead, I., Eades, L., Harrison Dening, K. and Weidner, W., 2017. Admiral Nurses delivering workplace clinics for family carers: Innovative practice. Dementia, p.1471301217705547.* ○ *McKay, T., Comfort, M., Lindquist, C. and Bir, A., 2016. If family matters: Supporting family relationships during incarceration and reentry. Criminology & Pub. Pol'y, 15, p.529.* ○ *Diffin, J., Ewing, G., Harvey, G. and Grande, G., 2018. Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: a qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention. BMC palliative care, 17(1), p.129.* ○ *Franke, A., Kramer, B., Jann, P.M., Zentgraf, A., Otto, U. and Bischofberger, I., 2019. Current findings on distance*	Thank you for your comment. The committee were certainly mindful of the fact that the provision of care and support by carers does not necessarily end when the cared for person moves into a care home. This is reflected in the recommendations that practitioners should be aware of this fact and should provide carers with the advice and information needed during and following a change (but not end) in the caring role, which includes when the cared for person moves away from home. In terms of other settings in which carers may need support, the committee were somewhat limited in the extent to which they draft recommendations for these areas since the remit of NICE guideline, in terms of audience, is health and social care practitioners. However, the importance of support for carers around work, education and training was acknowledged by stakeholders and in the scope for this guideline and it was therefore included as the specific focus of one of the evidence reviews. As a result the committee were able to draft a number of recommendations designed to support carers wishing to remain in, enter or return to work, education and training including recommendations directed at services providing welfare rights advice or back to work or education training as well as specifically at workplaces. Support for carers during the end of life period of the cared for person was also recognised as a key issue for this guideline with a specific evidence review on this subject. The committee were able to draft a number of recommendations about the provision of information and support to carers during the end of life period, specifically about advance care planning and also about support to carers to provide support to the dying person. You specifically mention evidence relating to the CSNAT, which was included in the review about carers assessments and used, with other relevant evidence, to draft recommendations in that section of the guideline. Finally, although there was not a specific review question about support for LGBTQ carers, the committee were able to draft a recommendation based on evidence about the perceived importance of non-discriminatory approaches to carer training programmes. Specifically,

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				caregiving: What do we know and what do we not (yet) know?. Zeitschrift fur Gerontologie und Geriatrie. We would also like to highlight the diversity of carers e.g. non family members, LGBTQ, see: ○ *Greenwood, N., McKevitt, C. and Milne, A., 2018. Time to rebalance and reconsider: are we pathologising informal, family carers?. Journal of the Royal Society of Medicine, 111(7), pp.253-254.* ○ *Greenwood, N., 2018. Supporting black and minority ethnic carers.* ○ *Kiraly, M., 2018. Nonfamilial kinship carers—Who are they and what support do they need to nurture children?. Child & Family Social Work.* *Martin, J., Butler, M., Muldowney, A. and Aleksandrs, G., 2019. Carers of people from LGBTQ communities interactions with mental health service* providers: Conflict and safety. *International journal of mental health nursing*, *28*(3), pp.766-775.	they recommended that training programmes should be inclusive and address the needs and preferences of diverse groups, such as lesbian, gay, bisexual and transgender carers and carers from diverse ethnic, religious and cultural backgrounds.
Dementia UK	Guideline	005	020	Our experience is that it is helpful to also explore how frequently carers may wish information and advice and recognise that wishes and preferences may change over time.	Thank you for your comment. The committee believe this is already addressed in the recommendations, for example in the section which is now described as 'communicating with carers' a recommendation states that practitioners should take into account the fact that carers information needs will change over time and whenever their circumstances or their caring role changes.
Dementia UK	Guideline	007	001	We would like to highlight the importance of recognising carers as both clients in their own right as well as caregivers. Whilst the draft guideline suggests actions that would fall into these two categories, we would recommend a stronger emphasis on the systematic assessment and support of carers as 'co-workers' in supporting patients, to ensure carers have the information, skills and equipment for this role and as 'clients' in their own right to preserve their own wellbeing and health (Ewing and Grande 2013, 2018), see: ○ *Ewing G, Grande GE (2013). Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice*	Thank you for your comment. In response to yours and other stakeholder comments the committee agreed to place a greater emphasis in the final guideline on the importance of treating carers as key members of the team supporting the cared for person. With respect to the two papers you list, Ewing and Grande 2013 was located by the search for the review of evidence about the acceptability of carers assessment tools. The paper was excluded on the grounds that it aimed to identify carer needs and then describe how the findings were used to create a carers assessment tool (the CSNAT). This was not judged to fit the protocol because it did not describe carers' experiences

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				at home: a qualitative study. Palliative Medicine; 27(3): 244-256. *Ewing G and Grande GE. (2018) Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK.*	of having their needs assessed. The second paper (Ewing and Grande, 2018) was not included in the review on carers assessments because it was judged not to meet the study design, as it reports 'recommendations' rather than research findings. Nevertheless, other publications and evidence by Ewing and colleagues were included in the evidence review on carers assessments and together with other relevant data, used as a basis for recommendations in that section of the guideline. The papers (Ewing 2016 and Ewing 2018) provided data about the benefits of the CSNAT, in particular the role of the assessment tool in legitimising support for carers themselves, assisting in the communication of carer support needs and as a means of facilitating discussions with carers about care giving and support during the end of life period. The committee concurred with these findings and therefore drafted recommendations based on evidence about the CSNAT and in line with many of the points you have highlighted in your comment. For example they recommended that health and social care practitioners carrying out carers assessments should ensure the assessment covers all relevant aspects of the carers health, wellbeing and social care needs. They also emphasised the importance of ensuring assessments are jointly produced with carers, reflecting what matters most to them (as opposed to taking a one size fits all approach). The committee also drew on the CSNAT evidence and their own related experience to make practitioners aware that a well conducted carers' assessment may in itself act as a therapeutic intervention or means of preventing future problems.
Dementia UK	Guideline	008	013	Our experience is that transitions between settings is an important time in the person and their carers lives and we recommend a strong emphasis on this in the guideline, see: ○ *Hirschman, K., Shaid, E., McCauley, K., Pauly, M., Naylor, M., (September 30, 2015) "Continuity of Care: The Transitional Care Model" OJIN: The Online Journal of Issues in Nursing Vol. 20, No. 3,*	Thank you for your comment. Evidence on the transitional care model as well as other approaches was included in the review underpinning this section of the guideline and helped to inform the recommendations. To avoid duplicating other NICE guidelines, the committee agreed it was relevant and appropriate to signpost from this guideline to NICE NG27 where there are detailed recommendations about supporting people and their carers through transitions between inpatient hospital settings and community or care home settings. The

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				Hirschman, K.B. and Hodgson, N.A., 2018. Evidence-based interventions for transitions in care for individuals living with dementia. The Gerontologist, 58(suppl_1), pp.S129-S140.	studies you have cited did not pertain to the carer outcomes that would have met our evidence search protocol's inclusion criteria for the current guideline, however their findings reinforce the recommendations we have made.
Dementia UK	Guideline	008	018	This recommendation can be a challenging in practice because of multiple IT systems across providers leading to a lack of shared understanding or systems for informed consent and co-ordinated information between services. It is helpful to emphasise the importance of shared consent and record keeping *Riordan, F., Papoutsi, C., Reed, J.E., Marston, C., Bell, D. and Majeed, A., 2015. Patient and public attitudes towards informed consent models and levels of awareness of Electronic Health Records in the UK. International journal of medical informatics, 84(4), pp.237-247.*	Thank you for your comment. The committee agrees with you that this is an important point but on the basis of the evidence they reviewed were unable to provide greater detail in the recommendation itself. The study you have cited would not have been located by the evidence searches because they did not specifically relate to any of our review areas. They have however provided additional information which were used in the supporting rationale and impact section for this recommendation.
Dementia UK	Guideline	008	018	We know from our experience that sometimes carers do not have separate records or identifying client numbers to that of the patient, which can make separate record keeping a challenge, see: *Diffin, J., Ewing, G., Harvey, G. and Grande, G., 2018. Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: a qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention. BMC palliative care, 17(1), p.129.*	Thank you for your comment. The committee recognised that practice in this area is currently inconsistent but that with this recommendation, the approach described will become standardised and identification and recording of carers will improve. The study you have cited was not included in our evidence review on carers assessment because the study was not designed to provide data about carer's experiences of needs assessments. Nevertheless, findings from other studies published by the same authors were included in the review and combined with other relevant evidence provided the basis for drafting recommendations which emphasised the importance of conducting holistic assessments of the carer's needs in their own right. There are also recommendations about the identification of carers, for example one stating that health and social care organisations should ensure their policies and systems encourage the identification of carers, including by developing formal processes to help them do so.
Dementia UK	Guideline	011	026	We support the need for individual carer assessment because of its long-term benefits, see: o *Seddon, D. and Robinson, C., 2015. Carer assessment: continuing tensions and dilemmas for social care*	Thank you for your comment and support. The studies you have cited were not included in our evidence review because they do not meet the protocol's inclusion criteria. However their conclusions support our findings and reinforce the recommendations we have made.

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				practice. Health & social care in the community, 23(1), pp.14-22. *Lopez Hartmann, M., De Almeida Mello, J., Anthierens, S., Declercq, A., Van Durme, T., Cès, S., Verhoeven, V., Wens, J., Macq, J. and Remmen, R., 2019. Caring for a frail older person: the association between informal caregiver burden and being unsatisfied with support from family and friends. Age and Ageing.*	
Dementia UK	Guideline	013	001	We value the emphasis on supporting carers to work because our experience is that financial considerations have significant impacts on carers. We also suggest a highlight on the needs of carers in the workplace, see: ○ *Gardiner, C., Taylor, B., Robinson, J. and Gott, M., 2019. Comparison of financial support for family caregivers of people at the end of life across six countries: A descriptive study. Palliative medicine, p.0269216319861925.* *Weatherhead, I., Eades, L., Harrison Dening, K. and Weidner, W., 2017. Admiral Nurses delivering workplace clinics for family carers: Innovative practice. Dementia, p.1471301217705547.*	Thank you for your comment and support for these recommendations. In line with your comment we have added further clarification to our recommendations about what might support carers within the workplace. The studies cited are not directly relevant to any of our evidence reviews so they were not included as a basis for the recommendations. However it is reassuring that their findings reinforce the recommendations we have made on the needs of carers in the workforce.
Dementia UK	Guideline	013	001	It is our experience to also consider the needs of a carer returning to work after the patient has died, i.e. bereavement supports needs at work, see: *Watts, J.H. and Cavaye, J., 2018. Being a Former Carer: Impacts on Health and Well-Being. Illness, Crisis & Loss, 26(4), pp.330-345.*	Thank you for your comment. The recommendation on extending support for people when their care role is finished would include bereavement support.
Dementia UK	Guideline	016	005	It is our experience to also consider the needs of a carer returning to work after the patient has died, i.e. bereavement supports needs at work, see: ○ *Watts, J.H. and Cavaye, J., 2018. Being a Former Carer: Impacts on Health and Well-Being. Illness, Crisis & Loss, 26(4), pp.330-345.* *Mattock, S. and McIntyre, A., 2016. Exploring the role of occupation for spouse-carers before and after the death of a spouse with dementia. British Journal of Occupational Therapy, 79(2), pp.69-77.*	Thank you for your comment. The committee considered that the recommendations relating to supporting a carer return to work, particularly with respect to "tailored advice", would include carers wanting to return to work after the one they cared for had died. In addition, the recommendation on extending support for people when their care role is finished would include bereavement support.

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Dementia UK	Guideline	016	21	We support education and training programmes for carers in a range of activities, see: ○ *Dalton, J., Thomas, S., Harden, M., Eastwood, A. and Parker, G., 2018. Updated meta-review of evidence on support for carers. Journal of health services research & policy, 23(3), pp.196-207.* ○ *Lambert, K., Rock, C., Whitaker, W. and O'Brien, J., 2019. 136 Empowering patients and carers: a programme to encourage 'thinking ahead'in the supportive phase of a palliative cancer diagnosis.* *Caswell, G., Hardy, B., Ewing, G., Kennedy, S. and Seymour, J., 2019. Supporting family carers in home-based end-of-life care: using participatory action research to develop a training programme for support workers and volunteers. BMJ supportive & palliative care, 9(1), pp.e4-e4.*	Thank you for your comment. We agree that Dalton reports findings that are relevant to the guideline, in particular reviews D, E and F. However unfortunately the methodology used does not fit our review protocols. Systematic reviews were considered the best available evidence for training programmes. Dalton et al clearly state that they conducted a 'rapid meta-review', which is not as exhaustive as a systematic review and has limitations, which are transparently described by the authors.Lambert et al. was a poster presentation and so did not meet our inclusion criteria Caswell et al. was published too recently to have been picked up by our literature search. However, it would not meet the inclusion criteria for our review because, as a participatory action research paper, it is not an RCT and does not collect or present any qualitative findings in a way that fits our protocol. However the conclusions in this paper are consistent with our findings and the recommendations we have made.
Dementia UK	Guideline	018	003	We welcome supporting carers in the use of adaptations and equipment but highlight that there can be a gap between referral, assessment and delivery of support or equipment which can delay e.g. transfer from hospital to home. Access to these services can vary geographically.	Thank you for your comment. The committee recognised that there is variability between areas in supporting carers but considered their recommendations would support best NHS and social care practice as well as reinforcing current legislation.
Dementia UK	Guideline	020	001	Please could it be considered to mention care homes in page 1, line 7 to match the wording here see point 5.	Thank you for your comment. The committee considered that the bullet "moves away from home" encompasses the situation where the person cared for transitions to a care home setting, and that information, emotional and practical support is recommended for the carer.
Dementia UK	Guideline	021	001	It may be helpful here to mention the Carers Support Needs Assessment Tool (CSNAT) and Daffodil Standards here as examples of robust carer assessment at the end of life, see: ○ *Ewing G, Grande GE (2013). Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice at home: a qualitative study. Palliative Medicine; 27(3): 244-256.* ○ *Ewing G and Grande GE. (2018) Providing comprehensive, person-centred assessment and support for family carers*	Thank you for your comment. Evidence related to CSNAT (Ewing 2016 & 2018) has been appraised elsewhere in evidence report C, and the evidence in this review has been used to inform the committee's recommendations on carers assessment.

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				towards the end of life: 10 recommendations for achieving organisational change. London: Hospice UK. *Millington-Sanders, C. and Noble, B., 2018. New UK general practice core standards for advanced serious illness and end of life care.*	
Dementia UK	Guideline	021	001	Hospices are also able to support carers here.	Thank you for your comment. Recommendations for practitioners in this section would include those working in hospices.
Dementia UK	Guideline	022	014	It is our experience that supporting carers in accessing and communicating with health and social care practitioners is also important here (e.g. out of hours) as well as considering anticipatory and future bereavement support and needs.	Thank you for your comment. The recommendations already made in previous sections about the importance of accessibility and communication apply equally to this section. In recognition of the comments we received we have also amended our recommendations in the section about changes to the caring role specifying that carers should be offered information and support for issues that arise around bereavement.
Dementia UK	Guideline	024	017	We support the recommendations for research.	Thank you for your support for this particular section of the guideline.
Dementia UK	Specific Question	Comment Form	N/A	***Q. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why****?* A. Dementia UK welcomes the Carers: provision of support for adult carers guideline and recommends that this and other guidelines (e.g dementia) are seen as dovetailing in with each other rather than individual guidelines in themselves. We believe individual assessment of carers will have the biggest impact if the assessment care plan can then be actioned. Implementation of actions will be the biggest challenge because of financial, capacity and competency considerations.	Thank you for your response to this question which is helpful for implementation of the guideline. The committee considered that more flexible and individualised assessments could have a resource impact but they also believed that this was consistent with statutory requirements.
Dementia UK	Specific Question	Comment Form	N/A	***Q. Would implementation of any of the draft recommendations have significant cost implications?*** A. Dementia UK believes the economic considerations of informal carers as well as different models of carer support is essential and will have significant cost implications, see: *Longo, F., Neves De Faria, R.I., Parker, G.M., Gridley, K., Aspinal, F.J., Van Den Berg, B. and Weatherly, H.L.A., 2019. Investigating the economic case of a service to support carers of people with dementia:*	Thank you for your response to this question which is helpful for implementation of the guideline.

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				a cross-sectional survey-based feasibility study in England. Health and Social Care in the Community.	
Dementia UK	Specific Question	Comment Form	N/A	**Q. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)** A. Dementia UK has experience of successfully implementing an approach aimed at supporting family carers of people living and dying with dementia and would be willing to submit its experiences to the NICE shared learning database, see: *Maio, L., Botsford, J., Harrison Dening, K. and Iliffe, S., 2019. Challenges and Lifelines: What Was Important to Family Carers of People With Dementia Accessing the Admiral Nurse Services, a Specialist Family-Centered Dementia Support?. SAGE Open, 9(2), p.2158244019856947.*	Thank you for your response to this question which is helpful for implementation of the guideline. We would welcome Dementia UK submitting this to the NICE shared learning database (SharedLearning@nice.nhs.uk)
Department of Health and Social Care	Guideline	General	General	How do NICE plan to promote guidelines? Clinicians and practitioners might be more used to looking for them, but this has a wider audience (e.g. LAs, voluntary service providers etc.) and carers.	Thank you for your comment. The publication will be available for all on the NICE website and further publicised at its launch. Care has been taken to keep the layout and terminology as accessible to the public as possible.
Department of Health and Social Care	Guideline	General	General	We feel that the introduction could set the reasons why the Guideline will be of benefit not only to carers but to the agencies themselves to introduce policies that support carers. It is not clear how the guideline should be used. At present there is no obligation or duty placed on health and social care agencies to implement the Guidance except in respect of those duties placed on them by the Care Act 2014. The Guideline does not give a carer the "right" to invoke the recommendations it sets out if he/she feels the support being given is not adequate. It merely sets out "good practice" for the benefit of those agencies who decide to implement the Guideline. What will happen in those areas where the health and social care agencies do not endorse the Guideline and limit their input to what the Care Act 2014 sets out? As mentioned, the only statutory duties placed on the authorities are those set out in the Care Act 2014 (to carry out carers	Thank you for your comment, in response to which the committee agreed to add further detail to the guideline introduction. Information about who the guideline is for is clearly set out and covers commissioners and provider organisations as well as carers themselves. While it is true that only the 'must' recommendations are mandatory because they are in line with legislation, the social care sector is rapidly becoming familiar with the importance of commissioning and providing services and support in line with evidence based NICE guidelines. Although they understand that NICE guidelines are not mandated by legislation, stakeholders are aware that NICE guidelines contribute to the inspection process of the CQC, which adds further weight to their importance.

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				assessments', information about accessing advocacy support services etc). In our opinion, carrying out these limited duties will in no way guarantee that carers will be well supported. Therefore, the introduction may be able help to explain this.	
Department of Health and Social Care	Guideline	005	012-019	Within this section, we would suggest including the need for those being cared for to consider having a Lasting Power of Attorney (LAP).	Thank you for your suggestion. The committee felt that the point about a Lasting Power of Attorney is more appropriately dealt with in the NICE guideline [NG108] on decision making and mental capacity, to which this guideline signposts.
Department of Health and Social Care	Guideline	007	001-025	Findings from the cross-government *Carers' Employment Digital Discovery project* reinforce the guideline's content around the importance of helping carers to self-identify and access information about their options (particularly around combining work and care) as early in their caring journey as possible. This project, delivered by DWP's Behavioural Science Team and co-funded by DWP, DHSC and GEO, explored the information needs of working people facing decisions about a relative or friend's care, and the extent to which these needs are met by current digital information. The project findings, recommendations and next steps are due to be published in Autumn 2019. Guideline 1.2: The project findings support the **crucial role that health care practitioners** (including doctors, nurses, receptionists, pharmacists etc.) can play in helping to identify carers and signposting them to sources of further support and information. These service providers often come into repeated contact with carers as they accompany the cared for to appointments or pick up prescriptions on their behalf and are in a unique position to proactively identify them. We recognise this can be challenge for services. NHS England's work with the CQC to develop quality standards for carer-friendly GP practices aims to support them to understand and monitor good practice in this area.	Thank you for your comment and for the information provided. The committee felt that the points you make about the important role of GPs and other primary care practitioners in identifying carers is already made in the guideline. Nevertheless in the final version they have added a reference to primary care networks and their potential role, for example in offering and promoting services. This recommendation with strengthened wording and emphasis can be found in the section on providing information and advice to carers. It may also be relevant to the digital discovery project that in the final version of the guideline there is a greater emphasis on the potential role of online and digital resources for the provision of support and information for carers.

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Department of Health and Social Care	Guideline	012 013 014	009-012 001-025 001-026	Findings from the cross-government *Carers' Employment Digital Discovery project* reinforce the guideline's content around the importance of helping carers to self-identify and access information about their options (particularly around combining work and care) as early in their caring journey as possible. This project, delivered by DWP's Behavioural Science Team and co-funded by DWP, DHSC and GEO, explored the information needs of working people facing decisions about a relative or friend's care, and the extent to which these needs are met by current digital information. The project findings, recommendations and next steps are due to be published in Autumn 2019. Guideline 1.3 .14 and 1.4: The findings also support the **importance of employment** in helping carers to maintain their financial and emotional wellbeing, including social networks and sense of independent identity outside of the caring role. Many people do not find out about their employment rights (e.g. to request flexible working) until it is too late and additionally struggle to consider and prioritise their own needs. *We ask that NICE use their guidelines to further reinforce the importance of helping carers to consider their own needs, as well those of the cared for, and that service providers consider them as second order users of healthcare services rather than simply as people fulfilling a social care/support role.* General Comments: Based on the findings of the study, we would ask NICE to also consider **the information and support needs of 'potential carers'** – i.e. those who are still in the process of making decisions about what role to play in caring for a friend or relative – as a discrete group from those of more established carers. Most service providers do not differentiate between the two groups and as a result can make assumptions about people's desire or capacity to take on the carer role. Such assumptions can detrimentally impact both the potential carer and the cared-for person by limiting the options that are	Thank you for your comment. We are pleased to hear that our guideline content on helping carers self-identify and access information reinforces findings from the Carers Employment Digital Discovery Project. We are also pleased that you consider our recommendations about flexible working support the importance of employment in helping carers to maintain their financial and emotional wellbeing. It was our intention to make the wellbeing of carers a central theme across the guideline. The population of this guideline defined in the scope is "Adult carers, aged 18 or over, who provide unpaid care for 1 or more people aged 16 years or over with health and social care needs" and therefore 'potential carers' are outside the scope and evidence on this group was not reviewed.

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				considered for meeting the care needs and leaving people feeling that they have no option other than to meet all the care needs themselves. *We would ask that NICE specifically acknowledge the importance of service providers not making any assumptions about how a person's care needs are going to be met, but instead ensuring that people have the information they need about prognosis, likely changes to care needs over the longer term, and their full range of options for meeting those care needs in order to support them make informed decisions.*	
Department of Health and Social Care	Guideline	013	024-025	NICE will wish to note that The Department for Business, Energy and Industrial Strategy intend to consult on dedicated employment rights for carers, such as looking at carer's leave. This may happening before the publication of the NICE guidance, hence the lines in the guidance may need updating before publication.	Thank you for your comment and bringing this to our attention.
Department of Health and Social Care	Guideline	017	016-019	Within Carers Training Programmes, we suggest including 'finance/ money management and nutrition training.	Thank you for your comment. We recognise the importance of 'managing diet and nutrition' and have added it to the recommendation. The committee also recognised the importance of ensuring carers have information and advice about finances and benefits and agreed to make changes in other recommendations (for example on the provision if information and support) to ensure this is provided.
Department of Health and Social Care	Guideline	023	016	Re definition of "carer": we would suggest that the definition of "carer" should be amended as follows to read "A carer is anyone who provides unpaid care and support ***on a regular basis*** to a family member....." Too wide a definition could well result in "full-time" carers getting less support from local agencies if the available resources used to support carers are spread too thinly if no additional funding is provided for carer support.	Thank you for your comment. The committee considered the feedback from yourselves and some other stakeholders, and have amended the wording to address the concerns raised.
Department of Health and Social Care	Guideline	023	020	Re Carers' Assessments. The Guideline is very comprehensive when it comes to setting out what should be considered when undertaking a carer assessment. But undertaking a "carer assessment" will not guarantee a good service. It seems to us that there is no obligation on	Thank you for your comment. We recognise the point you raise - that an assessment may not necessarily lead to better service. As an intervention we were able to review the evidence base on assessments and make concrete recommendations, but we were unable to find

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				agencies to provide support beyond undertaking a carer's assessment. The Guideline should state that a comprehensive Care Plan needs to be drawn up based on the assessment that clearly sets out how the findings of the assessment are to be implemented and what each agency will be contributing. The Guideline seems to be silent on this. The Care plan should, for instance, set out which agencies will be responsible for meeting the stated needs of the carer. The importance of a multidisciplinary/coordinated approach in providing support to carers should receive greater attention in the Guideline. It should also state that a hard copy of the carer's assessment should be given to the carer and to all agencies committed to providing support. A named key worker or plan coordinator should also be identified for the Care Plan whose responsibility it will be to ensure that the decisions/commitments made as part of the assessment are carried out. It is unreasonable to expect the carer to chase up the different agencies when agreed services are not being provided. The carer should be able to approach the "key worker" for the plan whose responsibility it will be to follow up on any issues/concerns. The Guideline should also set out guidance on regular reviews of the original assessment to ensure that the changing needs of a carer are being met.	evidence on what happens next. This can vary greatly depending on circumstances, region etc. In response we have changed the wording to encourage better follow-up. We utilised the evidence where we have it, but were not able to locate evidence or make comments specifically about key workers.
Department of Health and Social Care	Guideline	024	017	The research recommendations are well outlined, and decisions justified. The following are general comments: • For some of the recommendations, particularly around information and support or training doesn't cover much on the evidence around implementation/delivery – e.g. effective methods of delivery. Not sure if this was out of scope, due to lack of evidence, or just would make it too broad. Good to see coverage of suggested content where available though. • Was considering effectiveness of digital and technology in scope for this guideline e.g. recommendation to offer written	Thank you for your comment. Unfortunately we were not able to identify research for a population of UK carers specifying any single method of delivery for support, or a particular didactic approach to training, compared to another. We only identified evidence about what the content should be. However we have now added more emphasis on digital platforms after receiving significant feedback that this was important.

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				materials, we wondered if there has been any review of evidence around different forms of delivery (written versus digital, or online peer support) for supporting carers – particularly young carers?	
Hafal - Wales	Equality Act Impact Assessment	General	General	Failure to recognise specific needs of mental health Carers. Seems to suggest that mental health and long-term health conditions can all be lumped together – failure to recognise that there are often different ways that equality is impacted upon dependent on the type of disability. E.g. providing a ramp for access does not address issues for mental health carers.	Thank you for your comment. This guideline cannot go into specific detail about different carer support needs or interventions that may be associated with care in relation to a specific condition. The guideline has however tried to be inclusive in its considerations of what works for all adult carers. There are other NICE guidelines that deal with the carer's role in relation to certain health conditions or social care needs.
Hafal - Wales	Evidence Review G	General	General	While there is some recognition of improvement in the lives of carers of people with Bipolar disorder when the carer is provided with psychological support there appears to be a complete lack of understanding of the emotional and mental wellbeing needs associated with being the "Nearest Relative".	Thank you for your comment. This guideline cannot go into specific detail about different carer support needs or interventions that may be associated with care in relation to a specific condition. The guideline has however tried to be inclusive in its considerations of what works for all adult carers. There are other NICE guidelines that deal with the carers role in relation to certain health conditions or social care needs.
Hafal - Wales	Guideline	General	General	Failure to recognise the special place mental health carers occupy in relation to responsibilities under the Mental Health Act 1983 (as amended). Carers are almost always the "Nearest Relative" for the purposes of the Act and as such have a series of specific legal rights and responsibilities that do not exist for other Carers. While any Carer may take on responsibility under capacity legislation, Carers for mental health conditions have needs for specialist advice, support, advocacy and information that cannot easily be provided (if provided at all) by generic Carer services. The fact that the Guideline does not seem to recognise this casts some significant doubt on the validity of the whole exercise.	Thank you for your comment. This guideline cannot go into specific detail about different carer support needs or interventions that may be associated with care in relation to a specific condition, including mental health conditions. The guideline has however tried to be inclusive in its considerations of what works for all adult carers. There are other NICE guidelines that deal with the carers role in relation to certain health conditions or social care needs.
Hafal – Wales	Guideline	General	General	Failure to recognise legislation in other parts of the UK	Thank you for your comment. The remit of NICE guidelines is for England. However we agree that services and policymakers from other nations of the UK may wish to consider it's applicability to their setting.

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Hampshire County Council	Guideline	General	General	There should be stronger links with the Carer Quality Markers. It looks very social care focused and doesn't mention at all that carers should be registered with their GP as a carer, and the benefits that this can potentially bring. There is no consideration of the reasonable adjustments health providers should make to ensure that carers can access health appointments.	Thank you for your comment. The committee agreed to make specific reference to Carer Quality Markers in the context section of the final guideline. The committee also felt that there are a number of recommendations highlighting the importance of GPs and wider primary care networks in identifying and supporting carers. With respect to making reasonable adjustments, the committee did not make a specific reference to the Equality Act and reasonable adjustments in the recommendations themselves because NICE guidelines are all designed to advance equality and eliminate discrimination, as required by the Equality Act 2010. Nevertheless, considering the importance of your point, they strengthened a recommendation about facilitating access to information, stating that information should be made available to meet carers needs and preferences, for example with written leaflets and links to online or digital resources. The committee also felt your point was addressed through their recommendations about flexibilities related to the conduct of carers assessments, stating for example that the timing of assessments should be arranged according to the carers preferences, taking account of the level of stress they are experiencing and the timing of hospital discharge (of the cared for person). They also recommended flexibility in terms of how, when and where carers assessments are carried out, taking account of individual preferences and accommodating their caring responsibilities, working patterns and other circumstances. In another recommendation, the committee stated that health and social care appointments should offer flexibility for working carers, for example offering carer appointments outside of hours, workplace surgeries and digital and telephone appointments.
Hampshire County Council	Guideline	General	General	We agree contingency planning is a very important aspect of the carers support planning and we would recommend that professionals working with carers regularly have conversations about contingency planning, and as needs change. This will ensure that a carer is more able to look after their own health, and to prevent carer breakdown. Expectations on 'continually' in terms of practitioner capacity and cost	Thank you for your comment. In drafting the final guideline, the committee placed a greater emphasis on this kind of planning with carers; in particular ensuring assessments are regularly reviewed, including the carers' ability and willingness to provide support. This is in recognition that their willingness and ability should never be initially assumed and might change over time.

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				of this would be helpful to clarify, not necessarily a conversation but other systems in place to enable responsiveness to changing needs.	
Hampshire County Council	Guideline	General	General	We would like to see a recommendation that local authorities and other groups mentioned provide information and advice on support at all points on a "carer journey" to enable carers to continue their caring role.	Thank you for your suggestion. The committee felt there was already a big emphasis on duties surrounding the provision of information to carers and in drafting the final guideline they increased references to the importance of ongoing reviews of carers' needs, including information.
Hampshire County Council	Guideline	General	General	Information and advice: The focus appears to be on those who have had an assessment, rather than the provision of universal advice that people can access as they move through the carer journey.	Thank you for your comment, which the committee considered. They felt that there is already clarity in the guideline about duties surrounding the provision of information and there are also a number of detailed recommendations to identify carers and provide them with information and advice, including but not limited to their rights to a carers assessment.
Hampshire County Council	Guideline	General	General	The overall impression is that this is overly focussed on assessments and that assumptions are being made that people are "willing and able" to care (Care Act, 2014, S 10 (5)). There is too little focus on the "whole family approach" and not enough mentioned about early intervention/prevention (including information and advice provision). There is nothing about potential technical help that could be considered as part of the early intervention/prevention. We are concerned that there is no mention of contingency planning for carers, in terms of encouraging carers to consider the alternatives when an emergency arises (emergency planning).	Thank you for your comment. When they discussed your point, the committee were in agreement about the importance of avoiding assumptions about the willingness and ability of carers to provide support. They therefore ensured that this is more explicitly reflected by drafting a new, separate recommendation that practitioners conducting assessments (of both the carer and cared for person) should not assume carers are willing and able to provide support. In terms of the whole family approach to assessment, the review protocol on carers assessments was designed to locate evidence in this area but no relevant papers were located. In order to plug the gap in evidence the committee invited expert witnesses who presented insight from practice about the acceptability of the whole family approach to assessment. The testimony provided a positive endorsement of this approach to assessment but because no corresponding research evidence has been published to date, the committee did not feel they had a basis on which to specifically recommend the 'whole family approach'. Nevertheless, on the basis of discussions in this area the committee agreed to draft a recommendation that during assessment, discussions should take account of the carer's own context, namely their family and support networks, including for example whether they share

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					caring responsibilities with other people or whether they care for more than one person. In view of the lack of specific evidence on whole family approaches, the committee also agreed to draft a recommendation for research about the effectiveness, cost-effectiveness and acceptability of this approach. The committee discussed your point about contingency planning but since no evidence was located specifically about this, they did not feel they had the basis on which to draft a recommendation. That said, they felt that the recommendations about provision of information about the full range of available support and how to access it would ensure carers are made aware of any local emergency care arrangements. Furthermore, the committee agreed that the recommendations about conducting assessments in a way that reflects the context of the carers own family and support networks means discussions would cover planning for unexpected events or care break downs. Finally, the committee also pointed out that the guideline does include a recommendation to ensure that replacement care is discussed as part of carers' assessments, including planning for any emergency replacement care that might be needed, for example if the carer becomes suddenly unwell. On balance, the committee felt that through the recommendations described here, the point you raise is addressed by the guideline.
Hampshire County Council	Guideline	General	General	Hampshire County Council are currently implementing a Joint Carers Strategy working with partner organisations such as NHS CCGs, Third Sector providers and carers. We are more than happy to link in with NICE if this would be beneficial.	Thank you for your offer of support, which we will take it account as we consider the implementation of the guideline with partners.
Hampshire County Council	Guideline	013-014	General	It mentions "replacement care" so a person can attend work, education or training, but not about having a life alongside caring and for attending health appointments.	Thank you for your comment. The recommendations in this particular section reflected the guideline scope and the related evidence review. The committee considered that "having a life alongside caring and for attending health appointments" could be a clearly identified outcome for the carer in a carer's assessment.

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Hampshire County Council	Guideline	006	011-017	There is no mention of other media that could be used to provide information, for example, internet, social media etc that would give the carer the ability to get to the outcome sought.	Thank you for your comment. In light of yours and other stakeholder comments about the important role of digital technology the committee revised a number of recommendations. They did not revise the one to which your comment refers because they felt the point could be made more clearly in a revised recommendation about the importance of making information available in a range of formats, including via online and digital resources such as local and national websites and forums and social media.
Hampshire County Council	Guideline	009	002-010	The methods mentioned feel old fashioned and not grounded in the 21st Century. There is no mention of social media or other channels.	Thank you for your comment. In response to yours and other stakeholder comments the committee agreed to place a greater emphasis on the use of digital technology and communication. For example, the recommendation that health and social care organisations should encourage people to recognise their role and rights as carers through (a number of means including) digital communications, social media and online forums that engage with carers. There are other relevant reference including a recommendation to making information available to carers in a range formats now includes as examples 'links to online and digital resources (including local and national websites and forums and social media)'.
Hampshire County Council	Guideline	009	011-013	The recommendation implies that nominating a single "carer champion" will be the answer to the problem. We believe that identifying carers should be a core part of business as usual.	Thank you for your comment. It was not the intention of the committee to imply that nominating a single carer champion would resolve all issues in relation to carers. In the final version of this recommendation, the committee edited it slightly to say that carers champions would 'help' implement the recommendations in this guideline, reflecting the fact that no one individual should be solely expected to implement the Care Act in relation to carers and the recommendations in this guideline. It is also relevant that throughout the guideline there are recommendations that practitioners working with carers should have the knowledge and communication skills to support them effectively and provide information or access to information to support their wellbeing and to support them in their role.
Hampshire County Council	Guideline	010	003-006	It is helpful that 'social care organisations delegated by local authorities' is included in the recommendations as highlights the	Thank you for your support for this particular section of the guideline.

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				duties of the local authorities can be carried out by other organisations, which enables more creative and community focused assessment offers to be developed.	
Hampshire County Council	Guideline	010	020-021	There is a concern that the guidance is proposing a very traditional response to an acute emerging issue. Carers are increasingly giving large amounts of their time to care for people with high levels of need. Being a carer can range from a visit or two per week to being available 24 hours a day every day. Our evidence is that an increasing proportion of local authority service users rely on unpaid carers. The guidance focuses very heavily on the need for organisations to refer carers through for an assessment – even if they do not receive services or support at the end of it. It states "Be aware that a well-conducted carer's assessment may in itself be a therapeutic intervention or a means of preventing future problems." (1.3.5) This may be true for some people but having an assessment may not be the most effective way of supporting the carer. Eligibility under the Care Act is quite tight, so for many people it may be frustrating to have an assessment and then find they are not eligible for funded support. There is a cost attached to all assessments and in some instances this resource could be better used, for example, providing more voluntary sector support. However, local authorities will not be able to afford this, if the default position is for the voluntary sector to refer people straight back to the local authority. There needs to be a greater balance of "reasonableness" of when to encourage someone to have an assessment and when to offer community-based support. This way, more investment can be made in community-based support.	Thank you for your comment. There is a statutory right to a carer's assessment and a responsibility to inform carers of their right to statutory assessment. Our recommendations state that arrangements for such assessments should be made in accordance with the Care Act particularly taking into consideration the wellbeing and prevention principles. We have added an additional recommendation to the end of this section on identifying carers to make it clear that carers who do not need or want a formal assessment should still be offered information about how to access support.

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Hampshire County Council	Guideline	011	004-010	The options mentioned are very traditional and there is nothing mentioned about other more flexible choices such as online assessments or self-supported assessments.	Thank you for your suggestion. The recommendation to which you refer lists considerations for practitioners when planning the timing of assessments. It is less about how those assessments can be conducted.
Hampshire County Council	Guideline	011	011-012	Online assessments and technology enabled support for assessment would provide the flexibility suggested in this paragraph.	Thank you for your comment. We have amended this recommendation to reflect that the flexibility also relates to the methods of assessment.
Hampshire County Council	Guideline	011	011-012	We are concerned that there is the possibility that there would be 2 systems in place to provide a carer's assessment (hospital, then community) and duplication. We would hope that there could an integrated approach rather than duplication of assessment.	Thank you for your comment. We have amended the recommendation on actions arising from a carer's needs identified during a hospital assessment, to require that an effective process is in place to avoid duplication with the community-based statutory assessment.
Hampshire County Council	Guideline	012	013-015	Which practitioners are being referred to here? Regarding the level of knowledge, how do NICE see this being measured? Assessment may identify the need re. employment issues, however for a positive outcome, it may be that carers are linked to an appropriate agency.	Thank you for your comment. This refers to any practitioner currently conducting carers assessments in line with the Care Act 2014. The committee did not think further clarification was necessary.
Hampshire County Council	Guideline	013	007-010	The provision of advice on such topics as going back to work, education, training and so on should be core business and should not require the appointment of someone as a "carer champion". This also does not consider the scale of the issue i.e. adequate levels of service for numbers of Carers of working age projections will not be met through a carer champion.	Thank you for your comment. The committee considered that whilst everyone involved in the assessment and support of carers should have general knowledge of these things, that there was benefit in specialist knowledge, expert tailored advice and training for other practitioners working within these particular services. Appointing a named 'carer champion' was cited as an example of how this benefit could be provided.
Hampshire County Council	Guideline	013	019-023	We support the discussion between carer and employer about making reasonable adjustments. The examples given should include the use of technology to facilitate flexible working. Suggesting to an employer that they should provide a mobile phone to keep in touch with the cared for person in 2019 is likely to be considered unnecessary in most cases.	Thank you for this suggestion. The committee agreed to amend the recommendation to say 'technology to allow flexible working' and 'permission to use a mobile phone'.
Hampshire County Council	Guideline	014	015-018	There is an implication that the "commissioned services" mentioned here would fall on local authorities rather than the utilisation of 'universal services' or other community-based resources.	Thank you for your comment. We have added to an existing recommendation to "ensure that carer understands that some support may be means tested" in order to manage expectations as to what may be available.
Hampshire County Council	Guideline	015	003-010	The provision of regular updates to carers has a cost implication as "community services and other sources of support" can vary greatly	Thank you for your comment. The committee did not want to be prescriptive as to how the information is provided. The role for technology is covered in earlier recommendations.

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				over time. The use of technology here to provide the information in the first instance is to be welcomed.	
Hampshire County Council	Guideline	015	014-016	We are concerned that this is a very restrictive definition and consider that this is too narrow and lacking an innovative approach and not reflective of the context of social care resources. Our local carers have indicated that a break "in their own home" does not necessarily meet their needs. Residential respite is often not a preferred option of many and can be detrimental in terms of prevention in escalation of needs of the individual person cared for, it is also very expensive for local authorities. Alternative community-based resources and ability to access 'universal services' is both more able to meet needs/positive outcomes and gain a greater return on investment. Care providers can be inflexible when there is a nil provision of care by local authority.	Thank you for your comment. The committee did not consider that they had attempted to define carers breaks but rather allow for innovative approaches.
Hampshire County Council	Guideline	016	General	Although it is very important, providing carer training could have considerable cost implications. The guidelines also don't say whose responsibility it is (or who is best placed) to provide/commission it e.g. local authority or CCGs	Thank you for your comment. The Rationale and Impact section acknowledges that there may be cost implications from the recommendations but these were supported by cost-effectiveness evidence. See the section on "Who is this for?" which defines responsibility in general terms. It is not the usual remit of a NICE guideline to say who is best to commission services not least because organisational roles can change over time.
Hampshire County Council	Guideline	017	001-006	Courses designed specifically for carers need to be correctly positioned so carers get the benefit of them. As there are numerous "health conditions, disability or needs of the person they care for" courses may not be able to meet those needs.	Thank you for your comment. We agree that this is important. The recommendation to offer training programs "relevant to carers' circumstances, including the health condition, disability or needs of the person they care for" puts the responsibility on the providers to ensure this is the case.
Hampshire County Council	Guideline	017	007-015	It would be beneficial for carers to be included in shaping the courses accordingly as a minimum involvement.	Thank you for your comment. We have added a recommendation that carers should be involved in the planning and delivery of carer training.
Hampshire County Council	Guideline	017	022-025	The characteristic that is missing from this paragraph is age. For example, there is no recommendation about aiming specific training programmes at Young Carers.	Thank you for your comment. We have kept the concepts of inclusion and accessibility open throughout this guideline. The reason we specified some groups here is because evidence identified them specifically.

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Hampshire County Council	Guideline	018	001-002	It is hoped that part of the course would include a session on keeping in touch afterwards. The recommendation to "consider enabling opportunities" seems rather antiquated in this day and age of social media.	Thank you for your comment. The committee did not want to make assumptions about peoples comfort with technology, or about how forthcoming people may feel to initiate exchanging contact details themselves, and so concluded it was best to clarify with a recommendation.
Hampshire County Council	Guideline	023	General	Include the phrase "regardless of age" in this sentence after "A carer is anyone"	Thank you for your comment. In response to your comment we have amended this recommendation to read "In this guideline, a carer is an adult (aged 18 or over) who provides unpaid care and support to a family member, partner or friend (aged 16 or over) because of a disability, health condition, frailty, mental health problem, addiction or other health or social care needs."
Hampshire County Council	Guideline	024	General	The definition given is too narrow.	Thank you for your comment. Unfortunately from the details given we were not able to establish which definition on page 24 you were referring to. We apologise for not being able to respond.
Hampshire County Council	Specific Question	Comment Form	N/A	***Q1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.*** Overall our impression is that the guidance covers basic elements of good practice re. Carers, which is welcomed in terms of consistency and management of expectations for customers; carers and quality assurance of our existing practice. These are not new areas of practice and as such are already included within our strategic and delivery approach. However, the guidance does not strongly enough reflect the context of adult social care and health across the country and the complexities in prevention and demand management. This context requires a more transformational approach to how Carers are best supported within available statutory resources and as such there are critical challenges and competing priorities which these guidelines do not seem to take into account. For example, there is a lack of acknowledgement re. developments in technology enabled care,	Thank you for your response to this question which is helpful information for implementation of the guideline.

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				digital online channels for assessment and support, strength-based approaches to community resources and access to universal services. The guidance focuses very heavily on the need for organisations to refer carers through for an assessment – even if they do not receive services or support at the end of it. It states "Be aware that a well-conducted carer's assessment may in itself be a therapeutic intervention or a means of preventing future problems." (1.3.5) This may be true for some people but having an assessment may not be the most effective way of supporting the carer. Eligibility under the Care Act is quite specific, so for many people it may be frustrating to have an assessment and then find they are not eligible for funded support. There is a cost attached to all assessments and in some instances this resource could be better used, for example, providing more voluntary sector support. However, local authorities will not be able to afford this, if the default position is for referral to the local authority for assessment. There needs to be a greater balance of "reasonableness" of when to encourage someone to have an assessment and when to offer direct access to community-based support. This way, more investment can be made in community-based support. The inclusion of Carers within planning and designing of support and services does not come across strongly enough. Innovative developments can originate from effective engagement and influence locally tailored developments.	
Hampshire County Council	Specific Question	Comment Form	N/A	***Q2. Would implementation of any of the draft recommendations have significant cost implications?*** The presumption of face to face assessment. The definition of 'Short Breaks' as being '*this service gives carers a break by providing care for the person with care needs in their own home or in a residential setting'* implies commissioned service	Thank you for your response to this question which is helpful information for implementation of the guideline. The committee did not think these recommendations would have a significant cost impact as they largely reinforce current practice and legislation.

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				provision, when 'universal services' and other options may be more effective to promote the outcomes for individuals and offer improved value for money for local authorities. The reference to Carers training, depending on the expectations re. provider and scale etc. The reference to *continual* conversations re. contingency planning.	
Hampshire County Council	Specific Question	Comment Form	N/A	***Q3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)*** • Central Government funding for Carers support, in line with local demography projections of the increased numbers of Carers and recognition of the cost avoidance for statutory agencies provided via Carers. • A shift from a focus on statutory assessment (which is often only accessed when people recognise themselves as a Carer and at a point of stress) to the availability of community-based assessment via direct access routes including digitally enabled channels Changes in other Governmental Departments e.g. there is a rising number of older adults who are Carers and the end of Carers Allowance once the State Pension is provided does not recognise the continuation of their caring role and related costs associated with that, impacting on their available resources to privately pay for support and services; contribute to local authority provision.	Thank you for your response to this question which is helpful information for implementation of the guideline.
Healthwatch Lincolnshire	Guideline	004	005	We welcome the requirement to provide up to date information. However this is difficult to maintain in a large rural county where organisations come and go, lead contacts change on a regular basis and commissioning practices often result in the loss of what was a valued organisation.	Thank you for your comment. The committee were certainly mindful of the practice and resource context in which these recommendations will be implemented. The emphasis in the recommendations on information and advice is for practitioners to sign post to providers of those services,

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					not necessarily be the ones with the most up to date information or with responsibility for the provision of the information.
Healthwatch Lincolnshire	Guideline	005	017	The mental capacity, physical ability and willingness of the carer also need to be taken into account	Thank you for your suggestion, with which the committee agrees. They have therefore ensured that the final version of the guideline reflects the importance of ensuring that carers are willing and able to provide support. They achieved this though drafting an additional, separate recommendation that when completing assessments for carers or the cared for person, practitioners should not make assumptions about the willingness and ability of carers to carry out caring tasks. Also, that the carers willingness and ability should be explored through discussions about the assessment. The committee did not feel they had the basis on which to be more specific about the range of issues, situations or feelings that might affect a carer's willingness or ability to provide care, which may include but not be limited to their own mental capacity. They nevertheless drafted two recommendations, based on their discussion of the evidence about support for carers, highlighting that local authorities have a statutory study to provide information to carers about how to access advocacy services, in line with the Care Act 2014 and the Mental Capacity Act 2005.
Healthwatch Lincolnshire	Guideline	005	021	As you rightly say carers' needs change yet the care act 2014 only allows for an annual review if the carer requests one. Carers needs need to be reviewed regularly perhaps with each contact as the cared for person is reviewed, or GP contact is made such as is suggested at p6 line 28 and also at P9 line 11.	Thank you for your support for these recommendations, which highlight the importance of reviewing carers willingness and ability to provide care and the important role of GPs and primary care networks, for instance in nominating carer champions.
Healthwatch Lincolnshire	Guideline	006	001	We like the intention to repeat information to a carer several times (this could of course be different health and care professionals each doing it)	Thank you for your support for this particular section of the guideline.
Healthwatch Lincolnshire	Guideline	012	001	Replacement care is often very difficult to find or is only provided within the guidelines of the person receiving care and then often limited to say 28 days a year. P14 line 22 appears to deal with aspect. This would also link into the LA duty to monitor the market and maintain availability. This needs to extend to cover services for carers	Thank you for your comment. The committee hope that local authorities and health and social care organisations will find the recommendations useful when considering when to consider replacement care as a means of support for carers.

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Healthwatch Lincolnshire	Guideline	013	018	Carers should be entitled to paid leave for caring responsibilities in the same way maternity leave is available. Often a carer is needed in the early days of illness/condition occurring so carer could be more available and present to develop and encourage routines and practices which when in use could enable the carer to return to work. (It would also reduce the burden on the state regarding carers allowance payments as they will be paid (at least in part) by existing employer).	Thank you for this comment. We have added 'carers' leave' to the recommendation as an example of a supportive working arrangement to make caring possible in an employment context.
Healthwatch Lincolnshire	Guideline	021	004	Who are you asking /expecting to offer these frequent opportunities?	Thank you for your comment. This recommendation will apply to all health and social care staff and practitioners in England involved in giving carers information about the diagnosis or prognosis of the person they care for.
Hertfordshire County Council, Adult Care Services	Guideline	General	General	Consideration should be given to Carers Champions in community pharmacy	We have made a number of references to carer champions and have emphasised the emerging role of primary care networks in sharing knowledge and expertise about supporting carers, so the committee did not want to be too explicit about where carer champions should be based in primary care.
Hertfordshire County Council, Adult Care Services	Guideline	General	Resources	Any recommendations should be costed realistically and the implication is that either resources are increased or diverted from existing priorities. Without addressing this the recommendations will not be implemented. By resources we chiefly mean finances and time.	Thank you for your comment. The evidence reviews include a section on "The committee's discussion of the evidence" which includes a section on "Cost-effectiveness and resource use". The guideline also includes a rationale and impact section explaining why the committee made the recommendations and how they might affect practice. Given the expertise and experience on the committee we consider the recommendations are reasonable and are aligned to current legislation, whilst acknowledging that implementation may sometimes be challenging.
Hertfordshire County Council, Adult Care Services	Guideline	General	General	It doesn't make sense to continue to look at carers needs and the cared for as if they were separate, but there does need to be an overarching framework. The cared for would need to be the main focus if eligible and the framework would ideally be a Person Centred one, with carers potentially part of the 'circle of support'. In this way, statutory services would relate support to carers in the context of supporting the cared for, but in a way that they hopefully would not	Thank you for your comment. The evidence suggested that it was important to consider the assessment of the carers needs separately from the person being cared for but that it often made sense to link and connect these in some way with the consent of both parties. The committee decided to make a research recommendation about the effectiveness of whole family approaches to carer assessments.

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				be isolated. If carers had individual needs outside of this, they could primarily be met by information and guidance. And so carers would be in the frontline, along with practitioners, in supporting the cared for and their needs would be considered in that context.	
Hertfordshire County Council, Adult Care Services	Guideline	008	026	The reference to where there is mutual caring and where the carer has needs of their own talks of the need for a separate carer's assessment as well as the assessment of need. We would question whether that takes place and would have thought that generally it is part of the care needs assessment. This might be something to discuss and highlight as being good practice as increasingly there are carers who have care needs of their own.	Thank you for your comment. The committee made a small change to this recommendation, ensuring that it is clearly spelt out that people may be caring for more than one person and that they may not be living with the person they care for. There is also a specific section in the guideline on carers assessment emphasising and building on the Care Act duty to carry out assessments of the carers needs, in their own right.
Hertfordshire County Council, Adult Care Services	Guideline	009	001-004	Community pharmacy should be included as community pharmacy could help to identify carers	Thank you for your comment. The committee took this on board and agreed to make reference to pharmacies in this recommendation.
Hertfordshire County Council, Adult Care Services	Guideline	009	005	It should be noted that community pharmacy staff are used to supporting patients and carers and to signpost them to relevant organisations	Thank you for your comment. The committee took this on board and agreed to make reference to pharmacies in this recommendation.
Hertfordshire County Council, Adult Care Services	Guideline	010	020	The statement "properly conducted, a carer's assessment provides carers with psychosocial and emotional benefits and may be thought of as a therapeutic intervention in itself" it is very important that this should be recognised and used when promoting carer assessments. recognition needs to be given to the time that a carer assessment takes to complete, often over 2 visits with the second visit being to go through my draft assessment and to clarify and discuss plans, supports and goals. Services and information is obviously important and part of the assessment but from our own experience with even the most complex cases it is the overall process of being listened to and heard as a carer with all that entails that is really as described a therapeutic intervention. Perhaps to draw attention to then is the properly conducted as the person completing the assessment needs to adequately trained and confident in their knowledge of what supports are available for carers.	Thank you for your comment and your support for this recommendation. The committee agrees with you about the importance of practitioners having knowledge and awareness about carers issues to enable them to provide information, signpost to other sources of information and also have an understanding of carers needs so they can provide or arrange suitable support. The committee believe that there is sufficient emphasis on this within the recommendations, for example in the section on supporting carers to stay in, enter or return to work, education and employment and recommendations about the conduct of carers assessments.

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Hertfordshire County Council, Adult Care Services	Guideline	013	004	Carers and right to work and training is an area that also needs more staff training and knowledge of what is on offer for carers. I think it is something that people completing carer assessments may not have all the knowledge to know how to support carers so more could be done in this area.	Thank you for your comment. The committee considered that this point is addressed by the recommendation that states that "Health and social care organisations should ensure that practitioners who carry out or contribute to carers' assessments have training and skills in that role."
Hertfordshire County Council, Adult Care Services	Guideline	015	014	Need for carer's breaks – there are issues regarding availability and the time that carers are having to wait for breaks. There needs to be more provision and more varied provision. Carers who need to take a break and where the loved one requires nursing home care have limited choices as nursing homes do not hold nursing home respite beds. The fact that carers cannot access carer breaks easily leads to carer breakdown situations in my experience. The point about Carers Breaks links with the recent Guidance about Carer Breaks published by SCIE. There's a clear distinction identified between respite needed for a specific reason i.e. time off to attend to the carer's own needs, e.g. hospital appointments, & planning for regular breaks to enable carers to have time to do something for themselves: '"Breaks should not be seen in isolation. Carers want breaks to be part of a range of support that enables them and the person they care for to live well and also enables carers to have a life alongside their caring role. The approach should be holistic in terms of: • whole family approaches – addressing what works for particular families • the wider support that people need to live well – not compartmentalising people • integrated approaches across health and social care and wider agendas. Commissioners and providers need to see respite and breaks as part of the bigger picture of support in the local area. Don't plan it in isolation: think about what the carer and cared for-person needs before and after the break as well, otherwise the value of the break may be limited.'"	Thank you for your comment. The committee agrees that carers breaks should be seen within the wider context of supporting carers and did not think the recommendations suggested they should be offered in isolation. NICE guidelines are intended to reflect the evidence reviewed, which in this case was sparse. The intention was not necessarily go into great detail about the provision of a particular service but only to reflect the best available evidence and the committee's expertise in this area . The committee included a recommendation about how replacement care should be considered as part of a carers assessment and also about how replacement care should always be discussed in assessments when looking at the carers desire to stay in or return to work, education or training. The committee included recommendations about how carers breaks should be delivered to ensure carers feel the benefits of breaks, rather than the stress a badly organised break can cause. The committee were unable to make recommendations about the circumstances when carers breaks should be offered and this will need to be considered by local authorities in conjunction with local eligibility criteria and guidance such as the Care Act statutory guidance A more detailed reflection of why the committee drafted the recommendations about carer's breaks and replacement care and , their reflections on gaps in evidence and considerations about resource implications are described in the rationale and impact sections of this guideline and in the evidence reviews themselves.

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				When staff are trained to carry out carer assessment, we must be clear on the language used for example respite might refer to provision to cover the carer's absence, whereas breaks would be part of the on-going planning for supporting the carer's wellbeing.	
Hertfordshire County Council, Adult Care Services	Guideline	016	008	With regard to advocacy there needs to be some guidance for statutory staff if the advocate is a legal representative.	Thank you for your comment. The committee felt that such guidance was going beyond the scope of the guideline.
Hertfordshire County Council, Adult Care Services	Guideline	016	021	Training will be key for both staff and carers. Given the potentially wide scope of individual carers needs, this again needs to be properly costed to be realistically achieved. But given the PCP approach above, carers could be 'held' within the 'circle of support', so the focus of support for carers is considered by those most closely working with the carer and the cared for, not just statutory services. Training should include 'difficult conversations'.	Thank you for your comment. Funding is discussed in the section on "How the recommendations might affect practice". Whilst it is recognised that carer training may increase costs due to an increase in the number of requests for training and to train practitioners to deliver the training, it also notes that the components are based on evidence of effectiveness. The committee considered that "training in difficult" conversations is addressed in more general terms within the section of recommendations on psychosocial support.
Hertfordshire County Council, Adult Care Services	Guideline	017	014	Regarding the need for psychosocial support - again this is an area of great need for carers. There is some provision, but it needs to be greater and more varied.	Thank you for your comment. We agree about the value of psychosocial support. We encourage services to include this support within training, which we hope will trigger additional provision where it is currently lacking.
Hospice UK	Guideline	General	General	We are really pleased to see that the draft guideline takes a person-centred approach and spans health, social care, community and workplace dimensions. This is to be commended.	Thank you for your comment and your support for the recommendations.
Hospice UK	Guideline	General	General	While it is implicit in the draft guideline, it would be helpful and valuable to emphasise that in most instances, carers are experts in the care that they provide, and in the needs of the person that they are caring for.	Thank you for your comment, on the basis of which the committee agreed to place even greater emphasis on the importance of the carer as a critical part of the care team, stating in the section on 'working with and involving carers', that practitioners should work in partnership with carers and treat them as a valued member of the care team around the person being cared for. They also emphasised that carers should be involved in decision making and edited another recommendation to make it clear that during discussions with carers about the cared for person, practitioners should share with carers the information they

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					need to provide care effectively and safely. Finally, the committee also revised the recommendation about the value of recognising carers to highlight that the benefits of doing so not include addressing their needs but also the fact they can share valuable knowledge about the cared for person, which helps practitioners provide the right care and support.
Hospice UK	Guideline	006	018-020	Delivering this will require training for practitioners and a shift in practitioner and organisational culture.	Thank you for your comment. The committee decided not to make any changes to this recommendation because the provision of information to carers is a statutory duty on the part of local authorities (Care Act 2014) and as such should not require a shift in culture. For those practitioners with responsibility for providing information, it ought to be standard practice that they have the knowledge and skills to do so.
Hospice UK	Guideline	007	001	It is important to recognise that it is not always the person who is objectively closest to the person with care needs who is the carer. For example, it may be a child of a couple that is the main carer for one of that couple who may have care needs. It would be useful to remind practitioners of this in the context of identifying carers.	Thank you for your comment. The committee did not make any changes in response to this because they felt that the point is already covered in the recommendation about asking people whether anyone gives them help or support - taking into account that carers may not be family members, may not live with the person and finally, that there may be more than one person involved in caring.
Hospice UK	Guideline	008	003	While it is important and useful to encourage people to identify themselves as carers, it would also be helpful if GPs in particular were given some prompts to more proactively seek out carers. For example, in palliative and end of life care, GPs are encouraged to ask themselves the question of whether they would be surprised if the person in front of them died within the next 12 months. An equivalent question to prompt consideration of whether a person may be a carer could similarly be very helpful.	Thank you for your comment. The committee discussed this suggestion and agreed that there is already an emphasis in the recommendations on the benefits of identifying carers. There are also recommendations about the potential role that GPs and primary care networks can play in identifying and recognising carers. The committee therefore did not make any changes in light of this comment.
Hospice UK	Guideline	008	021	It is important to clarify with whom carers should be encouraged to have conversations, and to what end/purpose.	Thank you for your suggestion, which the committee considered. However they did not feel there was a basis to say any more in this recommendation, although in the final version they have added that carers should have the opportunity to have 'confidential' conversations about their own care needs, separately from the person they are supporting.

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Hospice UK	Guideline	009	015	In encouraging the development of systems to help organisations to identify carers, it is important to bear in the mind the rapid growth in the number of single person households, particularly among older people, and the way in which this can contribute not only to social isolation but also to the prevalence of people who will not have access to informal or family care.	Thank you for your comment. Although the committee recognise the issue you have identified, they did not make any changes to this recommendation. This is because they did not review evidence specifically relating to the issue. However they believe that through the recommendations about the range of ways of identifying carers (including GP appointments and home visits for the cared for person), practitioners would be able to establish whether or not an unpaid carer is providing support.
Hospice UK	Guideline	010	013	One of the key questions for practice is how the information from a carer's assessment will be shared appropriately across multiple organisations that may be providing support in a variety of different ways. Failure to promote appropriate information sharing will result in multiple and repetitive assessments being undertaken unnecessarily.	Thank you for your suggestion, with which the committee agreed. In the final version of the recommendations, reference is now made to appropriate information sharing, stating that following an assessment, information should be shared '(as appropriate) with other practitioners and organisations involved with the carer and the person they care for'.
Hospice UK	Guideline	010	020	As well as being a potentially therapeutic intervention in its own right, undertaking an assessment will also raise expectations that something will happen as a consequence of the assessment. It is important that practitioners undertaking these assessments are honest, open and clear with people about what might happen as a result, and, importantly, when.	Thank you for your comment. We have added a recommendation that before a carers' assessment, information should be shared with the carer to enable them to prepare. Also, a new section entitled 'after a carer's assessment' has been added and includes recommendations about the provision of information and the conduct of regular reviews. There is also a recommendation in the section on identifying carers that practitioners should be clear that some support may be means tested
Hospice UK	Guideline	011	016	It is unclear what is meant by the assessment being 'carer-led', particularly when it goes on to say that the assessment should also be 'jointly produced'.	Thank you for your comment. This recommendation has now been removed.
Hospice UK	Guideline	011	020-021	How information is shared with local authorities or a delegated care organisation is a critical issue. In practice, we know that the timescales involved can be long, and the processes can be complex. In describing the 'effective process' it would be helpful to practice if the guideline also said 'and timely'.	Thank you for your comment. The committee felt the current wording of this recommendation was succinct and that it implied that the local authority would be informed as soon as possible.
Hospice UK	Guideline	013	009	While we agree that appointing a 'carer champion' can be helpful in ensuring that people get expert support when needed, appointing such a champion cannot, and must not, undermine the importance of	Thank you for your comment. The committee considered that whilst everyone involved in the assessment and support of carers should have general knowledge of these things, that there was benefit in specialist knowledge, expert tailored advice and training for other practitioners

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				all practitioners having a better understanding (and responsibility) for meeting carers needs.	working within these particular services. Appointing a named 'carer champion' was cited as an example of how this benefit could be provided.
Hospice UK	Guideline	013	019-023	We fully support the important role that employers can play in providing support to carers in the workplace. Hospice UK will shortly be launching a new Compassionate Employers programme which will provide guidance, resources and support to employers to enable them to provide more appropriate support to carers. The programme is due to launch in September, and we would be happy to provide more information if it would be useful to the implementation of the guideline in due course.	Thank you for your comment. We are glad this recommendation compliments your current work. We will pass this information to our resource endorsement team.
Hospice UK	Guideline	014	012	In discussing 'replacement care' options to help carers who want to stay in, enter or return to work, education or training, it is also important to emphasise that such support is subject to means-testing.	Thank you for your comment. We have added to an existing recommendation to "ensure that carer understands that some support may be means tested" in order to manage expectations as to what may be available.
Hospice UK	Guideline	015	013	It is important to recognise that many carers use breaks for their basic survival (sleeping, resting, eating), rather than leisure activities.	Thank you for your comment. NICE recommendations are action focused and do not usually provide a rationale within the recommendation. The draft consultation version of the recommendation did not specify that carers' breaks would be for leisure activities. However, we have amended the recommendation to reflect the "value" of breaks as well as a discussion of the options.
Hospice UK	Guideline	016	016	A key question for practice and implementation is how this carer training would be funded	Thank you for your comment. The recommendations with respect to training carers are not prescriptive in mandating how such training should be produced and delivered, which allows commissioners to consider local priorities and needs. Funding is discussed in the section on "How the recommendations might affect practice". Whilst it is recognised that carer training may increase costs due to an increase in the number of requests for training and to train practitioners to deliver the training, it also notes that the components are based on evidence of cost-effectiveness.

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Hospice UK	Guideline	017	001-006	The carer training programmes should also take into account people's communication and literacy needs	Thank you for your comment. We have recommendations about making sure materials are accessible for all carers regardless of communication and literacy needs earlier in the guideline, in the section on how to provide information and advice.
Hospice UK	Guideline	017	022-025	It would be helpful if the guideline did not narrowly define inclusion and reminded people that there are also wider accessibility and inclusion issues that should also be considered, such as homelessness for example.	Thank you for your comment. We have been careful to keep the concepts of inclusion and accessibility open throughout the rest of this guideline. The reason we specified some groups here is because evidence identified them specifically. However we highlight that every service subject to these recommendations will also be subject to the Equalities Act - and the full meaning of inclusivity in their contexts should be something they are already aware of.
Hospice UK	Guideline	019	003	Advice on planning for the future should also include issues associated with death, dying and bereavement	Thank you for your comment. We make recommendations about planning for the future in the section about end of life, and that covers these issues.
Hospice UK	Guideline	020	012	Or dies.	Thank you for your comment. This recommendation has been amended along the lines suggested.
Hospice UK	Guideline	021	004-007	It is important for carer support to people during end of life care also addresses issues associated with pre-bereavement, loss, bereavement and grief.	Thank you for your comment. For greater clarification we have added to our recommendations to specify that carers are offered information and support for issues that arise around bereavement. This is now specified in a recommendation addressing a change in circumstances.
Hospice UK	Guideline	022	024-028	Most hospices provide support programmes to carers, and not just carers of people who have accessed hospice services.	Thank you for your comment. We have amended this recommendation to read "Help carers who are providing end of life care at home to access local services that could support them including from local hospices".
Hospice UK	Guideline	023	002-008	There is a distinction to be made between providing care and support to families and loved ones and providing care and support to carers when somebody is dying in hospital. It is important that practitioners do not make assumptions about who the carers might be for a particular person and recognise that they should expect separate arrivals of visitors (e.g. friends, or estranged family). The person or people who have been acting as a person's carer will also have unique and specific needs in this situation.	Thank you for your comment. The committee discussed the points you've raised and agreed to amend the wording to highlight about special accommodations needed by 'carers' beyond that of other visitors.

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Ian Stronge - Carer	Guideline	004	021	"planning the future care for the person they care for" and also their CURRENT care, please. Too many individuals have missing, incomplete &/or out-of-date care plans, and there seems to be no established audit for chasing up on this. Given that the cared-for person is most often at the centre of the carer's life, THIS IS THE INFORMATION THAT SHOULD BE UPDATED AND SORTED OUT FIRST AND FOREMOST.	No response needed - non-registered individual.
Ian Stronge - Carer	Guideline	005	010-011	"Work closely with carers and treat them as a valued member of the care team for the person they care for." These wonderful aspirations will continue to mean very little unless and until each carer has a single point of contact to sort out all the disjunctions and misunderstandings and conflicting motives (and funding rules) of the myriad organisations involved in caring for the cared-for, never mind caring for the carer. This single point of contact needs to have the seniority to call on colleagues and cooperating agencies to get their finger out, otherwise we're back to relying on lovely aspirations of partnership. Also, the single point of contact needs to publish an annual report instancing how the cared-for's and carer's.needs have – and have not – been addressed that year, backed up with an established audit procedure that would motivate the bureaucracies involved to deliver this month rather than sometime whenever. (As a nation, we can – almost - do this for education, why not for health and social care?)	No response needed - non-registered individual.
Ian Stronge - Carer	Guideline	005 006	005-020 006-028	SECTION "How to provide information and advice": This section emphasises INPUTS almost to the exclusion of MEASURING OUTPUTS. So, it's all about delivering information. There's nothing about asking the carer whether it's working for her/him. I'm reminded of the cartoon showing the Englishman Abroad, devising different ways of shouting at foreigners, but always in English. The better approach is to start by ASKING what the carer needs. That doesn't exclude offering more, but it does at least ground the conversation in the carer's current experience and understanding, before trying to build on that. (Most leaflets written by professionals explain things from within their bureaucratic context, and rarely update details of how to join up with	No response needed - non-registered individual.

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				other bureaucracies. Make no mistake, it's the carer who's left to join up the gaps and to try and get any partnerships to join up in practice.	
Ian Stronge - Carer	Guideline	009	001-020	Which leads us to: "Recommendations for service providers and organisations". Instead of "identifying carers", just publish what's available, and set a target for how many carers you can get through the door.	No response needed - non-registered individual.
Ian Stronge - Carer	Guideline	010	020-021	"Be aware that a well-conducted carer's assessment may in itself be a therapeutic intervention or a means of preventing future problems." – Maybe on some alternate planet?	No response needed - non-registered individual.
Ian Stronge - Carer	Guideline	015	002-010	"Community information, advice and support" – The best way to attract carers is to publish (at least quarterly) what services have been delivered and to how many carers.	No response needed - non-registered individual.
Ian Stronge - Carer	Guideline	016	005-007	"Support for former carers" The best thing former carers can do – and find so little opportunity to do – is pass on what they've learned to the next cohort of carers. Among other things, this shows there's some light at the end of the tunnels (plural).Services should organise their Carers Forums to include former carers alongside new and continuing carers.	No response needed - non-registered individual.
Ian Stronge - Carer	Guideline	016	016-017	"..should ensure that the provision of carer training meets local needs" Surely the essentail requirement is to deliver a nationally established minimum Carers Diploma of courses proven to help carers in a set of the most common situations – where is the guidance for this? Meanwhile, every small town Council and CCG is crafting their own "to meet local needs" – where's the resource-effectiveness in that?	No response needed - non-registered individual.
Ian Stronge - Carer	Guideline	020	001	"Support during changes to the caring role" Or you could title this "How to get results when services muck up their own 'transition' arrangements?" Or you could ask why this bureaucratically convenient funding change has to impact the cared-for at all? Becaue the main stress for carers is getting services to join up all over again, an entirely avoidable problem.	
Ian Stronge - Carer	Guideline	021	016-018	"Health and social care practitioners, including home care workers, should recognise that carers can find… help at home… invasive.". It's	No response needed - non-registered individual.

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				simple really. Are you a helper ('please would you help me with this') or an invader ('right let's get this done before my parking meter runs out')?	
Ian Stronge - Carer	Guideline	023	020	CARER'S ASESSMENT – "the right to discuss their own needs with their local council". What a lovely idea! Understandably, no one has the funding for little chats, so instead there's a form to fill in. Thus this becomes primarily a data collection exercise – look we've identified all these carers! So, the carer hands over all their data, and the council's algorithm looks to exclude them from as much funded provision as possible. Suitably forewarned, the carer might be able to trigger some unavoidable entitlements. Much like the benefits system. Until statutory authorities are mandated to publish what services they actually offer, and the entitlement thresholds for each of them, this will remain just a lovely idea.	No response needed - non-registered individual.
Ian Stronge - Carer	Guideline	025	018	Rationale and Impact: obviously I'm asking for the moon, given the fractured state of health and social care for chronic conditions. For example, why in any rational set-up would there be any need for a "Carer's Passport" – aren't I registered on a single Carers Database? So, NICE could go further than warm words and mandate some things. If services can do falls prevention, why can't they be mandated to accumulate other specific interventions? Don't leave this as a lost opportunity.	No response needed - non-registered individual.
Local Government Association	Guideline	General	General	It's worth noting that in June 2018, the Government published an action plan for carers setting out a 2-year programme of work to support unpaid carers, ahead of the forthcoming social care Green Paper (date TBC). The measures include: a new scheme to improve employment support for carers, a new Carer Innovations Fund to promote creative and innovative ways to support carers, and funding for a review of best practice in identifying young carers and access to support. Better practical support for families and carers is expected to be one of "the seven key principles" underpinning the forthcoming Green Paper on social care for older people.	Thank you for your comment. The committee were aware of this publication as a background to the development of the guideline and are reassured that many of those proposals are in line with the recommendations they drafted, especially those designed to support carers to enter, remain in or return to employment.

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Local Government Association	Guideline	General	General	The document does not have enough on risk and safeguarding how it relates to carers. Carers can be at risk of intentional or unintentional abuse or harm from the cared for person. And some cared for persons may be at risk of intentional or unintentional abuse or harm from carers. Ref: https://www.adass.org.uk/adassmedia/stories/Policy%20Networks/Carers/Carers%20and%20safeguarding%20document%20June%202011.pdf	Thank you for your suggestion. The committee did not feel that the evidence they reviewed provided a basis for drafting recommendations specifically about safeguarding as it relates to carers. This reflects the focus of the guideline scope, which was agreed through stakeholder consultation. Stakeholders did not identify risk and safeguarding as priority issues so they were not included as key areas of investigation through evidence reviews and committee discussions. Nevertheless the committee were satisfied that consideration of safeguarding issues would be implicit in a comprehensive assessment of the carers needs, in line with the Care Act, about which they drafted a number of detailed recommendations. In addition the committee drafted a recommendation that carers should be offered training to enable them to provide care safely. They also recommended that carers be given information about the condition or needs of the cared for person which will enable them to provide care effectively and safely (while respecting confidentiality). There is also a recommendation to consider including specific information in carer training programmes to ensure that carers remain safe in their caring role.
Local Government Association	Guideline	General	General	Subject to recommendations the new burdens doctrine may apply. The new burdens doctrine applies where central government requires or exhorts authorities to do something new or additional.	Thank you for this comment about the "New Burden's Doctrine". We believe the recommendations are all based on evidence about 'what works' and are in line with requirements under existing legislation, in particular the duties on local authorities as set out in the Care Act 2014 and associated statutory guidance. It is hoped the guideline will help local authorities to focus on areas which will impact most positively on carers.
Local Government Association	Guideline	046-047	008-026	Context would benefit from including information on gender, ethnicity, age, amount of care provided: Data from the 2011 Census show that, across the UK: **Gender**. Women represent 51% of the population but make up 58% of carers.29 However, of those aged 85 years or over, 12% of men and 5% of women provided unpaid care.30,31 On average, time spent	Thank you for your comment. We are grateful for this information which is useful context for supporting the implementation of the guideline. In addition we have added some demographic data to the context section, drawing on the material cited in your comment.

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				caring for adults, by people over 50 years, increased between 2000 and 2015. **Ethnicity**. People from the White ethnic group make up the largest proportion (94%) of carers, as they do as an overall proportion of the population (87%). However, further work is needed to look at whether this is shaped by the age structure and health of different ethnic populations. The proportion of people providing care, and its amount, varied amongst ethnic groups. For example, in England, Wales and Scotland, White British/Scottish, Irish, and Gypsy or Irish Traveller people were among the highest providers of unpaid care (in terms of hours of care provided). People of Chinese, White and Black African (only England and Wales), and African (only Scotland), were among the lowest providers of unpaid care. **Age**. Most carers are aged between 50–64 years. People aged 65 and over make up a higher proportion of carers (19%) than they do the population as a whole (12%) **Amount of care provided**. Most carers provide between 1 and 19 hours of unpaid care per week.38 Around 25% of carers provide more than 50 hours per week, and 15% provide 20–49 hours per week. Other data show that: Most carers care for just one person (83%), although they may also look after children or grandchildren. Over half (58%) of carers care for someone with a physical disability, 20% care for someone with a sensory impairment, 13% care for someone with a mental health condition, and 10% care for someone with dementia. There are concerns that there may not be sufficient numbers of unpaid carers in the future to meet demand, particularly from older people.5 Factors such as increasing female employment, fewer	

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				children, and higher divorce rates amongst men over 60 years may affect the future availability of children to provide unpaid care Reference https://researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-0582	
Local Government Association	Guideline	001	007	The guideline states that*: 'This guideline covers support for adults (aged 18 or over) who provide unpaid care for anyone aged over 16 with health and social care needs'*. However, it should also have more text on the needs of adult carers who care for children and links to key supporting documentation – such as the Children and Families Act. Also important to note that the Special Educational Needs and Disability (SEND) criteria covers young people to the age of 25.	Thank you for your comment, in light of which specific reference has been made to the fact that this guideline should be read together with the Children and Families Act 2014 (as well as the Care Act 2014 and statutory guidance).
Local Government Association	Guideline	004	005	The document should also refer to 'Social Workers' who are a regulated profession.	Thank you for your suggestion. The committee deliberately avoided specifying individual roles in the guideline unless they felt it was particularly relevant. They agreed that for most recommendations, responsibility should not fall on one particular role, not least because of variations in service configuration but also because carers may be in touch with a broad range of health and social care practitioners, all of whom should be aware of carers needs and rights.
Local Government Association	Guideline	019	020-024	The Guidelines says *'If a carer has an identified mental health problem, consider:* • *interventions in line with existing NICE guidelines or 22* • *referral to a mental health professional who can provide interventions in 23 line with existing NICE guidelines'* It is also important to add the need to intervene in a crisis or if there is a risk to carer of cared for person. Also recommend link in NHS advice to dealing with a mental health emergency. Also the heading for this section (Line 20) is: '**Psychotherapy and counselling**' – however such interventions may not always be appropriate for a person in crisis. And also could be time consuming to access.	Thank you for your suggestion. In light of your comment the committee agreed to strengthen the emphasis on support for carers as a means of maintaining their health, wellbeing and ability to provide care and thereby avoid a break down in caring and crisis situation. For example, they added a recommendation to the final version of the guideline which states that if a carer support plan is developed as a result of a carers assessment then it should be monitored and reviewed regularly. They also agreed to add a specific reference to ensuring meaningful support for carers is provided when the cared for person transfers from hospital, including during a crisis. Finally, the committee also addressed your point by placing a greater emphasis in the final version of the guideline on carefully establishing and then reviewing carers' willingness

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					and ability to provide support, avoiding assumptions and reducing the risk of a break down in caring arrangement.
London Borough of Newham	Guideline	General	General	The guidance states that an adult Carer includes those supporting an individual aged 16 or over. This is confusing, as within law these individuals are considered to be a child to 18 and as such parent Carer legislation applies. (This guideline covers support for adults (aged 18 or over) who provide unpaid care for anyone aged over 16 with health and social care needs. It aims to help people recognise themselves as a carer and understand their right to information and support.)	Thank you for your comment. The focus on carers aged 18 and over caring for people aged 16 and over was certainly an area for discussion during the scoping phase of this guideline. Stakeholders were supportive of this focus. The key was that the guideline is focussed on the support needs of adult carers, hence carers needing to be 18 and over – otherwise as you rightly point out different legislation would apply. The focus on the cared for person being 16 or over (and not 18 or over) is due to stakeholders previously confirming that the guideline should include recommendations about caring for young people as they transition to adults – and the implication for parents and other carers as the carer role changes during that transition. We have made a reference to the Children and Families Act 2014 in the opening introduction to the guideline and in the context section so that this is clearer.
London Borough of Newham	Guideline	009	014-016	We think implementing the standard is more than just a dedicated carer function it should be more about local areas having an integrated strategy and whole system approach.	Thank you for your comment. It was not the intention of the committee to imply that nominating a single carer champion would implement the standard. In the final version of this recommendation, the committee edited it slightly to say that carers champions would 'help' implement the recommendations in this guideline, reflecting the fact that no one individual should be solely expected to implement the Care Act in relation to carers and the recommendations in this guideline. It is also relevant that throughout the guideline there are recommendations that practitioners working with carers should have the knowledge and communication skills to support them effectively and provide information or access to information to support their wellbeing and to support them in their role. Finally, it is relevant to highlight that there is a specific recommendation for health and social care organisations to ensure their policies and systems are designed to encourage the identification of carers, which certainly supports a system wide approach.

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Macmillan Cancer Support	Guideline	General	General	We feel the guidance could include more information about Health and Social Care Professionals involving carers when a person is discharged home, making sure all necessary equipment, training etc has happened and primary/community support in place. Rationale: There are times when carers are pressured to take a person home and community services are not adequately set up or the carer adequately prepared.	Thank you for your comment. We have made a number of references throughout the guideline to the important decisions and information sharing that is needed at hospital discharge and included a number of recommendations about the actions that practitioners should take at this point around: identifying carers, joining up hospital assessments with community assessments, recognising the changing needs for the carer at this time and specific recommendations on the transition between hospital and home NICE guideline.
Macmillan Cancer Support	Guideline	General	General	The language used in the document is heavily focused in terms of needs- we suggest a focus on 'what matters' language and conversations	Thank you for your comment. We have added in references to 'what matters most' to carers throughout the guideline.
Macmillan Cancer Support	Guideline	General	General	We feel there is potential to draw out more in terms of MDT working, understanding who's involved in persons care and linking up with them etc	Thank you for your comment. We have added more in the guideline about practitioners treating carers as a valued member of the team around the person being cared for and in this sense improving clarity about who's involved in providing support and with whom it is important to communicate. The main areas in which the committee considered evidence about the importance of joint working between health and social care practitioners were the identification of carers and assessment of their needs. In finalising the guideline, the committee placed greater emphasis on these aspects, for example, recommending that every opportunity should be used to identify carers, including through GP appointments, outpatient appointments, social care and needs assessments and flu jab appointments. This emphasises that the identification of carers is within the remit of practitioners across health and social care. There is also now a more detailed recommendation in the final guideline stating that health and social care organisations should encourage people to recognise their role and rights as carers, for example through partnerships with community pharmacies or local carer support groups and through partnerships with local community organisations. In terms of assessing carers needs, the opening recommendation has now been strengthened and states that local authorities and social care organisations delegated by local authorities to carry out carers assessments should make arrangements for and

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					carry out assessments in cooperation with other relevant health and social care organisations. The committee were able to further emphasise joint working by recommending that health and social care practitioners work together to carry out or contribute to carers assessments to ensure they cover all relevant aspects of health, wellbeing and social care needs and that details of the assessment should be shared between the other practitioners and organisations involved. In terms of the remit of the guideline and the nature of the evidence located the committee agreed that they had placed as much emphasis in the guideline as possible on the importance of health and social care practitioners working together and taking responsibility for the identification and assessment of carers and ensuring they have the support and information needed to carry out their role and maintain their own health and wellbeing.
Macmillan Cancer Support	Guideline	004	017-018	Good to see information about employment and flexible working included here	Thank you for your comment. We are reassured that the recommendations address issues that you perceive to be important.
Macmillan Cancer Support	Guideline	006	001	Suggest add in "at all interactions reassured that they can ask questions at any time and come back if don't understand or need reminding"	Thank you for your suggestion, with which the committee agrees. In the final guideline this recommendation now refers to the importance of revisiting discussions.
Macmillan Cancer Support	Guideline	006	021	We recommend adding in a 'what matters to them' conversation to help them plan and prepare for any future changes.	Thank you for your suggestion. The committee agreed with your point but decided to add this into the recommendations about carers assessments.
Macmillan Cancer Support	Guideline	007	001-022	Suggest a line about not to making assumptions about who is and will providing care and their relationship to the individual needing care and support (need for sensitive conversations)	Thank you for your comment. In light of yours and other stakeholder comments, there is a greater emphasis in the final guideline on ensuring and then reviewing carers' willingness and ability to provide support.
Macmillan Cancer Support	Guideline	008	004	Include at the end of the sentence something about also being able to access support from work.	Thank you for your comment. The committee agreed your point is already addressed in the recommendation about information that should be provided by workplaces.

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Macmillan Cancer Support	Guideline	010	022	Suggest a recommendation to (where possible) share relevant information and questions before the assessment so that the carer has time to think and prepare for the assessment	Thank you for your suggestion. We have added a recommendation to state that practitioners should share information with carers before the assessment that help them to prepare.
Macmillan Cancer Support	Guideline	015	010	Add in another bullet point: support that could help them remain in, start or return to work.	Thank you for your comment. The committee considered this was already addressed in the section on helping carers stay in, enter or return to work, education or training.
Macmillan Cancer Support	Guideline	017	006	Add in another bullet point: available at a variety of times to accommodate other commitments, such as work or other caring responsibilities.	Thank you for your comment. We based this recommendation on the areas that were emphasised in the evidence. Nevertheless the recommendation is clear about the need for training to be "accessible" and "relevant to carers' circumstances" so the committee were happy that the point has been made that training should be provided in a way that is responsive to a range of needs.
Macmillan Cancer Support	Guideline	017	014	Add in another bullet point: support available to help them remain in, start or return to work	Thank you for your comments. This guideline already makes recommendations on support to remain in, start or return to work in that section of this guideline. We have been careful to avoid duplicating recommendations to stop the guideline becoming too repetitive.
Macmillan Cancer Support	Guideline	018	003	We feel it is important that Health and social care practitioners regularly review the use of equipment and provide ongoing support, recognising needs may change	Thank you for your comment. We agree this is important and have made sure to cover this in the section on support during changes to the caring role.
Macmillan Cancer Support	Guideline	018	013	It is important that the education and information provided to carers should be in language that is easy to understand, avoiding jargon. Evidence shows that if terminology is too technical, this can increase distress in carers and reduce ability to provide effective care. See: LeSeure P, et al. The Experience of Caregivers Living with Cancer Patients: A Systematic Review and Meta-Synthesis. J Pers Med. Dec 2015. 5(4): 406–439. Section 4.1.2	Thank you for your comment. We agree it is important to use accessible language when passing information to carers. We cover this in an earlier part of the guideline about how to provide information and advice, including a recommendation to NICE's guideline NG86 which gives further detail.
Macmillan Cancer Support	Guideline	018	021	Advice should also include the importance of breaks in caregiving where possible. See: LeSeure P, et al. The Experience of Caregivers Living with Cancer Patients: A Systematic Review and Meta-Synthesis. J Pers Med. Dec 2015. 5(4): 406–439. Section 4.2.2	Thank you for your comment. The guideline contains an earlier section dedicated to carers breaks.
Macmillan Cancer Support	Guideline	019	021	NICE Guidance: *Improving supportive and palliative care for adults with cancer* is relevant here and offers pathways for carers of people with cancer who require psychological support.	Thank you for your comment. The target population for this guideline is carers of adults with all conditions. To keep it succinct and applicable we

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					have had to avoid making too much reference to specific conditions such as cancer.
Macmillan Cancer Support	Guideline	021	023	Add in: 'think about ways they can get support from their family, friends, **employer** and wider…'	Thank you for your comment. This recommendation has been amended in line with your suggestion.
Macmillan Cancer Support	Guideline	022	012	It is important that the plan and consequences of any decision in the plan are understood by carers, to avoid unnecessary hospital admissions.	Thank you for your comment. The committee agreed this is important and felt the wording used for this recommendation enforces this point
Macmillan Cancer Support	Guideline	022	015-023	We feel there should be a more general point that is not just about medication "when managing care at the end of life, follow the principles of involving carers and the dying person as described in NICE's guideline on care of dying adults". Rationale: The guideline on care of dying adults also includes hydration and other symptoms not just medication management.	Thank you for your comments. The committee have expanded the recommendation to cover more than only medication in what should be considered and referred to in the other guideline.
Macmillan Cancer Support	Guideline	022	018	It is also important that carers understand how and where to access out of hours medicines and pain relief when providing end of life care at home.	Thanks for your comment. The committee considered this was addressed by the recommendation stating "When managing medication and other care at the end of life, follow the principles of involving carers and the dying person, described in NICE's guideline on care of dying adults in the last days of life."
Macmillan Cancer Support	Guideline	023	002	Dignity is also improved by allowing personal possessions to be brought into hospital, where appropriate. This has been shown to be beneficial to a person's end of life care. See: Kings Fund, Improving environments for care at end of life: Lessons from eight UK pilot sites, page 5.	Thank you for your comment. The committee discussed the changes you proposed and agreed to add this to the list.
Macmillan Cancer Support	Guideline	024	025-027	Research recommendation 2: We welcome the inclusion of this recommendation for further research	Thank you for your support for this particular section of the guideline.
Macmillan Cancer Support	Guideline	025	008-010	Research recommendation 4: We welcome the inclusion of this recommendation for further research. It would be helpful to have more evidence about carer passports, especially in the workplace.	Thank you for your support for this particular section of the guideline.
Macmillan Cancer Support	Guideline	025	013-015	Research recommendation 5: We welcome the inclusion of this recommendation for further research.	Thank you for your support for this particular section of the guideline.
Marie Curie	Guideline	General	General	There are some useful insights into the difficulties seen in identifying carers in Primary Care in the paper *Understanding the barriers to*	Thank you for your comments. We can confirm that both of these papers were located by our systematic searches and included in the

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				identifying carers of people with advanced illness in primary care: triangulating three data sources, by Marie Curie Research Leads Emma Carduff and Anne Finucane. The paper can be read at: https://bmcfampract.biomedcentral.com/articles/10.1186/1471-2296-15-48 This led to the development of an intervention, discussed in the paper *Piloting a new approach in primary care to identify, assess and support carers of people with terminal illnesses: a feasibility study*, by Emma Carduff et al. This paper can be read at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4750245/ This discussed having someone in a GP practice being nominated as a carer liaison, in order to keep track of carer assessments. Their initial role was to identify carers for the patient early and send out assessment packs (Carer Support Needs Assessment Tool, CSNAT) to those identified to assess their needs and concerns. This would be followed up intermittently until packs were returned and needs outlined. The aim of the process is to, having identified the carer at the earliest possible stage, ensure that all needs are similarly identified early and start addressing the main concerns right away with continued support.	evidence review about the identification of carers. The findings from the papers were synthesised with the other included evidence and clearly informed a number of recommendations, namely those in the section on 'identifying carers'. In particular, the recommendation about using every opportunity to identify carers, including GP appointments, flu jab appointments, home visits and outpatient appointments. In addition, the committee used the evidence to draft recommendation that health and social care organisations consider nominating a 'carer champion' to help implement the recommendations in this guideline and Care Act requirements in relation to identifying carers. Another example of using this evidence was the recommendation the committee drafted that primary care providers and primary care networks should explore ways of offering and promoting services to carers, including through partnership working (for example with local carer support services or nominating carer champions. Finally, evidence about the Carer Support Needs Assessment Tool was used with other relevant evidence to inform the recommendations about assessing carers needs in a way that takes account of their current and changing circumstances and which covers all relevant aspects of the carers health, wellbeing and social care needs.
Marie Curie	Guideline	General	General	**Question 3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)**	Thank you for this information, which will be considered as a response to the specific consultation questions. For information, evidence about the CSNAT was included in the development of the guideline and influenced recommendations about the assessment of carers needs.

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				A study, led by Maire Curie funded researchers Gail Ewing and Gunn Grande, looked at the state of discharge planning for carers and how beneficial the Carer Support Needs Assessment Tool (www.csnat.org) approach can be. It found that, understandably, a great deal of focus upon discharge is on the patient's needs. Meanwhile carers' needs and often unrealistic expectations of caring for the patient at home go unnoticed. CSNAT can act as a facilitator to carer support by helping address the realities of caring for someone at home towards the end of their life. It can be implemented initially while the patient is still in hospital, and then followed up once the patient is in their community setting. CSNAT is designed to make the transition between hospital and community as smooth as possible, with the carer keeping the relevant records – however, given that this transition process begins in the hospital setting the health care professionals involved in the patients care at this stage need to be involved and have some training in the use of the tool to ensure it I used effectively. CSNAT is a copyright tool available free of charge to the NHS and not-for-profit organisations. Registration and a licence are required for its use. The full paper can be found here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5946661/pdf/10.1177_0269216318756259.pdf	The papers provided data about the benefits of the CSNAT, in particular the role of the assessment tool in legitimising support for carers themselves, assisting in the communication of carer support needs and as a means of facilitating discussions with carers about care giving and support during the end of life period. The committee concurred with these findings and therefore drafted recommendations based on evidence about the CSNAT. For example, they recommended that health and social care practitioners carrying out carers assessments should ensure the assessment covers all relevant aspects of the carers health, wellbeing and social care needs. They also emphasised the importance of ensuring assessments are jointly produced with carers, reflecting what matters most to them (as opposed to taking a one size fits all approach). The committee also drew on the CSNAT evidence and their own related experience to make practitioners aware that a well conducted carers' assessment may in itself act as a therapeutic intervention or means of preventing future problems. Finally, with respect to the end of life period, the recommendations do emphasise the importance of identifying the needs of carers and supporting them in their role as carers but also providing information and support to promote their own health and wellbeing. For example, the committee recommended taking account of carers changing information and support needs in planning for their own future when the cared for person dies. This includes discussing with carers how to address their own needs. The committee also recommended that during the end of life period, carers should be encouraged to think of ways to access support, for example through family, friends and employers. In another recommendation the committee emphasised that carers should be helped to access local services for replacement care, palliative care and practical support. Having considered your comments, the committee felt they had addressed almost all the issues you identified including those around responding to the changing support and information needs of carers, particularly – although not limited to the end of life period.

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Marie Curie	Guideline	004	016	Among the information that should be provided to carers should be information on Carer's Allowance. Many carers are unaware of the potential financial benefits available to them, eligibility and how to claim. Health and social care practitioners should ensure they are aware of the potential benefits that may be available to clients and actively signpost them to benefits experts such as Citizen's Advice, or to relevant information via Gov.uk or other sources.	Thank you for your suggestion. Following a lengthy discussion of this comment and other stakeholder comments about this recommendation, the committee agreed to remove it and merge it with the earlier recommendation about the duty of local authorities around the provision of information. The long list of examples has also been removed because the committee were concerned that listing some but not other items might lead to absent items being overlooked. However the committee agreed to specifically add 'specialist benefits' to a recommendation about the provision of information about accessing community services and other sources of advice and support.
Marie Curie	Guideline	005	010	According to the Carduff & Finucane paper cited above, there is significant ambiguity about the legitimacy of carer needs and the role of the carer – on the part of both the primary care team and carers themselves. Professionals were not seen to legitimise carer needs, while carers are often confronted with a complex network of people – with some people caring for somebody with COPD finding external carers to be "intrusive and impersonal." In order for carers to be treated as a valued member of the care team for the person they care for, it is vital that professionals not only identify them as such but that their needs are seen as legitimate and their role is valued by professionals. The evidence from Carduff & Finucane suggests that this is not always the case in practice.	Thank you for your comment. The finding to which you refer is in line with the data located in the evidence reviews underpinning this guideline. This explains why such emphasis is placed on valuing the carer as a key member of the team surrounding the cared for person. In the final version of this recommendation the role of practitioners in ensuring carers are valued is underlined because it now also states that carers should be involved in decision making and care planning and are kept up to date.
Marie Curie	Guideline	005	020	In addition to taking account of formal changes in carers' circumstances due to, for example, changes in the condition of the cared-for person, health and social care practitioners should be aware that carers' lives can often be chaotic from day to day. This reinforces the need to ensure that information is provided in a manageable format – smaller chunks of information that can be easily digested, or information which can be accessed at any time to fit in with carers' lives, is the optimum way to provide the information carers need.	Thank you for your comment. The committee feel that all the issues you raise are addressed by the recommendations in this guideline. For example, the section now entitled 'communicating with carers' recommends making information available in a range of formats and according to carers' preferences. There is also a lot of emphasis in the guideline on the important role of practitioners in sign posting carers to sources of advice, information and support rather than necessarily relying on the practitioner to have all the latest information to hand or

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				Carduff & Finucane found that carers are dependent upon the knowledge of professionals and that professionals often lack knowledge about the range of services available to carers. GPs were also thought to be reactive rather than proactive, which discouraged carers from asking for help or advice. The presence of a carer expert in general practices is cited by Carduff & Finucane as a way to address this. Similarly, encouraging GPs to ask new patients at registration, and at intervals thereafter, whether they are a carer would be another way for general practices to understand who is a carer, and who may benefit from additional information on services that are available.	in their own mind. The recommendations also cover the important role that GPs play in identifying carers and the role of primary care networks, for example in nominating carer champions.
Marie Curie	Guideline	007	014	More than simply recognising that many carers do not know about their right to support, HSCPs should understand that many carers do not recognise themselves as carers. Carduff & Finucane's research shows that taking on the care of another person is often a gradual process, so carers might not immediately identify themselves as being a carer. This in turn could continue to make it difficult for health and social care practitioners to identify carers who do not self-identify as such. This would put up additional barriers to communicating information about carers assessments to the carer, if they continue to not see themselves in that role. In addition to many carers not self-identifying in that role, the all-encompassing nature of the role can often mean that carers do not recognise their own needs as legitimate or as needing support. Improving training for health and social care professionals will support them to not only identify carers who may not identify as such, but to be better-prepared to have conversations with that person and explain what support is available. The role of a carer champion should be central to this training.	Thank you for your comment and for the information provided. The evidence located as well as the expertise and experience of the committee seem to support the points you make about the reasons carers may not always identify as such. It is for this reason that the committee drafted the recommendation to explain to practitioners a range of possible reasons why carers might not identify themselves in that role and it is also why for example they recommend the nomination of carer champions.

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Marie Curie	Guideline	010	022	Practitioners should ensure that regular opportunities are provided for the carer to discuss issues with the practitioner/s, away from the cared-for person. This should relate not only to practical issues relating to the cared-for person's care but also the carer's own needs. Many carers feel pressure to appear confident and in-control in the presence of the cared-for person, or to agree to actions, so it is important that regular opportunities are given for the carer to discuss matters with professionals on private terms.	Thank you for your comment. The committee considered that this was addressed, if less explicitly, in the existing recommendations. For example, "The carer's assessment should be jointly produced with the carer, be undertaken within the context of the carers support and family environment and reflect what matters most to the carer and what might help them achieve this."
Marie Curie	Guideline	013	001	This would be hugely impactful if implemented effectively but will be challenging to implement. Research shows that as the cared-for person's condition deteriorates, the caring role often becomes all-encompassing; carers are managing competing demands and often feel unable to look after their own needs as well as those of the cared-for person. In this context, where carers often fear fearful of leaving the cared-for person and feel isolated in the caring role, it may be extremely challenging in some cases for carers to stay in or return to work. We must also recognise that while many carers can be supported in work, many people will want to stop working or take a break from working in order to care for somebody. This choice is as legitimate as remaining in or returning to work – practitioners should recognise this, and workplaces should be as accommodating as possible should a carer wish to take a break from working to care for someone.	Thank you for your comment. The points made are reasonable but the committee considered it implicit that this recommendation would be implemented with regard to the preferences of carers.
Marie Curie	Guideline	014	011	Ensuring that replacement care and carers' breaks are properly funded is vital.	Thank you for your comment. Although sectoral funding and allocation of budgets is not the explicit remit of NICE guidelines, we outline all of the committee's considerations about resource implications for this recommendation and all the others in the rational and impact section of this guideline .
Marie Curie	Guideline	016	014	In addition to providing training for carers to support them in fulfilling their role, practitioners should also recognise that carers are very often the expert in the wellbeing of the person they care for and will	Thank you for your comment. We have added a new recommendation stating that carers should be involved in the planning and delivery of carer training to ensure it reflects their skills and expertise.

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				often have intimate knowledge of the cared-for person's condition and needs. Practitioners should regard this expertise as a valuable resource and be encouraged to learn from the carer as much as support them to be better carers through training and support.	
Marie Curie	Guideline	016	022	Marie Curie's resources for carers include 'how to' guides on a range of issues from helping somebody to wash or to take medication, as well as tailored guides for different stages such as care in the last weeks and days of life or in the final moments of life, as well as information for carers after bereavement. These are comprised of short, manageable online resources with links to practical resources and further information and are designed to be easily digestible for busy carers. Training and information programmes for carers should adopt a similar approach; flexible and able to be accessed by carers in a way that fits around their lives and caring responsibilities. These guides can be found on Marie Curie's website at: https://www.mariecurie.org.uk/help/support/being-there	Thank you for your comment and for sharing information about these guides with us.
Marie Curie	Guideline	021	008	We know that many health and social care practitioners are not confident having conversations about death and dying with carers and family members, and in many cases with the person who is dying. In part this reflects a cultural taboo around talking about death and in part reflects a training need for health and social care practitioners – this should be provided for all practitioners and not only for those who provide end of life care. We are also aware that many people are not formally identified by medical professionals as being near the end of life even at the point of death; this is especially true among non-cancer patients but also applies to people living with terminal cancer. A study of GP practices showed that even at death, only 40% of non-cancer patients had been formally identified as being near the end of life for the purposes of providing palliative care. In the same study, while cancer patients	Thank you for your comment. Reflecting the evidence that was reviewed for this guideline, the committee agreed that practitioners may not be confident about having conversations about death and dying and we recommend that "Health and social care practitioners involved in providing end of life care should be competent to have conversations with carers about death and dying". However, identifying when patients are reaching the end of life is beyond the scope of this guideline and no evidence on this was reviewed.

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				were more likely to have been identified as at the end of life, one in four still had not been identified by the time of their death. As a result, conversations about death and dying are far less likely to occur where a patient has not been identified as nearing the end of life. Identifying when patients are reaching the end of life is vital for ensuring that these conversations take place – training for practitioners should include identifying when patients are reaching this stage as well as being competent to discuss the issue with carers and family members.	
Marie Curie	Guideline	023	009	It is vital that health and social care practitioners appreciate that the needs of carers are ongoing often long after the cared-for person has died. Many carers that we work with say that you never stop being a carer. The experience is life-changing and continues to have a profound impact on people after the death of their loved one. In many cases, carers continue to feel a negative impact on their health, mental wellbeing and financial circumstances long after the person they cared for has died. Some claim to feel like entirely different people, and it is quite common after bereavement for carers to give up, or not resume, social and leisure activities that they had enjoyed before caring. Health and social care practitioners should understand that they will have become part of the carer's social network; in many cases carers may have lost touch with other family or friends while caring and as such the withdrawal of services after the cared-for person has died can be profoundly isolating. The quality of interactions with health and social care practitioners at this point, and the way in which services are withdrawn can have long-lasting effects. As many as one in ten carers will have a very intense reaction to bereavement, known as prolonged grief disorder (PGD). This means they are likely to experience difficulty accepting the loss of their loved	Thank you for your comment. The committee considered this point and agreed to add more specific wording that carers should be offered information and support around bereavement. This is covered in the section about changing circumstances.

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				one, as well as numbness, identity disorientation and a feeling of being stuck in grief. This condition can have serious implications for their mental health. People who have cared for a spouse are particularly at risk. Research suggests that people should be screened for PGD when palliative care is introduced, and also six months after bereavement. Yet for many people the support has ended long before then. In addition, the financial costs of caring linger on after the death of the cared-for person; health and social care professionals should be aware of the costs of things such as funerals and taking extended leave from employment, and able to signpost bereaved carers to appropriate services and resources. In particular the Social Fund and Funeral Expenses Payment can help bereaved people in difficult financial circumstances pay for funerals, if they are already receiving some state benefits.	
Mencap	Guideline	General	General	Mencap welcomes this guideline on supporting carers of adults. We know that much more needs to be done to support those carers providing care to children and adults with a learning disability. We know this from calls to our helpline and our campaigns work with families. Recent research from New Forest Mencap[15] looking at the day-to-day experiences of carers providing care to loved ones with learning disabilities and/or autism also highlights this powerfully, for example, it found carers are not even getting the basics such as appropriate quality and frequency of respite.	Thank you for your comment. We are glad that our recommendations resonate with the needs that your organisation is identifying.
Mencap	Guideline	General	General	**Respecting and valuing carers** We suggest there is a section upfront in the guideline about the vital role carers play and the importance of respecting and valuing carers. The 'context' section at the end of the guideline references how much	Thank you for your comment. When the guideline is published on the NICE website a link to the context section will actually appear at the top of a list of contents - above 'recommendations'. This will help to emphasise the importance of the role of carers and the need for the

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[15] This will soon be published on www.newforestmencap.org.uk

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				unpaid carers are saving health and social care budgets, and the impact of caring on carers, however, we would welcome a strong message at the start that unpaid carers should be respected and valued. For example: 'Recognise the hugely valuable work that unpaid carers do. This recognition and respect should underpin all interaction between professionals and carers.'	guideline. Beyond the context section, the committee have been mindful throughout the development of the guideline about the importance of carers and of showing respect and support, according to their needs and preferences and this is reflected throughout the recommendations.
Mencap	Guideline	General	General	**Importance of carers understanding their rights and the rights of the person they are caring for, and professionals following the law.** The research by New Forest Mencap, as well the experiences of families Mencap works with and supports through its information and advice service, shows the Care Act is not being applied as it should. It is important carers know their right to support (and not just their right to a carer's assessment), and understand the rights of their loved ones. The 'context' section says that many carers do not think of themselves as carers and do not know about the support available. Carers are one of the audiences for the guideline and a clear intention is that the guideline helps improve outcomes for adult carers (pg 47), so this is an opportunity to help carers understand their rights, which can be crucial in securing appropriate support for carers and enabling them to continue caring, if they are willing and able to.	Thank you for your comment. The findings from the research you describe are certainly in line with the data located in the evidence reviews for this guideline and with the experiences and expertise of the committee. It was on this basis that the committee drafted recommendations to improve the identification of carers, to ensure their rights are clearly understood and information and advice are provided.
Mencap	Guideline	General	General	**LA legal duty** Carers must be 'willing and able' to care. LAs have a legal duty to step in if carers are not willing or able. Too often carers are told LA won't fund a placement when there is no other placement on the table. This is unlawful but we see it through our information and advice service all the time. Too many family members give up work or continue to care when they are not willing or able. We see carers caring when it is not safe or reasonable to expect them to discharge the caring role. It would be helpful if the guideline says that LAs have to communicate that they have a duty to provide care when one exists. As well as a need to act quickly in urgent situations to avoid detrimental impact on the carer or the person being cared for.	Thank you for your comment. When they discussed your point, the committee were in agreement about the importance of avoiding assumptions about the willingness and ability of carers to provide support. They therefore ensured that this is more explicitly reflected in the final recommendations.

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Mencap	Guideline	General	General	**A new section on support for planning for the future, including when the carer is no longer around or able/willing to care** We are aware that many carers of people with a learning disability are fearful of the future when they are no longer around or able to care for their family member. They are worried about who will make sure they get the support they need, fight for their loved one's rights if needed, and ensure they are happy and safe. We think there should be a specific section on planning for the future. Older carers of someone with a learning disability may need more support to enable their family member to live a full life, otherwise an adult son or daughter can end up living a life that mirrors their older parents. The person may need more support to access activities and proactive planning for the future will help identify this as early as possible. New Forest Mencap found in their research that transition to retirement is not happening, with older carers feeling they can't retire and pull back even though they are tired and have no energy left. In fact there can be more things to do as at the same time as their own health is deteriorating, their son or daughter is getting older and may be developing health needs (note: people with Down's syndrome are at increased risk of developing dementia). Planning for the future can help avoid crisis situations. It also means siblings can prepare for taking on a role if that is their intention when the parents are no longer around, eg providing emotional support, a 'care management' role etc, rather than being plunged into this role at a point of crisis. It would be helpful to include a focus on siblings elsewhere in the guideline and recognise that they may be taking over caring that parents have done up until then – they will need good information, advice, support and flexibility too.	Thank your comment. The population for this guideline was adult carers in general terms, rather than adult carers of people with particular needs. The evidence reviews were therefore focussed broadly and this may explain why findings like those you describe were not specifically located. There was nevertheless a review which located evidence about the importance of advance care planning and the importance of carers in that process. The committee recommended that advance care planning should take account of the wishes of any current or future carers, so this addresses your point to a certain extent. However, the more detailed issues that you raise - including the specific reference to the role of siblings - are actually addressed in another NICE guideline on the provision of care and support for people growing older with learning disabilities. Please follow this link to the NICE website https://www.nice.org.uk/guidance/ng96

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Mencap	Guideline	014-015	General	**Carers breaks and replacement care** It would be helpful to say these need to be clear in the needs assessment, carers assessment and care plan for the person. Respite care will be budgeted and planned in advance and this should be unpicked in the early stages of assessing need (both of the person with a learning disability and the carer). It can also be added in at a later stage if family circumstances change.	Thank you for your comment. The committee considered that existing recommendations addressed this. It is recommended that replacement care is discussed as part of the carers' assessment and that support plans be reviewed and monitored on an ongoing basis.
Mencap	Guideline	007	General	**Understanding the different types of carer – in term of who they are caring for, at what point they have become a carer (and what this means in relation to the support they may need)** It is important the guideline fully recognises carers of adults with a learning disability and their needs. Currently it seems to be more focused on people who become carers later on in life, for example, those who may become carers for elderly parents. This is also indicated by the fact there is a lengthy section about support for carers during end of life care and after the person dies. Many parent carers of people with a learning disability are likely to be outlived by their sons or daughters with a learning disability. Therefore, there are other key issues that need to be included in the guideline, in addition to support around end of life care. Many of those unpaid carers of adults with a learning disability will have been carers right from when their family member was born. They will have had the full impact of caring for someone with care and support needs due to their learning disability from day one. They will have had to navigate the complex system throughout the person's childhood. They are not becoming a carer later on in life. They are likely to be experts in the person's disability or condition by the time the person has reached adulthood. It would be helpful to make more reference to this group of carers who have already been caring for a long time prior to their child becoming an adult. They are likely to benefit from training which	Thank you for your comment. The remit of the guideline is adult carers in general, rather than a specific age group or carers of people with particular conditions. The recommendations are therefore intended to apply to all carers, and there are a number of recommendations which emphasise the importance of flexibility and providing support according to people's preferences and needs, which may vary depending on the stage of their caring experience. End of life care was a 'key issue' in the scope of the guideline, which is why there was a specific review question designed to locate evidence on that topic. Again, these are not intended to be age specific. Finally, please note that the specific issues you raise are addressed in some detail in the NICE guideline [NG96] on care and support for people growing older with learning disabilities https://www.nice.org.uk/guidance/ng96

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				builds on their existing knowledge and how support/ services and rights (theirs and their loved one's) may change once the person becomes an adult, eg. rights under the Care Act 2014 and the Mental Capacity Act 2005 (including rights to be involved in best interests decision-making/if or when they should apply for deputyship etc). Whereas someone who is becoming a carer for the first time in middle-age, eg. for their parents, is quite likely to have well-established social and professional networks by that point, families who have been providing intensive support for their family member may not have been able to develop and maintain those support networks and may be more isolated by the time their son or daughter is an adult. There are different types of support and training that may be helpful depending on their situation.	
Mencap	Guideline	007	General	**What caring involves** At the moment the guideline doesn't include a section on the different things that 'caring' may involve. We believe it would be helpful to include some examples as some people may think it is just hands-on direct support. This would help carers identify themselves and others identify carers and be able to direct them to information and support. The list could include things such as the following: - Direct care – eg. personal care - Paperwork, emailing, attending meetings and appointments in relation to their care and health (whether they are living with the carer or are living elsewhere eg in supported living). - Receiving multiple calls a day from their family member and providing emotional and practical support (wherever the person is living) - Supporting their family member to understand and access their rights, including challenging cuts - Support to access activities – eg. organising or coordinating activities, taking them to activities (wherever the person is living)	Thank you for your suggestion. The committee decided not to make specific changes in relation to this because they felt that the guideline already reflects the range of areas in which carers are likely to need support and the fact that this will be different for different carers in different situations and at different stages in their caring experience. The scope of the guideline was not designed to locate evidence that would provide the basis for developing a 'map' of the specific tasks that the cared for person would need to ask their carer for help with.

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Mencap	Guideline	007	General	**Identifying carers** **Who is a carer?** In the 'Identifying carers' section we think it would be helpful to include more about 'who' is a carer. We welcome it is recognised on pg 20 that caring responsibilities may not end when the person being cared for moves away from home. We would like to see this much earlier on in the guideline, in the 'identifying carers' section. This could be explicit in the list of why people don't always recognise themselves as carers (but should do), for example, 'because the person has moved away from home eg. they are now in supported living or residential care'. We think it should also be explicit in this list that you don't have to be in receipt or eligible for carers allowance in order to identify/ be identified as a 'carer'. Many families are doing huge amounts of caring for family members who are no longer living in the family home (see some of the caring activities listed in the section above). New Forest Mencap's research found older carers felt unable to retire because they were doing all this organising and coordinating of their family member's care. Mencap sees families of people who are stuck in inpatient units having to find care providers in the community, source housing, communicate with multiple professionals to develop a package of care for their loved one in order to enable their discharge. We see that if families don't do this, nothing moves forward. We also see families continue to have to take a key role in keeping the care arrangements working, once the person has been discharged. Mencap and New Forest Mencap are seeing many families of people with a learning disability doing this 'care manager'-type role. It can	Thank you for your suggestion. In the final version of the guideline in the section on identifying carers, the committee agreed to make reference to the fact that carers may not live with the cared for person and that this can be one of the challenges in encouraging people to identify as carers. The guideline also talks about carers often being in multiple caring roles e.g. parents and carers of older relatives. We have also included a definition of carers in the 'terms used in this guideline' section. We have included reference to means testing and eligibility criteria both in the recommendations and in the rationale and impact sections. However we did not make specific reference to carers allowance in the recommendations, as NICE guidelines tend not to make reference to specific benefits in order to future proof the recommendations as much as possible. We acknowledge your comment about the carer and the 'care manager' role. We have included a new section in the guideline about working with and involving carers to better acknowledge the importance of clear responsibilities between carers, paid carers and other practitioners. The guideline outlines exactly what GPs (and all health and social care professionals) should do when identifying a carer, including making sure they pass on the right information and support or else guidance on how to get it and making sure that information about the carer is recorded

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				involve a huge amount of work - for example, with direct payments and supported living families may have to do a lot of coordination to keep the person's support package together and enable the person to live a full life, it can be like running a business. We **recommend there is further research** into this 'care manager' role that carers are doing– including the reasons for it and the impact. In order to support carers effectively it is very important to understand what roles carers are doing. **Benefits of identifying carers** We would like to see it recognised that there is a benefit to health and social care services and professionals in relation to identification of carers – as it enables more effective planning of appropriate support for carers and will help prevent crisis situations, which can have a high human cost as well as high financial cost. **Opportunities for identifying carers** The guideline says that opportunities for identifying carers include GP appointments. We would like to see more detail here – for example, after identifying, what does the GP do with that information. Health professionals may not know much about how social care is delivered on the ground. How would this conversation with the GP be recorded, link with social services and translate into support for the carer and feed into local planning to understand and meet the needs of carers in the area. New Forest Mencap's research found carers are not being well-identified and there must be greater cooperation between GPs and Adult services and also a plan of action which is proactive in providing information and support to assist older carers.	
Mencap	Guideline	010	General	**A section on 'needs assessments' as well as 'carer's assessments', and clarity about the LA's responsibilities**	Thank you for your suggestion. Given the remit of this guideline, the focus is inevitably on carers and the assessment of their needs in their

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				We think it is important that in addition to a section on 'carers assessments' in the guideline, there is a section on 'needs assessments' (of the person who is receiving care). The needs assessment is a crucial point for identifying all the support the person needs. The Care Act says it must be 'carer blind'. Fully identifying the amount of care and support the person needs, and what family members are providing – at that initial assessment stage is very important. Good assessments describe in detail what family members will do. It is very important to do this - for the person, the carer and for the LA. It will help make sure that the carer gets the support they need, if they are willing and able to care, and will help prevent burnout and crisis.	own right. Nevertheless, the committee did draft recommendations which mention the assessment of the cared for person. For example, they recommend that practitioners should take every opportunity to identify carers, including GP appointments, flu jab appointments, home visits and social care other assessments – whether for the carer or the cared for person. In addition, the committee recommended that people with support needs should be asked whether anyone gives them help or support apart from paid practitioners. Finally, the committee also emphasised the importance of recognising carers and the valuable knowledge they can share about the cared for person so that practitioners can deliver the right care and support.
Mencap	Guideline	016	General	**Advocacy** Carers should be able to get an independent advocate for an assessment if they have substantial difficulty in understanding etc and they don't have someone to support them. It would be helpful to include more detail about rights to advocacy in the guideline, as independent advocacy support can be crucial in ensuring the needs assessments, carers assessments and care plans are comprehensive with all the person's needs identified, and clarity about any support that the carer is willing and able to provide, and support the carer needs to enable them to do this.	Thank you for your comment. To address your point we have amended an existing recommendation so that it now reads "Local authorities must provide information to carers about how to access advocacy support services, in line with the Care Act 2014, the Mental Capacity Act 2005 and the Mental Health Act 1983."
Mencap	Guideline	018	General	**Emotional and psychological support needed** It would be helpful if it could be reflected in the guideline that many carers say they would be 'ok' if their family member was getting the support they should be ie it is the constant fighting for the right support for their family member/ having to challenge potential cuts that causes huge stress and impacts greatly on their own wellbeing. Perhaps there could be a statement such as, 'Recognise the impact that having to fight for their loved one's rights/ against cuts is likely to have on the carer's stress levels and wellbeing. Recognise the benefit	Thank you for your comment. The remit of this guideline is support for carers themselves so it is difficult to also address some of the issues you raise, such as there being inadequate support for people using services. Nevertheless the guideline does make reference to the conduct of assessments both for the carer and cared for person and cites a number of assessments, conversations and aspects of care giving as opportunities for identifying the existence of an unpaid carer. There are also a number of recommendations about the importance of providing support - including psychosocial and psychoeducational interventions -

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				to the individual, the carer and the LA of partnership working and ensuring needs are met in a timely way.' Our helpline receives calls from carers on a huge range of issues connected to their loved ones' care, for example, proposed cuts to current services/ support package, proposed move/ change in accommodation, challenging charging decisions, poor care and abuse, concerns about quality of assessments, no services offered, placements have broken down etc. A recurring theme for our helpline is the need for emotional support. Emotional and psychological support is needed; however, we have not seen much evidence of carers actually being able to access it.	to carers. Finally, in light of your comment and those of other stakeholders, the committee agreed to place a greater emphasis on the importance of involving carers as key members of the team around the cared for person while at the same time ensuring that the willingness and ability of carers to provide care should be carefully established and then regularly reviewed. In addition, we would refer you to the following NICE guidance: People's experience in adult social care services: improving the experience of care and support for people using adult social care services (https://www.nice.org.uk/guidance/ng86) Patient experience in adult NHS services: improving the experience of care for people using adult NHS services (https://www.nice.org.uk/guidance/cg138)
Motor Neurone Disease Association	Guideline	General	General	Overall this guideline gives too little consideration to carers' needs for emotional and psychological support, especially in relation to bereavement. It is concerning that the section on providing care at end of life (pp. 22-23) contains no mention at all of support services relating to grief and bereavement. This is a major omission that must be addressed. In addition, the guideline should encourage signposting to information about welfare benefits available to carers.	Thank you for your suggestion. In the draft version of the guideline there was a section of recommendations dedicated to psychological and emotional support for carers and this remains in the final version. In addition there is a recommendation in the final guideline which states that information and emotional and practical support should be provided to help carers adjust to changes, including when the cared for person becomes terminally ill, needs end of life care or dies unexpectedly. In relation to information about welfare benefits, the committee agreed to strengthen a recommendation so that it now stipulates that local authorities ensure carers are regularly informed about sources of support and advice and how to access them, including 'specialist benefits, financial and legal advice'. The recommendations about the provision of welfare rights advice which appeared in the draft guideline in the section on 'helping carers to stay in, enter or return to work, education and training, remain in the final version.
Motor Neurone Disease Association	Guideline	010	022	The section on delivering carer's assessments should include consideration of possible impacts of a caring role on a carer's physical health. Caring for a person living with a disability can lead to physical strain and injury, e.g. from activities such as lifting and carrying. Carers	Thank you for your comment. We have amended this recommendation to state "ensure that the assessment covers all relevant aspects of health, wellbeing and social care needs". The committee considered

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				of people living with MND have told the MND Association about a range of impacts on their physical health such as fatigue, back pain, muscle strains and so on. A carers assessment should include opportunities for carers to discuss the health impacts of their role and be signposted to appropriate services where necessary.	that this recommendation would cover the range of impacts raised in the comment.
Motor Neurone Disease Association	Guideline	012	001-007	This list should include signposting to advice and information regarding welfare benefits available to carers.	Thank you for your comment. This list of examples has been removed from the recommendation as the committee, on reflection, considered that it could be misleading. The recommendation emphasises the importance of identified outcomes without providing examples as to what those outcomes might be. Other recommendations address the provision of welfare advice and signposting.
Motor Neurone Disease Association	Guideline	012	009	In addition to discussions around training, employment and education, the carer's assessment should include discussion of support available to carers through the benefits system.	Thank you for your comment. Support available from the benefits system was not within the scope of the review question on training and education. However, recommendations in the information section would be expected to encompass such discussions.
Motor Neurone Disease Association	Guideline	016	006	Support for former carers must also include consideration of bereavement and grief support.	Thank you for your comment. Bereavement and grief support are included within this recommendation which is intended to have a broader focus than former carers as a result of end of life.
Motor Neurone Disease Association	Guideline	020	008	This list should include: becomes terminally ill and/or requires end of life care	Thank you for your comment. This recommendation has been amended in line with your suggestion.
Motor Neurone Disease Association	Guideline	023	009	This section does not address the emotional impact of caring for someone at end of life and of bereavement. It should include recommendations for signposting to bereavement support services and other emotional support services where necessary.	Thank you for your comment. The committee considered this point and agreed to add more specific wording that carers should be offered information and support around bereavement. This is covered in the section about changing circumstances.
Multiple Sclerosis Society	Guideline	General	General	**About MS** Multiple Sclerosis (MS) is one of the most common disabling neurological conditions in the UK, affecting more than 100,000 people. Symptoms often become apparent in the 20s and 30s and can vary	Thank you for your support for this guideline. The committee reviewed the suggestions you made but did not make any specific changes to the recommendations because they felt the issues were already adequately covered by the guideline as a whole. For example there is a whole section dedicated to supporting carers to remain in, return to or enter education, employment and training, which seems to address one of the main areas of difficulties that you describe. In addition many of the

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				greatly between individuals, including; loss of balance, fatigue, pain, bladder and bowel problems, visual and memory impairment, and issues with speech. Many symptoms are 'hidden' and the progressive or fluctuating nature of MS means people require differing levels of care and support at different times in their lives, or even day. MS Society research suggest 85% of people with MS receive support or assistance from an unpaid carer – usually a family member or friend.[16] Caring for a person with MS often impacts on the physical health, mental health and well-being, financial stability and social activities of the individual. However, the needs of unpaid carers are often neglected and evidence suggests they feel undervalued and underrepresented.18~~18~~ Supporting this group will enable them to manage their evolving caring responsibilities, quality of life and economic stability. **About the MS Society** The MS Society is the UK's largest charity for people living with MS, with over 29,000 members and more than 270 volunteer-led branches, and is the largest charitable funder of research into MS in the UK. Since 1953, the MS Society has been providing information and support, funding research and fighting for change. We provide grants to individuals, for home adaptations for example. We are committed to bring high quality standards of health and social care within reach of everyone affected by MS.	recommendations emphasise the importance of providing information, support or training to carers in a way that responds to their specific needs or circumstances, including the specific needs or conditions of the cared for person. Finally, in light of a number of stakeholder comments the committee placed greater emphasis in the final version of the guideline on ascertaining and then regularly reviewing whether carers are in fact willing and able to provide care. Although this guideline does not make specific reference to carers of people with certain conditions, there are other relevant NICE guidelines, which address this directly, for example the NICE guideline on Multiple Sclerosis in adults: management [CG186] in which there are recommendations about the provision of information to carers of adults with MS.

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[16] MS Society (2016) My MS My Needs: https://www.mssociety.org.uk/care-and-support/resources-and-publications/publications-search/social-care-and-the-ms-community

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				General comments for draft guidance consultation 1.1. We support the recommendations in this guideline. 1.2. The draft guideline should make more explicit the importance of social care and carer's support being personalised and adaptive around the needs and lifestyle of working-age adults. Social care guidance often focuses on the needs of older people, but the number of working age adults who identify as having a disability has grown over the past decade and more are requiring care and support.[17] In a recent online survey of 714 people conducted by the MS Society, open from 1st March to 31st May 2019, 72% of carers of people with MS were under 65 years of age and three quarters revealed their caring responsibilities have impacted on their ability to work.[18] Working-age carers and those they support may want to stay in employment, education or training, and have young families, and support delivered needs to be sensitive to these needs. 1.3. Furthermore, carers of people with MS will frequently be dealing with symptoms that fluctuate over time – day to day and month to month etc. - due to the nature of the most common form (relapsing remitting MS). The	

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[17] Department for Work and Pensions (2018) Family Resources Survey 2017/18: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/791271/family-resources-survey-2017-18.pdf

[18] MS Society (2019) MS Family and Friends survey (not yet published)

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				guideline therefore needs to make explicit that support for carers and the person they care for needs to be responsive to changing needs, as per the Care Act 2014 statutory guidance. Caring changes the nature of relationship between the family/friend and the person they support, and this can be very difficult to adjust to both emotionally and practically. According to our recent survey, 64% of carers of people with MS are wives, husbands or partners. The guideline should acknowledge this and recommend that the information and support offered to carers is alert to the particular challenges this change in relationship may cause and make clear that people should not be made to feel forced into a caring role they don't want.	
Multiple Sclerosis Society	Guideline	008	001	1.1. In relation to point 1.2.4, social care assessments should also be included in this paragraph as an opportunity for carers to be identified. As per the Care Act 2014 guidance, carers should be offered the opportunity to have a needs assessment in their own right, but also offered a joint assessment with the person they care for, if they both would like. We hope that these recommendations will be useful during the consultation process. For any further information please contact Rachael Grant, Senior Policy Officer (Community and Social Care), Rachael.Grant@mssociety.org.uk, 0208 827 0285.	Thank you for your suggestion, with which the committee agreed. They revised this recommendation to emphasise that social care assessments represent an opportunity to encourage people to recognise themselves as carers. They also added a recommendation to the final guideline to specifically highlight that there may be occasions when a carers assessment is combined or linked with the assessment of the cared for person (with the consent of both parties); this recommendation is found in the section on preparing for and carrying out a carer's assessment.
Newcastle City Council	General	General	General	Inclusive Generally, covers information and advice well No real reference to online information and navigational support	Thank you for your suggestions. In response to yours and other stakeholder comments the committee agreed to place a greater emphasis on the use of digital technology and communication. For example, the recommendation about making information available to

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				Doesn't make any links or reference to advice, information and support from specific external services e.g. Carers Centres Highlights, but doesn't refer to the fact that health and social care professionals must recognise their knowledge limits, how they can navigate the system and where to find information and advice that can support carers	carers in a range formats, now includes 'links to online and digital resources (including local and national websites and forums and social media)'. The committee were in agreement with you about the importance of practitioners having the requisite skills and knowledge, for instance to conduct carers assessments, which are comprehensive and person centred. At the same time, the committee felt it was important to convey that not all health and social care practitioners should be expected to have all the knowledge and information to hand that carers will need. Nonetheless they should know how to access specialist advice, for example to help in the conduct of carers assessments and they should also know where to sign post carers to for further support and information, such as carers groups and forums.
Newcastle City Council	General	General	General	This section needs further clarity, it isn't particularly well written and is not as explicit as it should be in some areas and more explicit than it needs to be in others – it is not consistent. Should consider using a straight lift from the Care Act Statutory Guidance which is best practice for local authorities, and to a degree health professional involved in supporting carers	Thank you for your comment. The recommendations are meant to build on legislation rather than simply repeat it in the guideline. We have however included a statement up front to say that these recommendations need to be read together with the Care Act statutory guidance and have included more about the importance of this and other guidance in the context section of the guideline.
Newcastle City Council	General	General	General	This is already one of the NMET thresholds in terms of statutory support under the Care Act 2014 and is well covered in the Care Act Statutory Guidance Within this section, there are broad messages/actions that are the responsibility of all employers under statutory legislation e.g. Equalities Act – is delivering this detailed information the responsibility of health and care professionals?	Thank you for your comment. We have included a statement up front to say that these recommendations need to be read together with the Care Act statutory guidance and have included more about the importance of this and other guidance in the context section of the guideline. We have also included further references to the Equality Act 2010
Newcastle City Council	General	General	General	This area is one of the NMET thresholds in terms of statutory support under the Care Act 2014 and would always be considered as part of a statutory carers assessment. There are many 'broad' messages that are directed to/at employers – is it really the responsibility of health and care professionals to deliver them in such detail	Thank you for your comment. The scope of this guideline stipulated that "Support and advice to help adult carers to enter, remain in or return to work, education or training" was a key area to be covered. The recommendations in this section reflected the evidence reviewed and suggestions made by expert witnesses, complemented by the interpretation of the committee, which has extensive expertise and experience in social care.

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				Our opinion is that this recommendation is not yet fit for purpose and needs further consideration by NICE.	Many of the recommendations in this section are targeted at workplaces in general and commissioners of services. The committee agreed that those recommendations focusing specifically on health and social care professionals were reasonable in the context of providing support and advice to help adult carers to enter, remain in or return to work, education or training. We have included a statement up front to say that these recommendations need to be read together with the Care Act statutory guidance and have included more about the importance of this and other guidance in the context section of the guideline.
Newcastle City Council	General	General	General	This recommendation does not define, describe or guide professionals and carers to explore or access social and community support, it isolates them further. It makes no reference to volunteers, neglects to include co-production between statutory and voluntary services and appears to drift from being a guideline into legislation i.e. The Care Act. It is thin and totally misses the point of the recommendation heading	Thank you for your comment. The committee considered yours and other stakeholder responses and made a number of changes to the recommendations on social and community support for carers. The opening recommendation now states that local authorities should ensure carers are kept regularly informed about available community services and other sources of support and advice – and also how to access them. The listed examples of sources of support include local carer support services, community and faith groups and advice about self-care. There are other recommendations in the guideline which seek to ensure that carers do not feel isolated, for instance the one stating that health and social care practitioners should promote ways of working with carers that acknowledge them as expert partners in care and value their skills and knowledge about the person they care for. Another recommendation, at the start of the guideline, promotes the provision of up to date information that covers how to access social and community support for carers. These examples help to illustrate the importance of a circle of care which includes local authorities, carers and social and community support, which will include but not be limited to the voluntary sector.

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Newcastle City Council	General	General	General	This recommendation has a first draft feel to it and seems somewhat removed from reality There is something very important about providing carers with the skills and confidence to deliver care but remain individuals in their own right. It is very unclear as to who would be responsible for delivery of this recommendation e.g. health, local authority or a commissioned service No mention of the needs of diverse groups and/or how their needs should be discussed and addressed	Thank you for your comment. The guideline is aimed at health and social care practitioners so they are responsible for implementing the recommendations, unless the wording of a recommendation explicitly states otherwise. The committee agrees with your point about the role of training to support carers in their role while remaining individuals in their own right. In light of this and similar stakeholder comments the committee placed a greater emphasis on ensuring carer wellbeing by carefully ascertaining and then reviewing carers ability and willingness to provide care.
Newcastle City Council	General	General	General	The language in this recommendation is more considered than in other recommendations which highlighted the lack of consistent language throughout the documents. Consideration to changing the title of this recommendation to Carers physical, emotional health and wellbeing should be given – this would go a long way to removing stigma associated with caring (especially around mental health and substance misuse), the term 'psycho' and would encourage health and care professionals to consider the carer as an individual and understand/appreciate that caring for someone will have impacts The needs of carers as individuals should be considered - as it stands, this recommendation is about the individual carer yet blends the needs of the carer and the cared for under each sub-heading	Thank you for your comment. The recommendations in this section are based on review of evidence about psychological interventions for carers, to support their wellbeing and support them in their caring role. The committee are happy that the wording of the recommendations and the explanations about the rationale and expected impact of the recommendations do make this clear and as a result have not made any changes in light of your comment.
Newcastle City Council	General	General	General	This recommendation is very generic. It makes no reference to a young carer transitioning to a young adult/adult carer, the fact that the caring role may change as a result of changes to the carers health, the complexities around caring for an adult with mental health needs or substance misuse and who will be responsible for providing the information and practical support.	Thank you for your comment. Young carers were beyond the scope of this guideline. Nevertheless based on your comment the committee agreed to make reference to this, stating that practical and emotional support and information should be provided to people when they move from being a young carer to an adult carer.
Newcastle City Council	General	General	General	This recommendation is succinct, clear and concise and links to Dying Matters	Thank you for your support for this aspect of the guideline. The evidence review on which this recommendation was based was specifically focussed on supporting carers during the end of life period,

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				We would appreciate additional information and guidance to support carers of those with mental health needs or substance misuse problems who may have to deal with an unexpected end of life situation for example as a result of suicide or drug overdose (accidental or otherwise)	rather than specifically dealing with the aftermath of death. Nevertheless the committee agreed with the importance of the point you make and therefore made an addition to say that carers should be provided with emotional and practical support when the person they care for dies unexpectedly.
Newcastle City Council	General	General	General	Whilst there are practical suggestions to support carers throughout the recommendations, we believe that there is room for further development and improvement in the areas highlighted above and that there are additional areas that should be considered for inclusion • How to support carers caring for someone 'from a distance' • The importance of care, support and treatment for the person with care needs being accessible to both the carer and the cared for person for example, the cared for person is an inpatient at a mental health ward that is a considerable distance from the family home • The importance of including carers in discussions around discharge from hospital, especially around the coordination of other services e.g. district nurse. This is particularly important when the cared for person has had an 'emergency admission' that stops any previous health and social care support within the home and has to be restarted when the person is discharged • Strengthening the guidelines surrounding the legal and financial implications of caring including Powers of Attorney, Court of Protection and Advance Decisions • Ending caring relationships (for reasons other than those covered in the recommendations) and the difficulties surrounding this, especially for carers supporting someone in active addiction • The consideration of the needs of carers looking after someone with mental health needs or substance misuse or responding to the needs of carers looking after someone who is refusing support from health and/or care services.	Thank you for your comment. The committee felt that the recommendations already addressed the issues you raise in as much detail as the scope of the guideline and included evidence permitted. For example, in the section of the guideline about identifying carers, there is a recommendation which makes practitioners aware that some people may not identify themselves as carers for a range of reasons, including that they may not live with the cared for person or the person have moved into supported living or residential care. Similarly there are a number of recommendations about providing support for carers during changes to their caring role. One recommendation states that information and practical support should be provided to carers during changes, for example when the person they care for moves away. Another makes practitioners aware that caring responsibilities may not end just because the person being cared for moves away. In terms of including carers in discussions, this is one of the central messages of the guideline. For example one of the opening sections includes recommendations about involving carers and treating them as a valued member of the care team around the person being cared for. Also, that practitioners should be open and honest with carers about the health condition, disability or needs of the person they care for and that practitioners should share information with carers to enable them to provide care effectively and safely. The committee discussed the possibility that the recommendations perpetuate a stereotypical image of carers but on balance they do not agree. The example of divorce is given among a long list of scenarios resulting from which carers circumstances might change. This recommendation is an attempt to stimulate practitioners to consider the range of events or developments that might require the provision of

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				In addition, we do not feel that the recommendations are fully inclusive, in some areas they are stereotypical e.g. reference to changes in the caring role as a result of divorce which suggests that everyone who cares is married, there is scant reference to BAME and other communities of interest and their particular needs and that there should be an overall statement of purpose that covers this Whilst many of the recommendations are already being delivered there would be significant resource implications for both health and care organisations to deliver some of the suggestions - replacement care to cover a carer working a 37-hour week for example. The implementation of the recommendations would also impact on the resources our voluntary sector partners The final guidelines need to be consistent, workable and achievable.	information and emotional and practical support for carers. The committee also highlighted that there is a specific recommendation in the guideline to ensure that training programmes for carers are inclusive and address the needs and preferences of diverse groups, such as lesbian, gay, bisexual and transgender carers and carers from diverse ethnic, religious and cultural backgrounds. Another recommendation highlights that local authorities should keep carers regularly informed about community services and other sources of support and advice as well as how to access them and these include community and faith groups. The committee recognised that providing replacement care could have a resource impact in some areas, dependent on the current availability of services. However, they considered that their recommendations on replacement care were supported by evidence on cost-effectiveness and consistent with the Care Act and a duty for local authorities to promote individual wellbeing, which includes participation in work, education and training. The recommendations do not stipulate the amount of replacement care that should be provided nor that the local authority should necessarily fund this. The committee anticipated that their recommendations would encourage commissioners to develop local markets so that replacement care was available to purchase, whether that be through local authority or self-funding For some of those issues, for example Powers of Attorney and Advance Decisions, the committee agreed these were more appropriately addressed in other NICE guidelines, to which this guideline carefully signposts. In relation to carers of people with mental health related care needs, this does not reflect the scope of the guideline, which was on adult carers in general. However we have added in a link to the NICE guideline about Transition between inpatient mental health settings and community or care home settings in the section about carer

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					assessments to emphasise the importance of assessing needs for carers looking after people with mental health problems.
Newcastle City Council	Guideline	007-008	General	To this point, guidelines are good, easy to read/understand and concise	Thank you for your comment and for your support for the guideline.
Newcastle City Council	Guideline	004	005	At the very least signposting (and possibly referral) to services needs to be included here. Carers often need a helping hand to access service provision.	Thank you for your suggestion. The committee felt that this recommendation about telling carers where to obtain information and support and subsequent recommendations in this section (and indeed throughout the guideline) about the role of practitioners in sign posting carers adequately address your point.
Newcastle City Council	Guideline	004	016	Concerns about a health and social care workers professional ability to offer detailed financial, benefits and legal advice/information – this is a huge area of concern for carers and the information needs to cover a broader spectrum including the financial implications of being a self-funder and the associated risks to property to pay for social care services	Thank you for your comment. The recommendations about ensuring carers have relevant and up to date advice are couched in terms of health and social care practitioners having a sign posting role - not necessarily knowing or giving the advice themselves but instead knowing which other practitioners or organisations can provide carers with the advice and support they need. For information, the recommendation to which your comment refers has now been merged with an earlier recommendation in that section and the long list of information items has been removed.
Newcastle City Council	Guideline	005	001-002	Help with transport' – this in particular needs additional explanation and clarification – reading this, one might assume that this could relate to the provision of a motor vehicle – suggestion is to change this wording to help with 'travel costs'	Thank you for your suggestion. Following a lengthy discussion of this comment and other stakeholder comments about this recommendation, the committee agreed to remove it and merge it with the earlier recommendation about the duty of local authorities around the provision of information. The long list of examples has also been removed because the committee were concerned that listing some but not other items might lead to absent items being overlooked.
Newcastle City Council	Guideline	005	016	Use of limiting language - would replace the word 'constraints' with the word 'issues' as generic conversations can still happen with service providers, carers and family members that will result in positive conversations/outcomes without confidentiality being breached e.g. common-sense confidentiality - generic information about the treatment of a particular condition or the particular side effects of medication etc	Thank you for your suggestion, which the committee discussed. In this context the committee felt it was accurate to refer to the 'constraints' of confidentiality although in the final version of the guideline this appears in parenthesis following reference to 'respecting' confidentiality.

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Newcastle City Council	Guideline	006	004-008	Include supporting and enabling people to access and navigate information on-line	Thank you for your comment. In light of yours and other stakeholder comments about the important role of digital technology the committee revised a number of recommendations. This included the one to which you refer, which states that information should be made available in a range of formats to meet carers needs and preferences, for example with links to online and digital resources.
Newcastle City Council	Guideline	007	006	Add: 'what this is and the benefits of having a carers assessment'	Thank you for your suggestion, in response to which the committee added to this recommendation so that practitioners ensure carers know what an assessment is and understand the potential benefits.
Newcastle City Council	Guideline	007	008-013	Whilst this does support the identification of carers, this paragraph relates more to the benefits of having a carers assessment	Thank you for your comment. The committee felt it was important to emphasise the benefits of identifying and recognising carers as a means of encouraging practitioners to do so.
Newcastle City Council	Guideline	008	001	Add 'and support' so the sentence reads 'At every opportunity, encourage people who provide care and support to recognise…'	Thank you for this suggested addition, which the committee agreed to make.
Newcastle City Council	Guideline	008	021-022	Amend sentence to read 'Offer carers ongoing opportunities to have conversations about their own needs as carers separately from the person they are supporting'. The original sentence would suggest that this opportunity is only a 'one off'	Thank you for your comment. The committee decided not to make any changes to this recommendation because they feel it is already implied that this is more than a one off, since the plural 'conversations' is used.
Newcastle City Council	Guideline	009	011-013	Unclear Who does this paragraph refer to? • statutory, commissioned or contracted health and social care organisations • internal policies e.g. that relate to their workforce/employees or external policies relating to carers or both? Needs to include the fact that there are benefits to the service provider(s) when carers are a partner in care	Thank you for your comment, which the committee discussed. They agreed that it was not necessary to specify which organisations in the recommendation because it relates to all health and social care organisations. The committee did slightly amend this recommendation with the final version stating that carers champions would 'help' implement the recommendations in this guideline, reflecting the fact that no one individual should be solely expected to implement the Care Act in relation to carers and the recommendations in this guideline. Finally, it is also relevant to your comment to highlight that in finalising the guideline the committee placed a greater emphasis on the benefits of identifying carers, for example because they can provide valuable knowledge about the cared for person and practitioners can therefore deliver the right care and support.
Newcastle City Council	Guideline	010	013	What does this mean – are these the things that are important to the carer or is this from a statutory perspective?	Thank you for your comment. The committee agreed that the wording should be changed and this recommendation now refers to health and

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					wellbeing instead of 'aspects of health and social care'. The guideline now also refers to the Care Act definition of wellbeing so it is clear how the term is being used.
Newcastle City Council	Guideline	010	020-021	This is a really positive statement and is absolutely true – welcome this inclusion	Thank you for your support for this particular section of the guideline.
Newcastle City Council	Guideline	011	001-003	This paragraph is badly worded. Each carers circumstance is different, but they have the right to a combined or separate assessment	Thank you for your comment. In light of this and in line with the Care Act the committee agreed to edit the recommendation to say that assessments can be combined or linked with the assessment of the cared for person (with the consent of both parties).
Newcastle City Council	Guideline	011	004-010	Need to include the appropriateness of the location for a carer's assessment	Thank you for your suggestion. We have amended a recommendation to read "Provide flexibility in the time, location and method of carers' assessments, taking individual circumstances into account" as the committee considered that would encompass the appropriateness of the location.
Newcastle City Council	Guideline	011	011-012	Need flexibility for all carers, not just those who work – amend sentence to read 'Provide flexibility in the timing and location of carers assessment e.g. for carers who work or those with childcare responsibilities	Thank you for your comment. We have amended this recommendation so that the focus is no longer just carers who work.
Newcastle City Council	Guideline	011	026-027	Amend to read 'Ensure there are clearly identified and realistic outcomes for the carer following assessment which might include, depending on local provision…'	Thank you for your comment. As a result of a number of stakeholders comments this recommendation has been revised and now reads 'ensure there are clearly identified outcomes for the carer after their assessment'. Two further recommendations have been drafted alongside this one, which emphasise the importance of ensuring the carer understands and agrees the actions arising from the assessment, that information is shared with other relevant practitioners and that if a support plan is established, the carers needs are subsequently reviewed. There is also a recommendation under the section on 'identifying carers' to ensure carers are told that some support may be means tested. There are also a number of recommendations about ensuring carers understand the full range of available local support and ways of meeting their needs, including community support available regardless of a formal assessment.

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Newcastle City Council	Guideline	011 012	026-027 001-007	This whole paragraph needs to be realistic – who will deliver these options in the current financial climate and especially around adult social care resources – if a carer were to read these, they may be given false hope; also need to refer to potential waiting times for a carer assessment	Thank you for your comment. This recommendation has been amended and a list of example identified outcomes from the carer's assessment is no longer specified.
Newcastle City Council	Guideline	012	001-007	Bullet points should also include • No eligible needs Referral or signposting to other carer support services e.g. Carers Centre	Thank you for your comment. This list of examples has been removed from the recommendation as the committee, on reflection, considered that it could be misleading. The recommendation emphasises the importance of identifying and discussing outcomes without pre-empting what those outcomes might be. Elsewhere, we have amended a recommendation in the section on identification so that carers are made aware that some services might be means tested. In addition, there is a recommendation to ensure that carers know they can access local support without having had a formal carers assessment.
Newcastle City Council	Guideline	012	009-015	Realistically, providing replacement care in order that a carer can remain, enter or maintain work, education or training is not as easy as this paragraph makes it out to be, nor do we believe is the responsibility of health and social care professionals – to signpost or refer yes, but to give tailored information, no. Other than advice and information, support directly to carers from a local authority depends on that carer meeting the National Minimum Eligibility Thresholds as directed in the Care Act 2014. The provision of replacement care around the cared for person may actually be down to their own needs' assessment and their own care and support plan which would indirectly benefit the carer, bearing in mind that a cared for person may refuse either a financial assessment (if needed) or the replacement care itself.	Thank you for your comment. We acknowledge that the provision of any care and support to a carer is dependent on the outcome of their eligibility assessment, according to the Care Act 2014. By drafting this recommendation, the committee sought to emphasise the importance of enabling carers to remain in, enter or maintain work and providing replacement care to address that need as opposed to simply the need of the cared for person.
Newcastle City Council	Guideline	013	024	This line should be changed to read 'Where possible, workplaces should offer flexible working arrangements…'	Thank you for your suggestion. Committee members were not in favour of adding 'where possible' to this recommendation because of the

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				Carers have the right to request flexible working if they are an employee with 26 weeks (six months) continuous employment at the time they make an application. Employers have a duty to deal with the request as soon as possible, within a reasonable time, in a reasonable manner, and must consider the request. Employers can only refuse the request if they have good business reasons for it and this should be explained in writing, including relevant and accurate facts.	potential for workplaces to consider this as a get out clause. The committee agreed the evidence, combined with the expert witness testimony provided a sound basis for recommending that workplaces should offer flexible working arrangements and this was in line with existing NICE guidelines about workplace health.
Newcastle City Council	Guideline	014	003-004	This line should be changed to read 'Workplaces must ensure that staff with caring responsibilities have equal access to career development' Under the Equality Act 2010, it is illegal to discriminate against a carer because of their responsibilities as a carer, or because of the individual(s) they care for. This law applies to discrimination and harassment if they happen in the workplace, and also protect carers when they shop for goods	Thank you for your suggestion. We have now amended the wording in line with the Equalities Act (2010) in this section.
Newcastle City Council	Guideline	014	005-007	Flexibility when arranging appointments should apply to all carers, not just working carers	Thank you for your comment. Whilst our recommendations seek to encourage a flexible approach throughout, in the context of this recommendation, flexibility was specifically identified in the review of evidence about support for carers to stay in, enter or return to work, education or training. This is the basis on which the committee drafted a recommendation about flexibility when arranging appointments to support working carers.
Newcastle City Council	Guideline	014	011-026	Whilst replacement care is an option to support carers with eligible needs (or the adult with needs whether they qualify for local authority support or are self funders), this paragraph raises carer expectations, is resource heavy and sets both carers and local authorities up to fail. The finances needed to support this are just not available.	Thank you for your comment. Although sectoral funding and allocation of budgets is not the explicit remit of NICE guidelines, we outline all of the committee's considerations about resource implications for this recommendation and all the others in the rational and impact section of this guideline. The committee agreed it was still appropriate to recommend here. . We have also added to an existing recommendation in the section on identification to "ensure that the carer understands that some support may be means tested" in order to manage expectations as to what may be available.
Newcastle City Council	Guideline	015	007	Change this to read 'financial support' as opposed to financial assistance	Thank you for this suggestion. We have amended the recommendation in line with your suggestion.

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Newcastle City Council	Guideline	015	012-013	Change this to read 'Health and social care practitioners should regularly discuss with carers the importance of having a break from their caring role	Thank you for your comment. We have amended the recommendation wording from "options for" to "value of".
Newcastle City Council	Guideline	015	017-019	Some local authorities do not organise carer breaks so change to read 'Where appropriate, ensure that carers breaks are arranged…'	Thank you for your comment. The committee considered that it was appropriate for local authorities to organise carer breaks although the recommendations were not prescriptive with regard to the form carer breaks should take.
Newcastle City Council	Guideline	016	002-004	This paragraph refers to volunteers and peer support yet does not mention volunteers once	Thank you for your comment. We have removed reference to "Volunteers" in the section heading.
Newcastle City Council	Guideline	017	007-015	Additional bullet points • Managing challenging behaviours Caring with confidence	Thank you for your comment. We have added managing challenging behaviours to the considerations list in this section. We agree that improving ability to care with confidence is vital but the committee felt this is implied more broadly through the whole section and wider guideline.
Newcastle City Council	Guideline	017	010	Replace with 'Having a Voice' – carers may have all the communication skills in the world, but their voices may never be heard, and this would encompass far more.	Thank you for comment. With this recommendation the committee were referring to skills to help the carer communicate with the person they care for. However, we agree carers voices should be heard, and make recommendations earlier in this section and also in other sections about the importance or listening to the voices and expertise of carers. See, for example: • Involve carers in the planning and delivery of carer training to ensure it covers skills and expertise relevant to them The carer's assessment should: be jointly produced with the carer; reflect what matters most to the carer and what might help them achieve this
Newcastle City Council	Guideline	017	022-025	This is the first mention of diverse groups in the recommendation	Thank you for your comment. We have been careful to keep the concepts of inclusion and accessibility open throughout the rest of this guideline. The reason we specified some groups here is because evidence identified them specifically. However we highlight that every service subject to these recommendations will also be subject to the Equalities Act - and the full meaning of inclusivity in their contexts should be something they are already aware of.

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Newcastle City Council	Guideline	017	026-027	Not all carers want to meet with other carers Change to read 'Training programmes for carers should provide a balance between learning, enjoyment and where appropriate the chance to meet other carers	Thank you for your comment. The committee agree that not every carer will want to meet others, but felt that the wording about the 'chance' to meet other carers implies that it is only as the carer themselves wishes.
Newcastle City Council	Guideline	018	001-002	Not all carers want to keep in touch Change to read 'Where appropriate, consider enabling opportunities for carers to keep in touch with each other…'	Thank you for your comment. The committee were aware that not every carer would want to keep in touch, but felt that the wording about 'enabling opportunities' to do so implies that it is only as the carer wishes.
Newcastle City Council	Guideline	018	004-008	No direct reference to training – carers need more than advice and guidance about the use of equipment etc	Thank you for your comment. We agree that carers should get something more clear and formal than the word guidance implies. As a result the committee have changed the wording to ''training'.
Newcastle City Council	Guideline	018	010	The terms psychosocial and psychoeducational interventions are in the main understood by professionals but not necessarily a layperson – they need to be defined within this recommendation – consider replacing with mental health and wellbeing support	Thank you for your comment. The committee felt it was important to be clear about the exact interventions being referring to and where the evidence to support the recommendations came from. Therefore they have kept the current wording. However we agree this is a very important issue and so have added clear and accessible definitions in the glossary.
Newcastle City Council	Guideline	018	013-020	These bullet points would sit better under the training and support to care recommendation (6)	Thank you for your comment. We have now substantially revised both the training recommendations and the recommendations in the psychoeducational and psychosocial support section of the guideline. These recommendations were largely based on the same evidence and we have now separated out the components so that the most of the content and skills training components now sits within the training recommendations. Only the skills components relating to psychological and emotional support now sit within the psychoeducational and psychosocial section.
Newcastle City Council	Guideline	018	021-022	This bullet point was received favourably particularly by mental health professionals and carer support service provision	Thank you for your comment. We are glad that our recommendations are resonating with the experiences of others.
Newcastle City Council	Guideline	018	023-024	Question raised as to why this was being defined as a psychosocial or psychoeducational intervention	Thank you for your comment. Our review of the psychoeducation evidence, in particular the START intervention (Livingston 2014) identified planning enjoyable and meaningful activities with the person they care for as an outcome that can be promoted specifically through psychoeducation.

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Newcastle City Council	Guideline	019	003	Add the following bullet point Enriching lives and getting the balance right	Thank you for your comment. The items covered in this list were based upon what was suggested by our evidence search on psychosocial and psychoeducational interventions.
Newcastle City Council	Guideline	019	021	Change to read 'If a carer has an identified mental health need, consider'	Thank you for your comment. The widely accepted term used by NICE for the conditions we are referring to is 'mental health problem' and so we have maintained this here.
Newcastle City Council	Guideline	019	023	Amend the sentence to start/read 'consider priority referral to a mental health professional…'	Thank you for your comment. The committee considered your suggestion but felt that the need for a priority referral would vary according to individual circumstances.
Newcastle City Council	Guideline	023	010	Change sentence to read 'information and advice about financial, legal and logistical issues they need to…'	Thank you for your comment. The committee discussed the changes proposed and agreed to amend the wording to include what you proposed.
NHS England	General	General	General	This is a sensible guideline building on work that has already be done. There is a need for an increased constancy on approach and I am hopeful this guideline will achieve this. The biggest impact on practice will be a time element and the suggestion of having a 'champion'. Whilst some practices are embracing the social prescriber model not all are. I think challenges will be overcome by sharing of best practice and by a coordinated national media campaign to inform carers of what is available as often they are not aware. (IG)	Thank you for your comment and we are pleased you feel this is building well on previous and current work in the area. We have added a definition for carers champion and also tried to clarify this more clearly in the recommendations.
NHS England	Guideline	006	024-028	The draft describes a hypothetical "carer champion" in GP surgeries. This would be difficult to achieve within existing resources and the current GP contract. However, this role could be carried out by Social Prescribers who GPs are being reimbursed to employ via a Primary Care Network. (IG)	Thank you for your comment. The evidence on which this recommendation was based did specifically relate to the potential role of GP surgeries in this context. However, having discussed your point the committee agreed to broaden the recommendation in the final version of the guideline to refer to primary care providers and 'primary care networks' in the context of promoting services to carers, for example (but not limited to) nominating carer champions.
NHS England	Guideline	021	019-020	Whilst I totally agree that continuity of care is important within the end of life process this can be very difficult to achieve with modern working patterns and an increasingly diverse workforce being promoted as part of Primary Care Networks and GPs taking on more team leader roles. (IG)	Thank you for your comment. We are grateful for this information and this is useful context for supporting the implementation of the guideline. The recommendation recognised that continuity of care would not always be possible, but the committee, based on the

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					evidence, their experience and expertise, considered that this should be encouraged where practical.
NHS England	Guideline	022	002-009	Para 1.9.7 and Para 1.9.9 seem to be duplicating the same message. I suggest you amalgamate them – very important recommendation. (BW)	Thank you for highlighting this duplication, which has been addressed in the final version of the guideline.
NHS England	Guideline	022	027	Many social services departments do not supply domestic help and having access to this can be troublesome. As this is only an example I would remove it. (IG)	Thank you for your comment. We have removed domestic help from this list as per your suggestion.
Nottinghamshire County Council	Guideline	General	General	We are concerned that there may be some market development issues around replacement care and short breaks. It is difficult to ensure that enough provision is available to enable choice, flexibility and responsiveness as providers are unable to hold voids for these purposes and still be viable, cost-effective services. To enable this to happen more effectively there is likely to be an implication for adult social care budgets who would either be expected to pay a higher rate costs so that empty beds do not impact significantly on delivery or to pay for beds when they are vacant. There are also issue around how self-funders access this support and the price that they will need to pay for this.	Thank you for this comment. The committee considered that their recommendations on replacement care were supported by evidence on cost-effectiveness and are consistent with the Care Act and a duty for local authorities to promote individual wellbeing, which includes participation in work, education and training. We accept that there may be issues and challenges for implementation and therefore the recommendations are not prescriptive with regard to the amount of replacement care and carer breaks that should be provided and focus rather on the features of such a service. In addition, in order to manage carer expectation, we have amended a recommendation to emphasise that carers should understand that some support and services are subject to means testing.
Nottinghamshire County Council	Guideline	General	General	If there is no further money available to spend on commissioned services, local authorities and healthcare commissioners will need to look across the partnership to see where gaps could be met. In authorities with multiple CCGs and district councils this is likely to mean that there is not a parity of service across the area. This would also add to carers' concerns that the information and services they need is not in one place and therefore creates confusion for them. Whilst the guidance does refer to offsetting costs, there would be some initial outlay for this.	Thank you for this comment. Whilst, sectoral funding is not the remit of NICE guidelines the committee considered that their recommendations were cost effective and reflect best practice. This is reflected in the evidence reviews, which include a section on "The committee's discussion of the evidence" and specifically, a subsection on "Cost-effectiveness and resource use". The guideline also includes a rationale and impact section explaining why the committee made the recommendations and how they might affect practice. Given the expertise and experience on the committee we consider the recommendations are reasonable and are aligned to current legislation. Nevertheless we acknowledge that implementation may sometimes be challenging and that an initial outlay/investment is sometimes required in cases where there may be offsetting savings in the longer term.

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Nottinghamshire County Council	Guideline	General	General	Examples of good practice elsewhere would be helpful and adds support to business cases for doing things differently.	Thank you for your suggestion. NICE guidelines do not generally include good practice examples but we recognise these can be valuable tools for the sector in the implementation of the guideline.
Nottinghamshire County Council	Guideline	General	General	The guidance does not mention, or makes little mention of, utilising social media, IT or technological solutions to support carers. Given that these are often more cost effective than physical interventions and that new carers entering the system are likely to be conversant with these mechanisms it would appear a missed opportunity.	Thank you for your suggestion, in light of which the committee agreed to make reference to the potential use of digital communications, social media and online forums. For instance, one recommendation now states that information should be made available to carers in a range of formats, including through links to online and digital resources and another highlights that practitioners should encourage carers to recognise their role and rights through a number of means, including digital communications and social media.
Nottinghamshire County Council	Guideline	General	General	We are concerned that the document reads as if all carers were older people. Many carers are young people or working age adults who have their own set of needs and desired solutions some of which may be met through more innovative practices such as those mentioned in comment 4 above.	Thank you for your comment. Interestingly, a number of stakeholders observed that the draft recommendations did not focus sufficiently on older carers, particularly the sections on work, education and training. In finalising the recommendations the committee took steps to make specific references to young carers where it was appropriate to do so, for example acknowledging that people transitioning from being a young carer to an adult carer may have specific information and support needs. In other places the committee added references to the specific needs of older carers. The committee therefore hope to have struck the right balance in the final version of the guideline.
Parkinson's UK	Guideline	004	005-009	We believe it is vital that health and care professionals should share information and services that could support carers at every opportunity, therefore we endorse this recommendation. Our 2016 report showed that 59% of carers who responded weren't aware of their local authorities social care information and support and 76% of carers had never been offered an assessment of their needs. (Parkinson's UK, 2016, Caring about Parkinson's - https://www.parkinsons.org.uk/sites/default/files/2017-07/care_act_experience_report.pdf)	Thank you for your comment. We are reassured that our recommendations resonate with the needs that your organisation has identified.
Parkinson's UK	Guideline	005	010-011	We wholeheartedly agree with recommendation 1.1.5 as we believe that carers are often experts in the condition and the needs of the	Thank you for your comment, on the basis of which the committee agreed to place even greater emphasis on the importance of the carer

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				person they care for, therefore they must be seen as a valued member of the care team.	as a critical part of the team around the cared for person. They edited the recommendation to which you refer to underline that as a valued team member, the carer should be involved in decision making and care planning and be kept up to date.
Parkinson's UK	Guideline	009	011	We believe recommendation 1.2.12 should be amended so it reads "Health and social care organisations should nominate a 'carer champion' to implement the recommendations in this guideline and Care Act 2014 requirements in relation to identifying carers." We believe this amendment is important as organisations must do more than consider nominating a 'carer champion', for there to be real change in the identification of carers. There needs to be a nominated individual with responsibility for this task.	Thank you for your suggestion. Unfortunately the evidence underpinning this recommendation was insufficient for the committee to draft it in stronger terms. In the final version of this recommendation, the committee edited it slightly to say that carers champions would 'help' implement the recommendations in this guideline, reflecting the fact that no one individual should be solely expected to implement the Care Act in relation to carers and the recommendations in this guideline.
Parkinson's UK	Guideline	010	017-019	We wholeheartedly endorse recommendation 1.3.4. We believe there also needs to be up-to-date information on health conditions shared with these trained and skilled assessors and the ability to check their understanding with experts on the condition to ensure that they are making the correct decisions. Our 2016 report shared that only one third of Parkinson's Local Advisers who responded to the survey disagreed that "assessments in my area have been conducted with a good understanding of Parkinson's" or asked about how a person's condition fluctuates. These members of Parkinson's UK staff support people with the condition and their carers to access health and care services and associated support they need to live well with the condition. (Parkinson's UK, 2016, Caring about Parkinson's - https://www.parkinsons.org.uk/sites/default/files/2017-07/care_act_experience_report.pdf)	Thank you for your suggestion. In light of this the committee agreed to edit this recommendation, adding that practitioners conducting assessments should also have access to specialist advice.
Parkinson's UK	Guideline	011	016-017	We recommend that guidance is produced to help carers prepare for their assessment and that this is shared with the carer in plenty of time so they're able to make the most of their assessment. This guidance should be standardised and share across all local authorities.	Thank you for your suggestion. We have added a recommendation to state that practitioners should share information with carers before the assessment to help them prepare.
Parkinson's UK	Guideline	012	009-012	We recommend that *'where appropriate'* is added so the first sentence of this recommendation reads – "Discuss education, training	Thank you for your comment. The committee were reluctant to include'where appropriate' in case this led to these issues being

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				and employment with carers, where appropriate, during their carers' assessment." Generally, for carers of people with Parkinson's these discussions will not always be appropriate as they may be past retirement age and could place extra stress and pressure on someone.	overlooked. The committee believe that professional judgement would be employed to understand whether it is appropriate for these areas to be explored. We give further detail on the rationale (as well as the resource implications) for all of our recommendations in the rationale and impact section of this guideline.
Parkinson's UK	Guideline	013	011-014	We recommend that *'where appropriate'* is added to the end of this recommendation so it reads – Services providing welfare rights advice or back-to-work or education training should help carers recognise that the skills they have gained through caring are transferable and support them to describe their skills in a way that will appeal to employers, where appropriate." Generally, for carers of people with Parkinson's these discussions will not always be appropriate as they may be past retirement age and could place extra stress and pressure on someone.	Thank you for this comment. The committee considered that this recommendation would only apply in the context where it was appropriate.
Parkinson's UK	Guideline	016	015-020	We wholeheartedly agree with this recommendation and would also suggest that any training provided covers a range of conditions. Local authorities should work closely with both the local health service and local voluntary organisations who have expertise in various conditions. For instance the UK Parkinson's Excellence Network (Parkinson's UK https://www.parkinsons.org.uk/professionals/uk-parkinsons-excellence-network) has a range of learning and resources on Parkinson's for a variety of professionals that have been developed in conjunction with professionals and people with Parkinson's and carers. It is important that commissioned services and training to carers reflects the specific needs of the condition of the person they're caring for so they can be prepared for what's ahead and we'd be delighted if people using this guideline were signposted to use these resources and learning.	Thank you for your comment in support of the guideline. The committee considered that the current wording of the recommendations (e.g. "Offer carer training programmes relevant to carers' circumstances, including the health condition, disability or needs of the person they care for) addressed the point made with respect to training covering a range of conditions.
Parkinson's UK	Guideline	017	013	We would recommend that this bullet point is amended to read "information about relevant health and social care services, including how to complain." We think it is important that the training covers basics around how to complain as carers and people receiving services don't generally	Thank you for your comment. The committee felt that 'relevant services' could include a great number of services beyond only health and social care (including education, employment, benefits, welfare) depending on circumstances and so we did not want to limit it in this way. Dealing

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				complain about the quality of their care and this could drive important improvements. Healthwatch's 2014 report (Healthwatch, 2014, Suffering in silence - https://www.healthwatch.co.uk/report/2014-10-14/suffering-silence) found that fewer than half of people who receive poor care don't report it as they don't how or where to report it. While there have been improvements in NHS England complaints data it's remained fairly static since 2015, therefore we would argue that signposting to complaints procedures in training for carers would help to ensure that incidents of poor care are reported so improvements can be made.	with and managing complaints was not an area that was agreed as a priority to investigate in the guideline.
Parkinson's UK	Guideline	023	016-019	We know that many carers of people with Parkinson's don't see themselves as carers and therefore don't feel information for carers is relevant to them. It is useful to have this shared definition for health and care professionals to identify carers and ensure they are offered relevant information and support.	Thank you for your comment. We agree that this can be an issue, and have attempted to address this in our section on identifying carers.
Quality and Leadership Programme	Guideline	008	020	Is it possible to be more specific about where practitioners should record details about carers? In the care record of the person receiving care and support and/or separately?	Thank you for your comment, which the committee discussed. They concluded that it was not possible to be more specific because these details will be recorded differently in different areas, since there is no unified care record covering adult social care. The committee did however agree to state this explicitly in the rationale and impact section supporting this recommendation.
Quality and Leadership Programme	Guideline	011	004	It is not clear how the information in the bullet points should influence the timing of the assessment. Could it be interpreted that because the person they care for is near the end of life that the assessment should be delayed?	Thank you for your comment. The committee considered that the recommendation was clear that the timing of the assessment should be carer led.
Quality and Leadership Programme	Guideline	014	025	Can it be clearer who is responsible for reviewing replacement care?	Thank you for your comment. The committee were unable to be more specific about which practitioners should do this as they wanted to keep this flexible for local arrangements.
Quality and Leadership Programme	Guideline	019	006	Can it be clearer how the timing of support should take into account how long they have been caring?	Thank you for your comment. In the evidence report we explain it can affect carers experience in different ways. Carers say it would be most useful earlier on, but if delivered at later stages it should account for their experience and their own processes. The committee agreed it was

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					best to keep the recommendation simple and simply refer to consideration for how long they have been caring.
Royal College of General Practitioners	Guideline	001	007	The committee should consider adding higher education institutions and colleges. Some 18-25 year olds will still be in education whist also being a carer and support can be obtained from within the education setting. Universities do not fall under the remit of the local authority.	Thank you for your suggestion, in light of which the committee made specific reference to further education when recommending that health and social care practitioners establish partnerships with local organisations to ensure the widest dissemination of information about carers rights. Unfortunately, we were unable to add a specific reference to universities under 'who is it for' because it is beyond the remit of NICE guidance to make recommendations to that audience.
Royal College of General Practitioners	Guideline	004	005	The committee should consider recommendation that resources are available for practitioners in health care settings detailing what support is available for carers to enable this to be fulfilled. This information usually lies within social care or the third sector (voluntary organisations) rather than the health sector.	Thank you for your suggestion, which the committee discussed. They agreed not to make any changes to the recommendation, which actually emphasises the role of health and social care practitioners in telling carers about their rights and sign posting them to places with resources to provide relevant information and advice.
Royal College of General Practitioners	Guideline	005	014-019	The committee should consider re-ordering these statements. 1. Mental capacity and confidentiality statement - this is the most crucial 2. Explaining to the carers the constraints of confidentiality Share specific information the carers need - this information should only be shared if statement 1 is fulfilled.	Thank you for your suggestion, which the committee agreed to follow. The items in this list have been reordered in the final version, with reference to mental capacity being made in the first item.
Royal College of General Practitioners	Guideline	019	023	The committee should consider adding General Practitioner to this statement as many mental health conditions can be managed within primary care and a mental health professional is not always required.	Thank you for your comment. This recommendation has been amended in line with your suggestion.
Royal College of Nursing	Guideline	General	General	The Royal College of Nursing invited colleagues who care for people with this condition to review and comment on the draft consultation document for Antimicrobial prescribing for impetigo. There were no comments on the documents. Thank you for the opportunity to comment. Please acknowledge receipt.	Thank you for your support and comment, we acknowledge your response.

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Sheffield Teaching Hospitals NHS Foundation Trust	Guideline	General	General	Delivering this guideline will require an education programme for staff and Human Resources policies to reflect employer requirements.	Thank you for your comment. The evidence reviews include a section on "The committee's discussion of the evidence" which includes a section on "Cost-effectiveness and resource use". The guideline also includes a rationale and impact section explaining why the committee made the recommendations and how they might affect practice. Given the expertise and experience on the committee we consider the recommendations are reasonable and are aligned to current legislation, whilst acknowledging that implementation may sometimes be challenging.
Sheffield Teaching Hospitals NHS Foundation Trust	Guideline	General	General	The views of the person should be sought, to establish the extent to which they wish carers and others to be involved in the planning and delivery of their care.	Thank you for your comment. The focus of the guideline is on support for carers. We have been clear throughout the guideline that involvement of the carer in any care planning (e.g. advance care plans) would need to be with the consent of the person being cared for. Equally care plans, including advance care plans, should not include information about carers or possible future carers without the consent of the carer, who needs to be willing and able to offer that care.
Sheffield Teaching Hospitals NHS Foundation Trust	Guideline	General	General	Any written information for carers should take into account the person's literacy/understanding of the information they are given Information.	Thank you for your comment. We cover this consideration in the section on 'sharing information with carers'. And we include a link to NHS England's accessible information standard.
Sheffield Teaching Hospitals NHS Foundation Trust	Guideline	General	General	The primary carer(s) of a person should be offered an educational programme which: explains the nature, consequences and prognosis of a particular condition and what to do in the event of a further problem be that medical or support, teaches them how to provide care and support, and gives them opportunities to practice giving care.	Thank you for your comment. We have included recommendations about the importance of the carer having a good understanding of the health condition of the person they are caring for, where this information is relevant to the care they are giving. E.g. the involving and working with carers section and the section about training. There are also recommendations about the importance of psychosocial and psychoeducational interventions which address this issue.
Sheffield Teaching Hospitals NHS Foundation Trust	Guideline	013	024	As well as offering carers flexible working, there should be mention of increasing use of technology to enable employees to work remotely or a closer base. If carers could work at home for example it could help reduce stress. Also, no mention of supporting staff to take career breaks to undertake their caring responsibilities	Thank you for this suggestion. The examples included in this recommendation were not based on the evidence review but on suggestions made by the expert witnesses who provided testimony to the committee. The list given in the recommendation is not intended to be exhaustive but simply to provide examples and to stimulate discussion about the adjustments or flexibilities that might be appropriate to a carer and their employer. However, the committee

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					agreed that it would be useful to include 'permission to use a mobile phone' as an additional example.
Sheffield Teaching Hospitals NHS Foundation Trust	Guideline	014	008	This recommendation should be made wider to suggest that Carer support services should work with all organisations (not only EAPs) to raise awareness with line managers too as what is available to support their staff. Not all organisations have an EAP. Our Trust did not have a 24-hour EAP until February 2019.	Thank you for your comment. We have broadened this recommendation to include 'employers'.
Shropshire Council	Guideline	General	General	Active Carers – Active Carers is a long-established independent involvement group of battle-hardened but objective carers from across Shropshire and Telford & Wrekin who support adults with mental health issues. Members are very actively involved in all aspects of adult mental health and social care service provision in Shropshire. This document has only just come to our attention therefore the group is only commenting on the guidelines and not on the aspects that only concern physical health carers.	Thank you for your support and your efforts to collate and report the views of members.
Shropshire Council	Guideline	General	General	As chair, I was asked to pass on how good it is that there will be carer guidelines that can be quoted as local authorities and other statutory bodies seek to evade their statutory responsibilities. Also as chair, I have been asked to include submissions from members some of which cover several point and line numbers. I felt it was more appropriate for me to keep the comments together as they were given to me. My apologies if this complicates your data extraction.	Thank you for your support and your efforts to collate and report the views of members.
Shropshire Council	Guideline	General	General	Several of our members support adults on the autistic spectrum and also belong to Shropshire and Telford Asperger Carer Support (STACS) which I also chair. It was felt that, as the only condition that has its own specific legislation (Autism Act 2009) and statutory guidelines and that is also the only one cited in the Care Act 2014 as requiring specificity in carer support, autism carers need support rarely forthcoming from statutory services. Many years' experience has taught us that generic does not work as the understanding is absent. It was felt that this point ought to be noted and included perhaps in a discrete section given the 1%+ occurrence of ASC that on average affects 5 family members	Thank you for your comment. The scope of the guideline means that the focus is on adult carers in general so the evidence reviews were not designed to locate data about carers of people with particular conditions. For this reason the committee were unable to draft recommendations focussed on specific populations, for example carers of people on the autistic spectrum. Nevertheless the recommendations are very clear about the need for practitioners working with carers to have the skills and competence to understand their needs and to be able to work with them, communicate with them and respond to their preferences for information provision and timing and location of support, training or advice. These recommendations apply for carers

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					regardless of the condition or needs of the cared for person. The NICE guideline on autism spectrum disorders in adults [CG142] addresses your concerns more specifically as it does make recommendations for assessment and interventions for families, partners and carers.
Shropshire Council	Guideline	General	General	We felt there ought to be guidelines included for forensic carers. All too often, the statutory staff who are supporting these carers know less than the carers themselves. Whether in secure MH facilities, prison or where services touch the criminal justice system, forensic carers have regularly been let down, sometimes by several services not just MH. This frequently results in the carers becoming MH service users. One of our members co-produced the Forensic Carers Toolkit in collaboration with NHSE. The Carer's Concern procedure should become part of the process so that carers feel empowered to question and challenge professional assumptions and able to recognise and inform about trigger points. Please see Codd 2008 p18 and Cody 2007 that stress difficulties experienced by families and friends.	Thank you for your suggestion. The scope of the guideline means that the focus is on adult carers in general so the evidence reviews were not designed to locate data about carers of people with particular conditions or in particular situations. For this reason the committee were unable to draft recommendations focussed on specific.
Shropshire Council	Guideline	General	General	The above carer is a forensic/MH/autism carer and has tabled these thoughts agreed by the group:- 1. Service Providers should be required to prove they have (staff with) an in-depth understanding of Autism in order to assess and support the Carer adequately 2. Service Providers should be required to prove they have (staff with) an in-depth understanding of different Mental Health conditions in order to assess and support the Carer adequately 3. Service Providers should be required to prove they have (staff with) an in-depth understanding of Forensic cases in order to assess and support the Carer adequately 4. Service Providers should be required to prove they have (staff with) an in-depth understanding of how to work across different organisations such as the Probation Liaison	Thank you for passing on this feedback. The scope of the guideline means that the focus is on adult carers in general so the evidence reviews were not designed to locate data about carers of people with particular conditions. For this reason the committee were unable to draft recommendations focussed on specific populations. Nevertheless the recommendations are very clear about the need for practitioners working with carers to have the skills and competence to understand their needs and to be able to work with them, communicate with them and respond to their preferences for information provision and timing and location of support, training or advice. These recommendations apply for carers regardless of the condition or needs of the cared for person.

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				Officers in order to assess and support a Carer who has restrictions on their lives because of conditions affecting their cared-for, and therefore the Carer's options 5. Service Providers should be asked to give examples of how they work with other organisations in an effective way to support the Carer without opting out using confidentiality as an excuse Without assurances on points such as those above I think any Carer Support Service is going to struggle to even understand the problems carers face - let alone advise and support them!	
Shropshire Council	Guideline	General	General	There was no mention of **how to** access financial support either for carers or the need for them to be informed about service-user's rights to benefits so they can help with this. Being/becoming a carer in an acute situation is very stressful and how to pay for things is often not part of the carer's thinking at the time. Older carers need advice on financial planning for themselves both before and after retirement age. We believe this should be standard procedure and signposting is not enough.	Thank you for your suggestion, in response to which the committee agreed to strengthen a recommendation to say that specialist benefits, financial and legal advice should be included in support, advice and information provided by the local authority.
Shropshire Council	Guideline	General	General	There needs to be training on how to be a carer – not necessarily around practical requirements to support cared-for but on how to take care of ones self. Rethink Mental Health have co-produced excellent Caring for Carers and Caring for Yourself programmes with Meriden. These can be accessed online but does work better if guided.	Thank you for your suggestion. The committee thought this point was already addressed in the recommendation that training programmes for carers should include a component on self-care, health and wellbeing and to emphasise the point they added specific information that carers need to enable them to remain safe in their caring role should also be provided.
Shropshire Council	Guideline	General	General	In Shropshire, we carers are trying to work towards a standard procedure that would come into play whenever a carer becomes acutely ill or unable to continue. This would make it the duty of the first responder, whether blue light services, social care or GP to pass on the details to ALL relevant agencies that there is a cared-for to be informed and supported. This needs little more than buy-in and to be embedded in procedures. Existing emergency carer support systems, certainly in Shropshire, are for a very short period of time to allow	Thank you for your comment. The committee discussed your point about contingency planning but since no evidence was located specifically about this, they did not feel they had the basis on which to draft a recommendation. That said, they felt that the recommendations about provision of information about the full range of available support and how to access it would ensure carers are made aware of any local emergency care arrangements. Furthermore the committee agreed that the recommendations about conducting assessments in a way that

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				other arrangements to be made. This is only if the carer is registered for the service. Not everyone has a support network to call on. Such a process should apply whether the carer recognises themselves in that role or not.	reflects the context of the carers own family and support networks means discussions would cover planning for unexpected events or care break downs. Finally, the committee also pointed out that the guideline does include a recommendation to ensure that replacement care is discussed as part of carers' assessments, including planning for any emergency replacement care that might be needed, for example if the carer becomes suddenly unwell. On balance, the committee felt that through the recommendations described here, the point you raise is addressed by the guideline.
Shropshire Council	Guideline	General	General	Staff/professionals need to be aware and inform the carer that they also have a right to confidentiality	Thank you for your suggestion, as a result of which the committee agreed to clarify that carers should be offered opportunities for 'confidential' conversations about their own needs as carers separately from the person they are supporting.
Shropshire Council	Guideline	General	General	The group thought this a very good document but the whole needed a much longer consultation period to allow time for overworked carers to work through the huge number of pages.	Thank you for your comment. We publish the consultation dates more than a year in advance so organisations can be prepared. However please do contact NICE so you might be a part of our pool of registered organisations to alert when other guidelines are published.
Shropshire Council	Guideline	005	010	Although the Triangle of Care is a MH principle, it transfers across all carer interactions. It has become even more important with the announcement of the NHS Long Term Plan and the drive to integrate health and social care. Everyone needs to be singing from the same hymn sheet.	Thank you for your comment, on the basis of which the committee agreed to place even greater emphasis on the importance of the carer as a critical part of the team around the cared for person. They edited the recommendation to which you refer to underline that as a valued team member, the carer should be involved in decision making and care planning and be kept up to date.
Shropshire Council	Guideline	005	016	In our experience, staff need focussed training around confidentiality to empower them not to fear overstepping boundaries	Thank you for your suggestion. The committee believes that the recommendations as a whole already emphasise the importance of recognising carers and involving them as a key member of the team around the cared for person. The recommendations also emphasise the importance of giving carers the opportunity to have confidential conversations, separate from the cared for person. Given the scope of the evidence reviews and therefore the data on which recommendations are based, the committee agree that this is as far as

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					the guideline can go in terms of 'teaching' practitioners about the nuances of confidentiality procedures.
Shropshire Council	Guideline	005	017	We think this should read – the mental capacity **at the time.** We also this this requires regular review as opinions on confidentiality can change depending on the degree on mental ill health	Thank you for your suggestion. The committee agreed that your point is already addressed by virtue of signposting to the NICE guideline on decision making and mental capacity. The scope of that guideline makes it far more relevant to cover the specific details about assessing and reviewing mental capacity rather than in this guideline.
Shropshire Council	Guideline	006	018	We believe this requires mandatory training	Thank you for your suggestion. Unfortunately it is outside the remit of NICE guidelines to recommend that any training be made mandatory. The guideline can only set out the skills needed to ensure the recommendations are delivered.
Shropshire Council	Guideline	007	007	First time or new carers should be supported into assessment not just signposted	Thank you for your suggestion. The committee believe that the final version of the guideline emphasises the need to support carers before and during an assessment of their needs, ensuring they understand what it is, what the potential benefits are and how to prepare for it.
Shropshire Council	Guideline	007	008	Should stress the benefits also to the professional whose role can be made easier by carer support and input	Thank you for your suggestion, in response to which the committee added to this recommendation so that practitioners ensure carers know what an assessment is and understand the potential benefits.
Shropshire Council	Guideline	008	013	Transfer between hospitals also needs to be considered	Thank you for your suggestion. The committee did not make this addition because they felt it was unnecessary given that the recommendation already states "transferring people to and from hospital", which would include transfer between hospitals as well as transfer to and from home and hospital.
Shropshire Council	Guideline	008	018	Admissions needs to be considered	Thank you for your suggestion. The committee did not change the recommendation because they felt that admission is already covered by referring to 'transferring people to and from hospital'.
Shropshire Council	Guideline	008	021	Very important	Thank you for your comment and your support for this particular section of the guideline.
Shropshire Council	Guideline	010	017	Very important	Thank you for your comment and your support for this particular section of the guideline.
Shropshire Council	Guideline	010	020	Very important	Thank you for your comment. We are glad that our recommendations are covering topics that others also consider important.

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Shropshire Council	Guideline	010	024	Not only what it involves but the benefits. Carer assessment numbers are falling because there is no real benefit or support. Carers cannot see the point if there is no offer. Could the process not be triggered by health?	Thank you for your comment. We have amended this recommendation and moved it to the section on identifying carers. This recommendation informs carers that the assessment need not be a formal one and that a formal assessment is not required to access community resources.
Shropshire Council	Guideline	011	011	Consider the difficulties of travel in a rural environment.	Thank you for your comment. In the section on preparing for and carrying out carers assessments we have a recommendation that states there should be flexibility in the timing, location and method of carers' assessments in order to reflect individual circumstances.
Shropshire Council	Guideline	011	022-025	Very important	Thank you for your comment. We are glad that our recommendations are covering topics that others also consider important.
Shropshire Council	Guideline	012	003-005	Sounds wonderful but no funding to deliver	**Thank you for your comment. This recommendation has been amended and a list of example identified outcomes from the carer's assessment is no longer specified.**
Shropshire Council	Guideline	012	009	Assumes carers are of working age or ability	Thank you for your comment. This does not assume all carers are of working age or ability. However, it does reflect the scope which specified that "Support and advice to help adult carers to enter, remain in or return to work, education or training" was a key area to be covered. Consequently, this population was the focus of the evidence review undertaken to inform these recommendations. In addition we now recommend that replacement care should be discussed as part of the carer's assessment without reference to work, training or education status or plans.
Shropshire Council	Guideline	013	021	Support needed to consider the financial implications of reduction in working hours.	Thank you for your comment. Support for the financial implications of a reduction in working hours is beyond the scope of this guideline.
Shropshire Council	Guideline	015	019	We do not know any carers who get one	Thank you for your comment. The committee is aware that practice may vary geographically but hope that their recommendations would promote best and cost-effective practice.
Shropshire Council	Guideline	016	006	This is asking a lot of peer groups unless they are supported to do this	Thank you for your comment. This recommendation was based on some evidence of benefit from peer support. Whilst no particular configuration of volunteer support is mandated it is acknowledged in the section on "How the recommendations might affect practice" that the recommendation could lead to an increased demand for volunteer

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					and peer support, with a potential impact on coordination and training costs. However, the committee considered that the benefits of peer support, such as reduced social isolation, would represent a cost effective use of resources especially as such support would usually be only required for a short time.
Shropshire Council	Guideline	016	011	This needs to state the right of the advocate/representative to speak. This is often not allowed if representative is a family member	Thank you for your comment. The committee considered that this was addressed within the recommendation which states that where the carer chooses to have an advocate, representative health or social care organisations "should recognise this person's contribution and include them in discussions".
Shropshire Council	Guideline	017	020	Training programmes should be co-produced	Thank you for your comment. We have added a recommendation that carers should be involved in the planning and delivery of carer training.
Shropshire Council	Guideline	020	002	Important	Thank you for your comment. We are glad our recommendations cover topics that are considered important by stakeholders.
Shropshire Council	Guideline	021	018	? "care" missing	Thank you for your comment. We have corrected this typo.
Shropshire Council	Guideline	022	002	If the carer is part of the care plan, they have the **right** to be involved. They will be the one taking the risk and responsibility.	Thank you for your suggestion. Having clarified this we have established that consent is still required for the carer to be part of advanced care planning.
Surrey & Borders Partnership Trust (SABP)	Guideline	3	2	Information and advice section should have a paragraph re GPs role in identifying carers as these are the healthcare professionals who tend to come across carers first.	Thanks for your comment. We have covered this in the section on identifying carers. To keep the guideline succinct we have tried to avoid repeating recommendations in other sections where they could also apply.
Surrey & Borders Partnership Trust (SABP)	Guideline	5	10	This point needs clarification: what does "a valued member of the care team" look like?	Thank you for your feedback. In light of your comment we have added more clarification to this recommendation.
Surrey & Borders Partnership Trust (SABP)	Guideline	8	27	Should there be something about how to manage record keeping/confidentiality in the mutual caring section?	Thank you for comments. The committee has reviewed how we discus confidentiality and this has now been expanded on within its own section.
Surrey & Borders Partnership Trust (SABP)	Guideline	14	3	Can the equality act or other employment acts be referenced here- so HCPs can signpost carers to these? Workplaces are unlikely to be reading these guidelines and so something they can relate to is required to start conversations of this nature	Thank you for your comment. As this is a requirement of the equalities act we have strengthened this recommendation to say 'must'. This is an indicator to all readers that this is based on a statutory requirement.

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Surrey & Borders Partnership Trust (SABP)	Guideline	17	7	Training should also include what constitutes abuse and reference to laws around capacity The inclusion criteria …	Thank you for your comment. We agree that these topics are important, and have covered them in other sections. We make recommendations about talking to carers about capacity in the section on advanced care planning. The committee considered keeping carers safe from abuse to be something covered under 'safety' which is referenced in our recommendations about information and also training.
Surrey & Borders Partnership Trust (SABP)	Guideline	23	12	Should reference be made to organisations which provide counselling for carers of people at the end of life?	Thank you for your comment. The committee has extended the recommendation on sources of support for carers at this time. However, we have avoided reference to specific organisations, because of how organisations and their provision of services can change.
Suzanne Bourne	Guideline	010	022	These recommendations would significantly increase the number of carers assessments taking place, they would need to happen at a much earlier stage in the caring journey and be more proactive - this is positive but would need additional resources or a different approach to carrying out a carers assessment. Could some of the earlier stages be completed online or in groups (where this suited individuals) and include automated signposting and next steps suggestions.	No response needed - non-registered individual.
Suzanne Bourne	Guideline	016	021	References to "training" "education" and providing "information" don't seem to take into account more current thinking on personal learning and development. Just teaching or telling people what they need to know or do will not result in action. Approaches such as individual and group coaching, workshops and peer learning should be at the forefront of this.	No response needed - non-registered individual.
Suzanne Bourne	Guideline	017	003	Online approaches should be used - not just online info resources - eg Zoom groups, webinars, 1-1 video calls - can reduce cost of delivery and increase accessibility with flexibility in time delivered eg evenings and weekends and meeting the needs of the housebound, those in rural communities or where respite care is not available for cared for. (not suitable for all, but suitable for more than you would think if support in available in the set up)	No response needed - non-registered individual.
Suzanne Bourne	Guideline	017	007-021	A great list of content and recognition of peer support approaches. Peer-support approaches require the facilitation of creating a safe space and agreed joint contract / house rules	No response needed - non-registered individual.

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Suzanne Bourne	Guideline	017	027	Add in personal development	No response needed - non-registered individual.
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review A	006	028	Within our neurological community, we see a number of people who do not identify as caregivers because they are also patients. There is a distinct 'separation' process that comes into play. When one partner needs medical intervention and receives an assessment, the other partner does not have a comparable assessment as a caregiver. We have seen carers hospitalised without their GP knowing they were a caregiver and yet served the needs of the husband or wife who were disabled. This increases the stress on both people because they do not want to impact on each other needs, but invariably leads to a crisis situation which could have been avoided.	Thank you for your comment. The committee discussed issues in relation to mutual carers and where carers themselves have health or social care needs. They made specific references to these circumstances, for example recommending that after the death of the cared for person, there should be discussions with carers about meeting their own needs. The committee also recommended that carers' assessments should take account of their own family and support networks.
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review A	007	028	Outcomes; there should be an acknowledgement of patient carers because public services do not recognise that someone can be both. The public sector only recognises that people are patients *or* caregivers. Would also like to see kinship and parent carers recognised as we have a cohort of people from 50-75yrs who are kinship or parent carers for people with learning disabilities/epilepsy/Foetal Alcohol Spectrum Disorder Many or our community identify as carers by joining peer support groups offered by national Charities about the condition, disease or disability, not as caregiver. Public sector staff do not engage, signpost or offer information and this is a particular barrier to people accessing timely and appropriate guidance and support.	Thank you for your comment. The committee discussed issues in relation to mutual carers and where carers themselves have health or social care needs. They made specific references to these circumstances, for example recommending that after the death of the cared for person, there should be discussions with carers about meeting their own needs. The committee also recommended that carers' assessments should take account of their own family and support networks, including that they may care for more than one person. The committee agreed that health and social care practitioners have an important role in signposting carers to information and support. The guideline reflects that those practitioners are not necessarily expected to have all relevant information to hand but do need to know sources of support and information, to which they can direct carers. The opening recommendations of the guideline state that practitioners should use every opportunity to tell carers they have a right to information and where to get it. Also, that information for carers should cover how to access local carer services, for example carer information centres and community voluntary sector organisations. On the basis of evidence presented to them, the committee were also able to specifically recommend that carers should be told about the benefits of peer

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					support and how to access it, which seems aligned with the experiences of carers within your community..
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review A	013	010	Whilst carers need an opportunity for a separate consultation to the person they care for, there is a stigma attached to carers identifying themselves because they worry about public sector scrutiny and the ramifications on their or the person they care for employment status	Thank you for your comment. The committee discussed this in detail and included recommendations setting out the many reasons why people may not wish to identify as carers and the importance of practitioners sharing information with people in a caring role about the possible benefits of seeking information and support as a carer. This included the importance of associated benefits, welfare and financial advice and this has now been made more explicit in the guideline.
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review B	006	015-021	Views and experiences; Through a recent Diverse Carers project we have also identified a gender difference in the attitudes of caregivers where males do not identify with the model of Carers Centre. They more readily identify with condition-specific peer support as part of a similar community to share up-to-date information with other male carers. One gentleman commented the Carers Centre was just a 'gossip factory' and he did not want to sit on a database or have activity that separated him from his wife. The rise of the Men's Shed approach has been welcomed but for male carers, there is a heightened sense of stress that is, not letting the wife or partner suffer by them not being in attendance. The single biggest issue is public sector funding for statutory duty of care and support goes to just one organisation which homogenises the information and generally, fits no-one. The reality now is that caregiving roles are very diverse and the one-stop shop approach creates more unmet needs than it satisfies. Working carers cannot access a Carers Centre during work hours. As mentioned, kinship or parent carers, working carers, patient carers are almost excluded by the current model of Carer Centre with a heavy preoccupation for the Carers Assessment and nothing else. Our community regularly report that they needed more of a friendly support mechanism that was going to be available for their caregiving journey, not short-term quick	Thank you for your comment. The committee discussed and noted this comment but did not wish to make changes to the recommendations to set out different types of care and support based on gender. In fact, there was a concern that an attempt to do so could create more discrimination and implied exclusion of certain groups. The committee concluded that service design should be locally determined. However the committee talked at length about the need for services, support and the provision of information to be tailored to the needs of individual carers, for example drafting a recommendation that carers assessments should take account of their own family and support networks, including that they may care for more than one person. The committee also agreed it was important to ensure that carers assessments are carried out taking account of individual preferences, accommodating caring responsibilities, working patterns and other circumstances. They also drafted a number of recommendations specifically designed to support carers wishing to return to, remain in or enter work, education and training. For example, that health and social care organisations should offer flexibility when arranging appointments for working carers and the cared for person, with examples including workplace surgeries, carer appointments outside hours and digital and telephone appointments. Finally, the committee recommended that commissioners should be aware of the benefits of replacement care for supporting carers, which may or may not be in an emergency situation.

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				fix solutions to satisfy the capacity of the public sector. Parent carers of people with mental health disorders are particularly marginalised by public services and are not advised or supported under the terms of the Care Act. In our view, this whole environment is still predicated on the basis of 'not creating dependency' but carers are dependent long term on a range of services and need first rate communications between those agencies to ensure the carer and the person they care for feel safe in knowledge, income and when an emergency occurs.	
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review B	007	034	Outcomes; Under benefit of information received should include a mechanism for prevention of crisis and some relevance for contribution to a care plan or pathway. Due to constraints on public sector, information is rarely timely and can impact on a carer's ability to make decisions. There must be a greater emphasis on more joined up thinking that is part of an organisational culture, not just at the behest of a single, compassionate person.	Thank you for your comment. The outcomes as set out in the evidence reviews are agreed by the committee before the review of the evidence takes place so are not subject to change at this point. We hope that recommendations about the importance of timely information for carers will help address your concerns.
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review C	006	004	Our community often complain that the Carers assessment is meaningless to them. They do not get specific information or signposting, do not qualify for Carers allowance or do not want to access respite breaks away from the person they care for. Working carers are in a permanent state of exhaustion. People really want practical support more than carers support groups, massages or respite. They need someone to mow the lawn, clip the hedge, fix the fence, clean windows, fetch medical prescriptions or take the dog to the vets. There should be a re-think about choices and perhaps carers could 'commute' their eligibility for respite care over to more practical support. This could have a financial or timed value which would release some time for the carer outside of work hours or in the case of full-time carers be one less thing they have to worry about.	Thank you for your comment. We have amended the guideline to say that a carers assessment or carers support plan should not be the only route to receiving good community carer support. We have included reference to personal budgets in the context section to the guideline as these do enable people to purchase care and support that is most needed by them, including the examples you have included here.

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Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review C	007	037	Outcomes; assessment tool identifying areas of need - this is a barrier for many carers. The identification of need currently is about the path of least resistance and therefore, we see incidents such as a carer recently being told if the CHC team offered an extra 15minutes per day so the carer could prepare for work, the carer would have 'nothing to do'. Wording in this element will be crucial to the effectiveness of the whole protocol. Again, instead of simply focussing on areas of need should record contribution to prevention of crisis and relevance for contribution to a care plan or pathway. This should be part of the assessment process as an aspect of co-production of the journey *with* the carer not *for* the carer.	Thank you for your comment. The outcomes as set out in the evidence reviews are agreed by the committee before the review of the evidence takes place so are not subject to change at this point.
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review D	007	012-015	Scope, Epilepsy Action, Parkinson's UK, Huntington's disease Association and MS Society all have data on the impact of employment rates of people with neurological disorders post diagnosis which has a huge impact on carers. We need to see the environment become much more inclusive of the 'partnership in care' which would help with prevention of crisis.	Thank you for your comment. We have added a new section in the guideline about the importance of practitioners involving and working with carers and seeing carers as equal partners in the planning and delivery of care (always in the context of the consent of the person being cared for). This new subsection is called 'Working with and involving carers' and appears within the first main section of recommendations about information and support for carers. We hope the guideline as a whole will help create the conditions for the more inclusive environment you would like to see.
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review E	006	022	Diverse carers require a diverse range of organisations with the appropriate expertise that are funded to deliver the training and support needs. This has been a long-since neglected area and social care personnel often rely on the expertise of the carer to deliver their training needs. Refer to point 4.	Thank you for comment. Whilst the remit for NICE guidelines does not include making recommendations for levels of funding we acknowledge the point made. We have added a recommendation that requires the carers skills and expertise to be reflected in the planning and delivery of training for carers.
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review E	007	004	Outcomes - Qualitative - should again refer collaboration or co-production to acknowledge care partnership	Thank you for your comment. The outcomes as set out in the evidence reviews are agreed by the committee before the review of the evidence takes place so are not subject to change at this point. The guideline is very clear about involving carers as equal partners in discussions and decision making about their own information and support needs as well as the care and support needed by the person their care caring for (always with the persons consent).

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Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review E	008	Table 1	Outcomes - Qualitative - should again refer collaboration or co-production to acknowledge care partnership	Thank you for your comment. The outcomes as set out in the evidence reviews are agreed by the committee before the review of the evidence takes place so are not subject to change at this point. The guideline is very clear about involving carers as equal partners in discussions and decision making about their own information and support needs as well as the care and support needed by the person their care caring for (always with the persons consent).
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review G	007	030	The Tees regional CCG's have co-commissioned the Improving Access to Psychological Therapies (IAPTs) where people self-refer to their GP. However, timelines are quite short, 6-week courses and only daytime availability which exclude working carers. Psychological and emotional support should only be integrated with information, advice and practical support where services can signpost to relevant expertise and support the carer through the process. Short term quick fix solutions are no solution and encourage a long-term slide into clinical depression.	Thank you for this comment. This is introductory text intended to explain the current context. It is not clear that the stakeholder considers that any recommendations need to be amended to reflect the views expressed in their comment.
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review H	009	Table 1	Hospices are now broadening the range of services available for carers and in particular, anticipatory grief on loss but one aspect is absent from service delivery is access to financial support when cared for dies and benefits and CHC funding is withdrawn. Lack of expertise and capacity in the marketplace is significant. The welfare benefits agenda is chronically difficult to navigate.	Thank you for your comment. The committee agreed to make a more explicit reference to the issues you identify and in the final guideline there is a recommendation that carers should be given up to date and accurate information and advice about financial, legal and logistical issues that they need to address when preparing for or following the death of the cared for person.
Tees Valley, Durham & North Yorkshire Neurological Alliance – Neurokey	Evidence Review I	009	Table 1	Consideration should be given to when the carer becomes the patient and there is a need for dual assessments where married couples/established partners take care of each other.	Thank you for your comment. The committee discussed issues in relation to mutual carers and where carers have health or social care needs and are also in need of care and support and have included recommendations in the guideline in a number of sections, including assessment and changes to the caring role.
The Royal College of Nursing	General	General	General	The Royal College of Nursing welcomes the opportunity to comment on the NICE draft guidelines for Provision for support for adult carers.	Thank you for your comment. We are grateful for your contribution.
The Royal College of Nursing	General	General	General	These proposed guidance will support the implementation of the Care Act 2014 and give clear recommendations.	Thank you for your comment in support of the guideline. The committee carefully considered issues connected with the

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				It is essential that the infrastructure and support required for carers is funded and monitored to ensure appropriate implementation.	implementation and potential resource implications of this guideline. The evidence reviews include a section on "The committee's discussion of the evidence" which includes a section on "Cost-effectiveness and resource use". The guideline also includes a rationale and impact section explaining why the committee made the recommendations and how they might affect practice.
The Royal College of Nursing	General	General	General	The training and ongoing CPD required for health and social care workers to deliver this guidance needs to be funded and be available. This may include integrating into existing pre and post registration education programmes.	Thank you for your comment. The committee carefully considered issues around implementation and the potential resource implications of the guideline and these are discussed in detail in the 'Rationale and Impact' sections of the guideline.
The Royal College of Nursing	General	General	General	We welcome that carer wellbeing is considered in these guidelines, the acute shortage of both health and social care workforce means that services people need may not be available with family and friends having to take on the role of carer.	Thank you for your comment in support of the guideline. The committee recognise that family and friends are often relied upon to provide unpaid care for people with support needs. This is a key factor underpinning the need for this guideline, which aims to ensure that carers are identified, their needs are assessed and support provided to help them in their role and to maintain their own health and wellbeing.
Think Local, Act Personal	Guideline	General	General	We are surprised, given the level of recent practical engagement between NICE and the Think Local Act Personal Partnership, of which NICE is a member, that the 'Making It Real' framework is not referenced at all. We believe it would be a helpful way of contributing to framing and guiding practice across the sector in interacting with Carers and providing them appropriate and tailored support	Thank you for your suggestion. Reference to the Making it Real framework is now made in the context section.
Think Local, Act Personal	Guideline	General	General	We were pleased to see the guidance cite and use Think Local Act Personal's Jargon Buster as a primary source to define terminology	Thank you for your support.

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Think Local, Act Personal	Guideline	General	General	Whilst the definition at the beginning of the document of who the guidance is for is relatively broad, we think this could be more specific about the breadth of functions, roles and organisations that can support carers- for example other Local Authority roles like Housing Officers, Registrars, Welfare Rights and Benefits advice services, Leisure and Tourism Services, Arts and Cultural Services, Parking and Enforcement Officers, Transport. Officers like Bus Drivers. It is disappointing to see interactions across sectors represented in the main within health settings and between Health and Care practitioners	Thank you for your comment. This particular aspect of the guideline is taken directly from the scope, which was itself subject to consultation. To clarify, it is the remit of NICE guidelines to publish recommendations for health and social care and not beyond.
Think Local, Act Personal	Guideline	General	General	We were surprised that the words 'co-production' or 'co-produce' were not used at all throughout the document. We believe that carers need to coproduce both their own support and play a key role in the coproduction of the care and support provided to those they care for with practitioners	Thank you for your comment. The committee were satisfied that the guideline as a whole places great emphasis on the importance of involving carers as a key part of the team around the cared for person, that their knowledge and experience is recognised and used to inform the delivery of care and support and that their preferences and own needs are taken into account and reviewed regularly. The principles of co-production did of course feature in their discussions but they did not feel there was any advantage to adding the term itself to the recommendations and they were happy that the wording used did clearly articulate the importance of centrally involving and enabling carers.
Think Local, Act Personal	Guideline	005	020	This whole section could reference Making It Real as a description of what good looks like from people's and organisations perspectives - specifically around information - Theme 'Having the information I need, when I need it'. It's associated 'we' statements define the behaviours of organisations and practitioners expected by carers as well as people using services	Thank you for your suggestion. The committee agreed that rather than make explicit mention of Making it Real in the recommendations, it would be more appropriate to describe this framework in the context section for the whole guideline.
Think Local, Act Personal	Guideline	006	002	'for example if the information is complicated' Whilst this might be the case for some, it could be an insulting over generalisation, suggest '...is too complicated for the carer to take in at a specific point in time'	Thank you for your suggestion, with which the committee agrees. In the final guideline, this recommendation now emphasises the importance of providing the same information several times, if needed, for example if there is a lot of complicated information. It no longer uses the phrase 'if there is anything they do not understand'.

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Think Local, Act Personal	Guideline	007	008-013	Would this section benefit by being reframed around a coproduced practitioner/cared for/carer arrangement? It could have this added as a separate statement. 'It is important to co-produce support both for the cared for and the carer so that each person's lived experience can inform the best support arrangements for all going forward. This can only happen if carers are identified and recognised as such'	Thank you for your suggestion. The committee edited this recommendation to emphasise that one of the benefits of identifying and recognising carers is that they can share valuable knowledge and help to ensure the right care and support is provided to the cared for person. In finalising the guideline the committee also ensured greater emphasis on the role of the carer as a key member of the team around the cared for person.
Think Local, Act Personal	Guideline	008	005-007	Could this point also cite another professional role in addition to, or in the place of GP's as GP's begins to frame support to Carers as purely the role of health and Social Care professionals – for example Fire Officers, or Welfare Rights and Benefits advisors	Thank you for your comment. The committee decided not to make changes to this recommendation since it is constructed as a 'be aware' recommendation rather than a recommendation to take action and because the evidence on which it was based was specifically about the potential role of GPs and the fact that carers often do not see them as a natural source of support.
Think Local, Act Personal	Guideline	008	021-022	Could this statement be strengthened – we hear that some carers do not know that an assessment of their needs has been undertaken. Should this position be recommended as a default preference?	Thank you for this suggestion. The committee agreed to respond to your point by strengthening the assessment section of the guideline, for example recommending that before a carers assessment take places, practitioners should ensure information is shared with the carer to help them prepare and also to ensure that following the assessment, there are identified outcomes for the carer.
Think Local, Act Personal	Guideline	009	014-016	Is there an opportunity to promote the wider responsibilities and recognition of provision and responsibility for carer services across wider government services. This could be led and promoted by the 'carers champion' recommended in the previous lines. At line 14, 'and other organisations and professionals providing support to carers' could be added after 'Heath and Social Care Organisations'	Thank you for your suggestion. Given the remit of NICE guidelines, recommendations are mainly aimed at health and social care organisations. Nevertheless because there was supporting evidence, the committee did draft some recommendations (around work, education and training), which were aimed at employers and to some extent further education.
Think Local, Act Personal	Guideline	011	016	This would be an excellent place to reframe the wording and explicitly use the word 'co-production'	Thank you for your suggestion. The committee agreed that using the term 'jointly produced' is clearer than the term 'co-produced', which although commonly used among practitioners is not necessarily common parlance among the general public including carers or potential carers using this guideline. Please note that this recommendation has now been removed but the term 'jointly produced' has been added to another recommendation, which states

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					that (the carer's assessment) 'should be jointly produced with the carer and reflect what matters most to them'.
Think Local, Act Personal	Guideline	011	018-025	This section could reference Making It Real as a way of defining expected behaviours 'We make sure we share information about what we do and how people can access our service with other relevant organisations so we can all work more effectively' and 'We work in partnership with others to make sure that all our services work seamlessly together from the perspective of the person accessing services.'	Thank you for your comment. We have added a reference to Making it Real in the context section of Evidence Review C.
Think Local, Act Personal	Guideline	012	003	'A carer's break' would suggest they get just one - suggest 'sufficient breaks from their caring role in a way that is most meaningful to them'	Thank you for your comment. This list of examples has been removed from the recommendation as the committee, on reflection, considered that it could be misleading.
Think Local, Act Personal	Guideline	012	005	We believe that a carers support plan is not the outcome of the assessment, it is the next step in the process, the outcomes from the assessment need to feed into it	Thank you for your comment. We now have a recommendation that states that a carer's support plan is a possible outcome of a carer's assessment. Where this is the case we recommend that the support plan be monitored and reviewed on an on-going basis. We additionally recommend that there are clearly identified outcomes for the carer after their assessment but we no longer provide examples as to what those outcomes might be.
Think Local, Act Personal	Guideline	012	006	Carers get on with the job in hand in the most meaningful way to their relationship to the cared for, it might be better to say 'training where the carer is unclear how best to perform caring and support tasks in an appropriate and safe way'	Thank you for this suggestion. We have amended this recommendation and the example list of identified outcomes, including carer training, has been removed. There are recommendations in another section on providing training in care and support.
Think Local, Act Personal	Guideline	012	008	Whilst we recognise the importance of this area for those concerned, it is not relevant for approximately 50% of Carers who are no longer economically active because they have retired (there is difficulty in defining this because of equality considerations, but what we mean is that they have reached 'retirement age') This has been repeatedly borne out by survey work we have done in conjunction with In Control for example in the POET Surveys where many respondents say this kind of support is 'not relevant'. We suggest some way of differentiating this kind of support is considered. Some Carers who	Thank you for your comment. The guideline is for all carers which led the committee to see the subgroup who are economically active as important, and they were confident that professional judgement would be employed to understand whether it is appropriate for these areas to be explored. The recommendations in this section reflect a key area specified in the scope and the evidence review used to inform these recommendations was based on searches specific to the population of carers who are 'economically active'.

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				have retired are also active in society through volunteering, or continue to learn for leisure and pleasure, or would like to if they weren't so busy caring, thereby enhancing their wellbeing.	
Think Local, Act Personal	Guideline	013	001-002	See comment 16 above, suggest a similar appropriate qualification is added maybe 'for those who have not yet retired'	Thank you for your comment. As your previous point highlighted this recommendation is applicable to approximately 50% of carers. The committee believe that professional judgement will be employed to understand whether it is appropriate for these areas to be explored the subgroup who are economically active is important and the recommendations in this section reflect a key area specified in the scope. The evidence review used to inform these recommendations was based on searches specific to the population of carers who wish to enter, remain in or return to employment, training or education.
Think Local, Act Personal	Guideline	015	001-010	This section seems limited in its perspective - the wellbeing principle of the care act extends to carers in equal measure and information advice and support should have a wide perspective about 'the possible' rather than this rather limited and staid view of what can support a carers needs	Thank you for your comment. This recommendation was based on evidence about people's preferred sources of support and strengthened by the committee's expertise about the most appropriate means of making support available. However in response to yours and other stakeholder comments, the committee expanded this recommendation, which now states that local authorities should ensure carers are kept regularly informed about available community services and other sources of advice and support and how to access them, including community and faith groups, specialist benefits, financial and legal advice and financial support (among others). There are also additional references in the guideline to the use of online forums and digital technology as means of accessing information and support. Finally, the committee also amended a number of recommendations in order to place a greater emphasis on the wellbeing principle. For example one recommendation now states that "Practitioners from health and social care carrying out or contributing to carers' assessments should work together to ensure that the assessment covers all relevant aspects of health, wellbeing and social care needs" and in another recommendation, that in discussions around assessments, assumptions about the carers willingness and ability to provide support should not be made.

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Think Local, Act Personal	Guideline	015	011-019	Often, carers find breaks from the daily routine of caring in the normal home environment extremely effective-this means that the break is not from caring, but that the break is taken with the cared for person away from the home - maybe a short holiday together.	Thank you for your comment. The committee considered this a good point but considered that this was implicit in the recommendation. However, the point has been added to the committee discussion of the evidence.
Think Local, Act Personal	Guideline	016	001-004	We suggest removing the word Volunteer from the title of this section, or being more explicit about how volunteers might provide support to carers. Volunteers are not referenced in the text that follows the title.	Thank you for your comment. We have removed reference to "Volunteers" in the section heading.
Think Local, Act Personal	Guideline	021	007	Reference the word 'jargon' Whilst we agree with this point we wondered if it needs stating here as it is universally promoted at page 6 line 13	Thank you for your comment. The committee agreed to keep this wording here as we had specific evidence about the importance of avoiding unclear language at this time.
Think Local, Act Personal	Guideline	021	018	It seems to us the words 'care and support' (or just 'care' as seems to be your preference) are missing after the words 'end of life'	Thank you for your comment. We have corrected this typo.
Think Local, Act Personal	Guideline	021	020-021	Would it be better to say 'can be assured of consistent support from people they trust at this point' - building a relationship at the cared for's end of life seems counter productive	Thank you for your comment. The committee made this recommendation based on evidence about what carers valued at this time. At the end of life it is likely that new care and support staff will be needed and this recommendation is to encourage services to provide as much continuity of care as is possible.
Think Local, Act Personal	Guideline	021	022-024	would it be better to say '''Encourage carers who are caring for someone near the end of their life to be receptive to support from family, friends and wider social network. Then add, 'this might mean encouraging them to ask for it, as those people might think it too intrusive and insensitive to offer support because of the situation at end of life'	Thank you for your comment. The committee deliberated the wording of this sentence and agreed that it was important to keep the wording as action orientated as possible. We were keen to avoid 'encouraging' carers to do anything other than consider their options, as ultimately they know their own situation best and should have their judgements valued.
Think Local, Act Personal	Guideline	022 023	024-028 001	Might it also include the emotional support of specialist practitioners like Admiral Nurses, Parkinson's Nurses and MacMillan Nurses	Thank you for your comment. We agree these services may be relevant, and in light of the feedback we received we have added local hospices to this list. However, the committee did not feel it was possible or useful to define an exhaustive list and wanted to avoid specifying services for specific recommendations.
Think Local, Act Personal	Guideline	023	009-011	A prime example of wider practice and workforce that could be referenced to give a sense of the breadth of services that support carers outside Health and Social Care- Registrars and Funeral services	Thank you for your comment. The committee felt that these services are already covered by the current wording of this recommendation.

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University of Manchester & Cambridge joint submission	Evidence review D	General	General	We are concerned that the NICE evidence review (review – D) for support needs of adult carers who are caring for people at the end of life (EOL) care has missed important evidence, both regarding carers' support needs during EOL caregiving, and the benefits of person-centred carer assessment and support interventions for EOL that encompass key support needs not covered by statutory assessment. We outline our concerns in more detail below. <u>Benefits of person-centred assessment and support - CSNAT Intervention</u> The review of caregiving for people at EOL excludes a paper by Aoun et al (2015a) on a trial of a Carer Support Needs Assessment Tool (CSNAT) because (a) the intervention was not considered to be an 'intervention of interest' and (b) it was not a 'support intervention for adult carers'. However, the CSNAT intervention is a clearly defined intervention specifically designed to support adult carers of patients at end of life. Further, the NICE review of Assessment of Carers informing the same NICE Guidelines refers to the 'CSNAT intervention' and appears to consider it of relevance to carers. There therefore appears to be a misperception of this intervention in the EOL care review which has prevented it from being included despite its relevance. The CSNAT intervention has two components: an evidence based comprehensive assessment tool that is delivered within a 5-stage person-centred process of assessment and support that is facilitated by practitioners, but carer-led to ensure support is tailored towards carers' priorities and carer-identified supportive input. It is not an assessment tool only, but a full carer support intervention, although the process starts with a validated assessment tool. It was shown in the Aoun et al (2015) trial that the CSNAT intervention significantly reduced carer strain during caregiving. A further trial in	Thank you for your comment. These studies, (Aoun et al, 2015 and Grande 2013), were located by our search for review H and excluded because according to the review protocols the CNAT was not judged to be an intervention to support carers during the end of life period. Instead it was judged to be an approach to assessing carers needs. For this reason evidence about the CSNAT was included in review C on carers assessments. This was a qualitative review, reporting evidence about the acceptability of tools and approaches for assessing carers needs and the 2 papers about CSNAT that were included in the review were Ewing 2016 and Ewing 2018. The papers provided data about the benefits of the CSNAT, in particular the role of the assessment tool in legitimising support for carers themselves, assisting in the communication of carer support needs and as a means of facilitating discussions with carers about care giving and support during the end of life period. The committee concurred with these findings and therefore drafted recommendations based on evidence about the CSNAT and in line with many of the points you have highlighted in your comment. For example they recommended that health and social care practitioners carrying out carers assessments should ensure the assessment covers all relevant aspects of the carers health, wellbeing and social care needs. They also emphasised the importance of ensuring assessments are jointly produced with carers, reflecting what matters most to them (as opposed to taking a one size fits all approach). The committee also drew on the CSNAT evidence and their own related experience to make practitioners aware that a well conducted carers' assessment may in itself act as a therapeutic intervention or means of preventing future problems. Finally, with respect to the end of life period, the recommendations do emphasise the importance of identifying the needs of carers and supporting them in their role as carers but also providing information and support to promote their own health and wellbeing. For example, the committee recommended taking account of carers changing information and support needs in planning for their own future when the cared for person dies. This includes discussing with

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				the UK (Grande et al, 2017) showed that this intervention also reduced early grief and improved mental and physical health post bereavement. Further qualitative evidence from the Aoun et al (2015b, 2015c) trial showed that added benefits of the intervention from carers' and practitioners' perspective, included enabling visibility and legitimacy of carers' needs, reassurance and empowerment. This intervention has correspondingly been recommended for EOL primary care by the RCGP/ Marie Curie Daffodil Standards and the forthcoming NHS England Quality and Outcomes Framework (QOF) Quality Improvement; has been recommended in a Norwegian Government report; is being adopted within healthcare services across the whole province of Alberta, Canada; and has generally been adopted by numerous healthcare services nationally (140 practice organisations in UK and abroad hold licences to use the intervention in practice and another 52 licences are held for research programmes on carer assessment and support. The CSNAT research team have training 122 organisations in the CSNAT intervention both nationally and internationally. <u>Support needs of carers providing EOL care and the role of healthcare practitioners</u> The review of the qualitative EOL literature missed a large scale, in-depth qualitative study of 75 carers' experiences regarding what they needed to support them during end of life caregiving (Ewing & Grande, 2013). This was despite the objective of the qualitative review being "to determine what the most important support needs of adult carers are at the end of life". Ewing & Grande (2013) identified the support needs carers have both to enable them to support the patient in their role of co-worker, and support required to look after their own health and wellbeing, in their role as clients. Support needs relating to the co-worker role mainly	carers how to address their own needs. The committee also recommended that during the end of life period, carers should be encouraged to think of ways to access support, for example through family, friends and employers. In another recommendation the committee emphasised that carers should be helped to access local services for replacement care, palliative care and practical support. Having considered your comments, the committee felt they had addressed almost all the issues you identified including those around responding to the changing support and information needs of carers, particularly – although not limited to the end of life period.

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				require healthcare practitioner support (e.g. support with knowing who to contact when concerned, understanding the patient's illness, knowing what to expect in the future, dealing with symptoms and medicines), while carers' support needs as clients mainly relate to areas covered by the statutory carer assessment (e.g. support with finance, respite). The support needs identified have since been validated as both comprehensive and sufficient in capturing support needs of carers of patients at end of life in a study with 225 carers (Ewing et al, 2013). Findings from Ewing & Grande (2013) therefore not only provide a comprehensive overview of support needs, but highlight that a major bulk of carers' support needs during EOL care requires the input of healthcare professionals, rather than statutory assessment input. Finally, findings show that the supportive input required within each domain of support needs is individual and different from carer to carer, and requires tailored, rather than standardised input. Implications for NICE recommendations These omissions lead to important gaps in the NICE recommendations for EOLC. Firstly, they mean that there are considerable gaps in the recommendations' outline of the support needs of carers of people towards the end of life. Carers' support needs at this stage are considerable and wide ranging, particularly as there is an expectation for them to support patients at home towards EOL in line with patients' preferences. However, the support needs of carers at EOL as currently presented in the guidelines are quite limited. Further, the omission of qualitative and trials evidence above underplays the importance of frontline healthcare staff in assessing and supporting carers of patients at end of life, although their role is mentioned. The NICE recommendations have a heavy and	

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				understandable emphasis on statutory carer assessment. However, what carers require support with during EOL caregiving for a large part requires healthcare input. If healthcare staff are not routinely involved in assessing and supporting these carers, important support needs are unlikely to be addressed. This does not preclude statutory assessment, indeed early healthcare assessment and support is likely to lead to earlier referral to statutory assessment for support needs where statutory assessment input is relevant. Finally, our trials evidence indicates that an intervention that enables healthcare practitioners to tailor their carer support according to carers' self-identified priorities and supportive solutions within a clear, staged process, does lead to improved carer outcomes. This is important for the NICE recommendations, because they currently miss the importance of a structured and comprehensive person-centred process of assessment and support by healthcare professionals. If we are promoting care at home towards the end of life, we need to give carers the required input to support them, and statutory assessment misses key support needs at this point, and furthermore is less likely to be sufficiently quick and flexible to respond to the changing landscape for the carer during EOL care. **References** Aoun SM, Grande G, Howting D, Deas K, Toye C, Troeung L, et al. (2015a) The Impact of the Carer Support Needs Assessment Tool (CSNAT) in Community Palliative Care Using a Stepped Wedge Cluster Trial. PLoS ONE 10(4): e0123012. doi:10.1371/journal.pone.0123012 Aoun S, Deas K, Toye C, Ewing E, Grande G, Stajduhar K (2015b). Supporting family caregivers to identify their own needs in end-of-life care: qualitative findings from a stepped wedge cluster trial. Palliative Medicine; 29(6): 508-517. doi: 10.1177/0269216314566061	

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				Aoun S, Toye C, Deas K, Howting D, Ewing G, Grande G, Stajduhar K (2015c). Enabling a family caregiver-led assessment of support needs in home-based palliative care: potential translation into practice. Palliative Medicine; 29(10): 929-938. DOI: 10.1177/0269216315583436 Ewing G, Brundle C, Payne S, Grande G (2013). The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end of life care at home: a validation study. *Journal of Pain and Symptom Management. 46 (3): 395-405.* http://dx.doi.org/10.1016/j.jpainsymman.2012.09.008 Ewing G, Grande GE (2013). Development of a Carer Support Needs Assessment Tool (CSNAT) for end of life care practice at home: a qualitative study. *Palliative Medicine*; 27(3): 244 - 256. DOI: 10.1177/0269216312440607 Grande G, Austin L, Ewing G, O'Leary N, Roberts C (2017). Assessing the impact of a Carer Support Needs Assessment (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. BMJ Supportive & Palliative Care; 7: 326-334. doi:10.1136/bmjspcare-2014-000829 (Online first 2015).	
University of Manchester & Cambridge joint submission	Guideline	General	General	We note that there is mention of 'individualised care', 'carer-led assessment' and 'tailored support' which is to be welcomed, but we are concerned that throughout the Guideline little attention has been paid to the organisational structures and processes that need to be in place within end of life care (using the NHS England definition of end of life to be the last year of life) in order to achieve these individualised processes. There is some mention of 'carer champions' but little detail on what their role is and how this role is supported within organisations. There is also mention of practitioners having the	Thank you for your comment. There was no review question within the development of this guideline about the effectiveness of training for staff supporting carers. The committee were nevertheless able to draw on included evidence, supported by their own experience and expertise to emphasise particular areas where attention is needed on the competence and knowledge of practitioners. It is then the responsibility of employers, royal colleges and other professional training bodies to consider how to ensure employees and professionals acquire those skills. In terms of your point about organisational structures for end of

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				'knowledge, time and communication skills' to support carers but there is no guidance on how this can be achieved in everyday practice. Throughout our considerable experience of implementing a comprehensive, carer-led assessment and support intervention, lack of attention to a number of key organisational structures and processes has been shown to affect adoption and embedding of the intervention in practice. A recent report from Hospice UK on organisational change to achieve comprehensive person-centred assessment and support for carers in end of life care details ten recommendations for organisational change: these recommendations are the findings from a mixed methods study including a wide ranging stakeholder consultation. The ten recommendations are: **1.** Consistent identification of carers within the care setting. **2.** Demographic and contextual data on who the carer is and their situation. **3.** A protocol for assessing carers and responding to the assessment. **4.** A recording system for carer information, separate from patient data. **5.** A process for training practitioners about carer assessment and support. **6.** Available time/workload capacity for carer assessment and support. **7.** Support from senior managers for carer assessment and support. **8.** Role models/champions for carer assessment and support. **9.** Pathways for communication about carer assessment and support. **10.** Procedures for monitoring/auditing processes and outcomes of carer assessment and support.	life care, this is beyond the remit of this guideline which sought evidence on people's experiences of support for carers during the end of life care period and the effectiveness of that support. The data largely focussed on people's information needs and preferences, carers' opinions about having help at home and their need for sensitive treatment and advice, including after the person has died. These data would not have provided the basis for the committee to draw conclusions about the organisational structures required to deliver support for carers in this context. This aspect is more appropriately addressed by the NICE service delivery guideline on end of life care for adults [NG142], which includes advice on services for carers.

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				This set of recommendations were identified as key building blocks to achieving more consistent processes of identifying, assessing and supporting carers but also in supporting and sustaining implementation of comprehensive, person-centred care for carers which is not the current practice norm. **Reference:** Ewing G and Grande GE. *Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change*. London: Hospice UK, 2018.	
University of Manchester & Cambridge joint submission	Guideline	024	017	Recommendations for research. As a research team whose work has also included studies of implementation in practice we feel there is a missed opportunity for further research on implementation of carer assessment in routine practice in end of life care.	Thank you for your comment. The committee agree that implementation issues around carers assessments are important and that end of life care is a critical period. However none of the reviews were designed to locate evidence specifically about carers assessments in the end of life care period so this was not indicated as an evidence gap. The particular gap in relation to evidence on carers assessments was around the Care Act 'whole family approach' to assessments, which the committee prioritised for further research. It is likely that messages for implementation would emerge from this type of research.

**None of the stakeholders who comments on this clinical guideline have declared any links to the tobacco industry.*