NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards

Briefing paper

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| Quality standard topic: Supporting adult carers  Output: Prioritised quality improvement areas for development.  Date of Quality Standards Advisory Committee meeting: 11th August 2020 |

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1. Introduction

This briefing paper presents a structured overview of potential quality improvement areas for supporting adult carers. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

* 1. Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

* 1. Development source

The key development source referenced in this briefing paper is:

[Supporting adult carers](https://www.nice.org.uk/guidance/ng150). NICE guideline NG150. Published January 2020.

1. Overview
   1. Focus of quality standard

This quality standard will cover the provision of support for adults aged 18 or over who provide unpaid care for 1 or more people aged over 16 with health and social care needs. It will not include people who provide paid care or do so as voluntary work.

* 1. Definition

[The Care Act](http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted) defines a carer as an adult, aged 18 or over, who provides, or intends to provide, care for another adult who needs care because of a disability, health condition, frailty, mental health problem, addiction or other health or care needs.

* 1. Population

[The 2011 Census](https://www.ons.gov.uk/census/2011census) showed there were around 6.5 million unpaid carers in the UK, with 1.3 million of them over 65 years old. Most carers were aged between 50 and 64 but people aged 65 and over made up a higher proportion of carers (19%) than in the population as a whole.

[Carers UK (2019)](https://www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2019) estimated that 8.8 million adults in the UK were carers in 2019 (17% of adults). The rise from 2011 is linked with the increasing number of people aged over 85, the continued closure of care and nursing homes and the increased use of care at home ([The state of health care and adult social care in England 2018/19, Care Quality Commission](https://www.cqc.org.uk/publications/major-report/state-care)). In addition, according to a survey conducted by Dying Matters, 70% of people expressed a wish to stay in their own home, and to die at home rather than in hospital or a nursing home. This is likely to further increase reliance on family members and friends.

A recent [Carers UK research report](https://www.carersuk.org/for-professionals/policy/policy-library/carers-week-2020-research-report) indicated that 4.5 million people in the UK started providing unpaid care since the start of the COVID-19 pandemic. The report estimated that 26% of UK adults (13.6 million) were providing unpaid care to an older, disabled or ill relative or friend in May 2020.

Caring for someone can take its toll on a person's health and wellbeing. According to Carers UK ([Juggling work and unpaid care](https://www.carersuk.org/for-professionals/policy/policy-library/juggling-work-and-unpaid-care)), almost 1 in 10 UK adults have given up work or reduced their hours to accommodate care. Leaving or reducing work affects carers' own independence and wellbeing and their contribution to the economy. This may also have a substantial effect on their former employers' productivity and lead to high costs in recruitment and training.

Carers may also give up other activities and may face isolation; they may report feelings of depression and a reduced quality of life. Carers UK ([Caring behind closed doors](https://www.carersuk.org/for-professionals/policy/policy-library/caring-behind-closed-doors-report)) highlighted that 70% of carers indicated that they were providing more care due to the COVID-19 pandemic.

* 1. Current service delivery and management

Even though the pressures on carers are recognised, both [Carers UK's State of caring report 2019](https://www.carersuk.org/news-and-campaigns/news/state-of-caring-report-2019) and the [Government response to the 2016 carers call for evidence](https://www.gov.uk/government/consultations/carers-strategy-call-for-evidence) (in advance of the [Carers action plan 2018 to 2020](https://www.gov.uk/government/publications/carers-action-plan-2018-to-2020)) report clear evidence that many carers did not feel adequately supported and that although caring can be immensely rewarding, many found that they did not feel respected, valued and supported for the contribution they made.

Good quality, consistent support helps to address this, providing benefits for the health, wellbeing and resilience of unpaid carers. It can also enhance the life of the person being supported and help to reduce admissions to hospital and support earlier discharge. However, the amount and quality of support available to unpaid carers varies widely across the UK. Even where it is available, it may be neither appropriate nor affordable and complex local systems can be difficult to navigate with little guidance and direction ([Government response to the 2016 carers call for evidence](https://www.gov.uk/government/consultations/carers-strategy-call-for-evidence)).

The NHS long term plan emphasises the vital contribution of carers and the need for more integrated and personalised support (including greater use of personal health budgets). The Care Act 2014 expects the NHS and social care to work together and where possible to integrate services and support. The Care Quality Commission has introduced Quality Markers in Primary Care (usually the first means of identifying carers) and the Association of Directors of Adult Social Services (ADASS) Carers Policy Network reports encouraging evidence of greater cooperation between health and social care in their regularly updated [Guide to efficient and effective interventions for implementing the Care Act](https://www.adass.org.uk/a-guide-to-efficient-and-effective-interventions-for-implementing-the-care-act). Similarly, principles of co-production and interventions such as Think Local Act Personal (TLAP)'s 'Make it real' offer new approaches to more actively engaging carers as 'experts by experience' and co-designing their own care and support.

A key barrier to the provision of appropriate support to carers is that they are often not identified. Many carers do not think of themselves as carers or are not identified by health and social care practitioners as such (so called 'hidden carers') and do not know about the support available. The [Care Act 2014](http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted) and [Department of Health and Social Care's Care and support statutory guidance](https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance) attempted to address this, substantially strengthening the rights and recognition of adult carers within the social care system. The Act entitles carers to assessment in their own right, together with information and advice to help them make the best choices about support for their own health and wellbeing.

The Care Act introduces carer support plans setting out how identified and eligible needs may be met, including personal budgets and the option of direct payments. These duties reflect the emphasis on universal personalised support for carers as set out in the [NHS long term plan](https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/) (NHS England). However, it is still the case that only a small proportion (in one area estimated as 7%) are identified as unpaid carers by social care and health organisations, so many are missing out on help and support.

The emergency Coronavirus Act 2020 removed the duty for local authorities to carry out carers’ assessments and replaced it with a power to carry out these assessments and to meet eligible needs. [Carers UK](https://www.carersuk.org/for-professionals/policy/policy-library/briefing-on-the-impact-of-coronavirus-act-2020-on-carers) highlighted the importance of monitoring the impact of this temporary legislation on carers.

* 1. Resource impact

We do not expect this quality standard to have a significant impact on resources. When the [supporting adult carers](https://www.nice.org.uk/guidance/ng150) guideline was developed, a resource impact statement was produced which noted that:

* the resource impact of implementing any single guideline recommendation will be less than £1 million per year in England (or £1,800 per 100,000 population) and

the resource impact of implementing the whole guideline in England will be less than £5 million per year (or £9,100 per 100,000 population).

Where practice changes as a result of this guideline, there will not be a significant change in resource use.

Many of the recommendations are in line with existing requirements of the Care Act 2014, existing NICE guidelines and current best practice. There may be costs associated with raising awareness and training relating to some recommendations. However the costs from these activities are outweighed by savings to health and social care organisations.

Health and social care services are commissioned by NHS England, clinical commissioning groups and local authorities. Providers are NHS hospital trusts, community providers, mental health trusts, primary care providers, GPs and social care services.

1. Summary of suggestions
   1. Responses

In total, 19 registered stakeholders responded to the 2-week engagement exercise 30/1/20 to 13/2/20. 13 of these registered stakeholders provided areas for quality improvement and 6 advised that they were unable to comment at this stage or had no comments to make. We also received comments from 7 specialist committee members. The responses have been merged and summarised in table 1 for further consideration by the committee.

Full details of all the suggestions provided are given in appendix 2 for information.

### Table 1 Summary of suggested quality improvement areas

| Suggested area for improvement | Stakeholders |
| --- | --- |
| Identifying carers   * Identifying carers * Information and advice | * CT, DHSC, MC, NCC, RCN, SCMs, CBF, TLAP * CT, DHSC, NCC, PCFT, SCMs |
| Involving carers   * Working with and involving carers * Training to provide care and support | * DHSC, MC, PCFT, SCMs, CBF, RRA, TLAP * OHFT, RCN, SCM, CBF |
| Assessing carers’ needs   * Access to carers’ assessments * Quality of carers’ assessments | * CT, DHSC, NCC, PHE, SCMs * CT, DHSC, MC, OHFT, PHE, RCN |
| Supporting carers   * Helping carers stay in, enter or return to work, education or training * Social and community support * Psychological and emotional support * Carers breaks | * PHE, SCMs, TLAP * MC, MSAT, PHE, RCN, SCMs, BTC, TLAP * MC, MSAT, PCFT, PHE, SCMs, BTC, CBF * MSAT, SCM, TLAP |
| Supporting carers at specific times   * Support during changes to the caring role * Support during end of life care | * NCC, SCM, CBF, RRA * NCC |
| Additional areas   * Care coordinator * Financial support * Joined up services | * MSAT, BTC * MSAT * DHSC |
| Abbreviations:  BTC, The Brain Tumour Charity  CBF, The Challenging Behaviour Foundation  CT, Carers Trust  DHSC, Department of Health and Social Care  MC, Mencap  MSAT, Multiple System Atrophy Trust  NCC, Newcastle City Council and partners  OHFT, Oxford Health NHS Foundation Trust  PCFT, Pennine Care NHS Foundation Trust  PHE, Public Health England  RRA, Relatives and Residents Association  RCN, Royal College of Nursing  SCM, Specialist Committee Member  TLAP, Think Local Act Personal | |

* 1. Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1846 papers were identified for support for adult carers. In addition, 161 papers were suggested by stakeholders at topic engagement and 155 papers internally at project scoping.

Of these papers, 14 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

* 1. Priorities for committee discussion

The format of this briefing paper has been amended to support the move to virtual committee meetings. Table 2 summarises the availability of information presented in the briefing paper for each suggested quality improvement area. We have used this to suggest priority areas for the quality standards advisory committee to discuss. The areas that are not suggested as a priority for discussion are shaded in grey within the briefing paper. These are suggestions only however and the committee on 11th August 2020 will decide which areas it wishes to discuss.

Table 2 Summary of information available for suggested areas for improvement

| Suggested area for improvement | In scope | Guideline recs | Current practice evidence | Existing QS statement | Priority to discuss? |
| --- | --- | --- | --- | --- | --- |
| Identifying and informing carers   * Identifying carers * Information and advice | Yes  Yes | Yes  Yes | Yes  Yes | No  No | **Yes**  **Yes** |
| Involving carers   * Working with and involving carers * Training to provide care and support | Yes  Yes | Yes  Yes | Yes  Limited | Yes  No | **Yes**  **Yes** |
| Assessing carers’ needs   * Access to carers’ assessments * Quality of carers’ assessments | Yes  Yes | Yes  Yes | Yes  Yes | No  No | **Yes**  **Yes** |
| Supporting carers   * Helping carers stay in, enter or return to work, education or training * Social and community support * Psychological and emotional support * Carers breaks | Yes  Yes  Yes  Yes | Yes  Yes  Consider only  Yes | Yes  Limited  No  Yes | No  No  No  No | **Yes**  **Yes**  **No**  **Yes** |
| Supporting carers at specific times   * Support during changes to the caring role * Support during end of life care | Yes  Yes | Yes  Yes | No  Yes | Yes  Yes | **No**  **No** |
| Additional areas   * Care coordinator * Financial support * Joined up services | No  No  No | No  No  No | N/A  N/A  N/A | Yes  No  No | **No**  **No**  **No** |

1. Suggested improvement areas
   1. Identifying and informing carers
      1. Identifying carers

### Summary of suggestions

Stakeholders suggested that identifying carers at the earliest opportunity is a priority to ensure they are recognised as partners in the care of the person they are supporting and so they can access the information and support they may need. Currently many carers are not identified by local health and care services, including primary care and hospitals. It was suggested that other organisations such as employers and faith and community organisations could also help to identify carers. Carers may not self-identify because they see themselves primarily as a family member or friend.

Improved identification of carers is needed to inform planning of local support and services for carers. It was suggested that currently there is poor data collection in relation to carers in NHS IT systems.

### Selected recommendations from development source

Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.2.2

Use every opportunity to identify carers, including GP appointments, flu jab appointments, home visits, outpatient appointments, social care and other needs assessments, including admission and discharge assessments and planning meetings. Record details about carers you have identified (with the carer's consent).

Recommendation 1.2.4

When identifying carers, be aware that some people may not view themselves as a carer because:

* becoming a carer can be a gradual process, and carers may not recognise the changing nature of their relationship with the person they support
* carers may prefer to continue identifying primarily as a husband, wife, partner, sibling, parent, child or friend rather than as a carer
* carers often become engulfed by competing demands, including working and caring, and as a result may overlook their own needs as a carer and may not seek support
* the person being supported may not accept that they have care and support needs

the carer does not live with the person or the person has moved away from home, for example into supported living or residential care.

Recommendation 1.2.6

Ask people with care and support needs whether anyone gives them help or support, apart from paid practitioners. Avoid making assumptions about who might be providing their care. Take into account that:

* other people offering help or support may not be family members or may not live with the person

there may be more than 1 person involved in caring.

Recommendation 1.2.11

Health and social care organisations should encourage people to recognise their role and rights as carers through:

* publicity campaigns involving local community services, for example posters and leaflets in GP surgeries, libraries and pharmacies
* digital communications, social media and online forums that engage with carers
* partnerships with community pharmacies, local carer support organisations and carer groups, for example in hospital settings

partnerships with local community organisations who can help disseminate information more widely, such as further education colleges, sports centres and supermarkets.

Use descriptions that carers will relate to and include details of where to find further information and advice.

Recommendation 1.2.13

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.

### Current UK practice

[Carers UK Missing Out: Research briefing on the State of Caring 2019](https://www.carersuk.org/for-professionals/policy/policy-library/missing-out-research-briefing-on-the-state-of-caring-2019-survey) (based on survey responses from 7,000 carers) found that over half of all carers (55%) took over a year to recognise their caring role and 23% took over 5 years to recognise themselves as a carer. 36% of carers said they missed out on financial support as a result of not identifying as a carer and 47% said they missed out on practical support.

[Carers UK Supporting carers to be healthy and connected: Research summary for carers week 2018](https://www.carersweek.org/media-and-updates/item/486949-carers-week-2018-press-release) indicated that 72% of carers who responded to the State of Caring 2018 survey (6,828 responses) said their GP knew they were a carer. Almost 3 in 10 carers said their GP either did not know they were a carer (11%) or that they did not know if their GP knew (18%). Carers trying to juggle their caring responsibilities with paid work were less likely to report that their GP knew they were a carer (59%).

A [Healthwatch briefing on What is it like to be a carer](https://www.healthwatch.co.uk/report/2018-10-01/whats-it-being-carer-0) indicated that 48% of local authorities in England did not know or had made no assessment of the number of carers who lived in their area (based on a Freedom of Information request in 2018).

[The Department of Health and Social Care 2016 How can we improve support for carers?](https://www.gov.uk/government/consultations/carers-strategy-call-for-evidence) call for evidence received more than 6,000 responses on identifying carers, with half of responses indicating that they had not received any help to identify themselves as a carer. They felt that this was a real gap because it made them feel more alone and left them unaware of the support available for them.

* + 1. Information and advice

### Summary of suggestions

It was suggested that when carers are identified they should be given advice and information about the support available to them. It is important to ensure that information is accessible and meets the person’s needs. There should be a consistent approach to providing advice and information to carers across services.

Carers should be given information about their right to a separate assessment. It was suggested that front-line staff often tell carers that they are only entitled to a joint assessment with the person they care for.

### Selected recommendations from development source

Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.1.1

Local authorities should provide information to carers to support them in their caring role. Information provision must meet the requirements of the Care Act 2014.

Recommendation 1.1.2

Practitioners in health and social care (including healthcare professionals in primary and secondary care, social care practitioners, care and support workers and personal assistants) should use every opportunity to tell carers they have a right to information and support and how to get it (see section 1.2).

Recommendation 1.1.3

Information for carers should be up to date and cover:

* the range of support and advice recommended in this guideline
* how to access social and community support for carers (see section 1.5)

useful further sources of information and support such as carer groups and forums.

Recommendation 1.2.1

Actively seek to identify carers (in line with the requirements of the Care Act 2014) and ensure that they know:

* about their right to a carer's assessment, what this is and the benefits of having one
* how to obtain a carer's assessment
* that some support may be means tested

that they can still access community support without formal assessment.

Recommendation 1.2.10

Ensure that carers who don't want or need a statutory carer's assessment are still offered information about how to access support.

### Current UK practice

[NHS Digital’s Personal Social Services Survey of Adult Carers in England 2018-19](https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19) (based on a survey of 50,800 carers known to Local Authorities) indicated that 51.4% of carers had received information and advice to help them as a carer over the last 12 months. The survey also showed that 37.5% of carers who had tried to find information and advice about support, services or benefits over the last 12 months had found it fairly or very difficult to find. The majority (86.5%) of those who did find information and advice found it very of fairly helpful.

[Carers UK Supporting carers to be healthy and connected: Research summary for carers week 2018](https://www.carersweek.org/media-and-updates/item/486949-carers-week-2018-press-release) indicated that 38% of carers whose GP knew they were a carer reported that their GP had not talked to them about any of a range of information and support. 9% of those whose GPs knew they were a carer said that their GP had talked to them about general information, advice and support for being a carer or where they could go to get this.

The [Healthwatch briefing on What is it like to be a carer](https://www.healthwatch.co.uk/report/2018-10-01/whats-it-being-carer-0) highlighted that 188,000 carers accessed a local authority information and advice service in 2016/17 which was a decrease of 2% compared to 2010. They concluded that this was surprising given the increasing level of need.

The [Department of Health and Social Care 2016 How can we improve support for carers?](https://www.gov.uk/government/consultations/carers-strategy-call-for-evidence) call for evidence received more than 6,000 responses on information and advice about caring. 48% said they had received information about caring and the support available, 43% said they had not and 9 percent were not sure.

### Committee discussion

|  |
| --- |
| For discussion |
| * What is the priority for improvement? * What is the key action that will lead to improvement? * Could we focus on a specific audience or setting? * Can we develop a specific, measurable statement? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Involving carers
     1. Working with and involving carers

### Summary of suggestions

Stakeholders suggested that health and social care practitioners should involve carers more in the care for the person they support (including those living in residential care). They should be treated as a valuable member of the team with expert knowledge about the person they support. Sharing information and involving them in care planning for the person they support will enhance the plan, promote ownership and help them to feel prepared and able to cope.

It was also suggested that the needs and circumstances of the carer should be considered when deciding on actions for the person being supported. Involving carers could help to improve patient outcomes including reducing readmissions following discharge from hospital and improving adherence to medication and care plans.

A stakeholder suggested that carers passports can help to ensure carers are involved and are included in the NHS Long Term Plan.

### Selected recommendations from development source

Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.1.10

Health and social care organisations 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. These approaches should be incorporated into formal policies and processes.

Recommendation 1.1.11

Health and social care practitioners should work in partnership with carers and treat them as a valued member of the care team around the person being cared for, with the person's consent. This should include involving carers in decision making and care planning and keeping them up to date.

Recommendation 1.1.12

During discussions with carers about the person they are caring for:

* take into account the mental capacity of the person being cared for and their wishes around confidentiality (see NICE's guideline on decision making and mental capacity)

share with carers the information they need to provide care effectively and safely while respecting confidentiality (explain to them the constraints of confidentiality).

Recommendation 1.1.13

Be open and honest with carers about the health condition, disability or needs of the person they care for (with the person's consent), including when information is difficult or upsetting. Explain how it is likely to progress so that carers understand how their caring role might change in the future.

### Statements in existing quality standards

[NICE QS15 Patient experience in adult NHS services](https://www.nice.org.uk/guidance/qs15) statement 5

People using adult NHS services have their preferences for sharing information with their family members and carers established, respected and reviewed throughout their care.

### Current UK practice

[NHS Digital’s Personal Social Services Survey of Adult Carers in England 2018-19](https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19) (based on a survey of 50,800 carers known to Local Authorities) found that among carers who were aware of discussions about the support or services provided to the person they care for, 39.7% always felt involved or consulted, 30% usually, 22.5% sometimes and 7.8% never.

[Carers UK State of Caring report 2017](https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-report-2017) (based on a survey of 7,286 carers) indicated that 58% of carers with experience of hospital discharge in the previous year said they were either not consulted about the discharge (23%) or were consulted but only at the last minute (35%).

The [Carers UK Building Carer Friendly Communities: Research report for Carers Week 2016](https://www.carersuk.org/for-professionals/policy/policy-library/building-carer-friendly-communities-research-report-for-carers-week-2016) (based on a survey of 6,149 carers) reported that 21% of carers said their hospital does not recognise their caring role.

[The Department of Health and Social Care 2016 How can we improve support for carers?](https://www.gov.uk/government/consultations/carers-strategy-call-for-evidence) call for evidence received over 6,000 responses on valuing carers. 39% said they had generally felt valued and involved by services supporting the cared for person, 45% said they had not and 16% were not sure.

* + 1. Training to provide care and support

### Summary of suggestions

It was suggested that carers should receive training to provide care and support to improve their knowledge and skills and support them in their role. This can benefit the person being cared for as well as the carer themselves.

It was suggested that there is considerable variation in the training offered in different local areas and access to face to face training is limited. It was suggested that training should include understanding of specific health conditions, signs of deterioration and how to prevent problems, complex care tasks, and medicines management.

### Selected recommendations from development source

Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.6.1

Offer training to enable carers to provide care safely. Training could include structured programmes or one-to-one guidance from a practitioner.

Recommendation 1.6.5

Training programmes for carers should include the following components, as relevant:

* general education about the health condition, disability or needs of the person they care for
* skills training to help them provide care, including how to understand and respond to changes in mood and behaviour
* principles of self-care
* training in communication skills to improve interactions with the person they care for
* advice on planning enjoyable and meaningful activities with the person they care for
* information about relevant services and how to access them

future planning, including preparing for transitions.

Recommendation 1.6.6

Consider including the following in carer training programmes, as relevant:

* managing medicines
* managing diet and nutrition
* maintaining personal hygiene
* managing behaviour that challenges
* use of digital and assistive technology

specific information that carers need to enable them to remain safe in their caring role.

Recommendation 1.6.11

Health and social care practitioners should ensure carers have access to advice, guidance and training about appropriate use of equipment and adaptations, and safe moving and handling techniques.

### Current UK practice

[NHS Digital’s Personal Social Services Survey of Adult Carers in England 2018-19](https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19) indicated that 5.3% of carers who are in touch with local authorities had received training for carers over the last 12 months.

### Committee discussion

|  |
| --- |
| For discussion |
| * What is the priority for improvement? * What is the key action that will lead to improvement? * Could we focus on a specific population, audience or setting? * Can we develop a specific, measurable statement? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Assessing carers’ needs
     1. Access to carers’ assessments

### Summary of suggestions

Stakeholders suggested that not enough carers are getting a carers’ assessment which can be a therapeutic intervention and help carers to maintain their caring role. There was some concern that waiting times for carers assessments may be too long and reviews are not regular enough, undermining a preventative approach to ensure crises do not occur. There is currently variation in how Local Authorities conduct carers assessments. Many carers are not given a choice of how the assessment takes place, with Local Authorities defaulting to tagging it on to the end of the assessment for the person being supported. It was suggested that carers should be made aware that, depending on their needs, they can have a formal or informal assessment via a non-statutory service.

### Selected recommendations from development source

### Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.2.8

Offer carers the opportunity to have confidential conversations about their own needs as carers separately from the person they are supporting.

Recommendation 1.3.1

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 (in accordance with the Care Act 2014 and associated Care and support statutory guidance and the Children and Families Act 2014).

Recommendation 1.3.6

Arrange the timing of the carer's assessment according to the carer's preferences and the urgency of their need for support. For example, take into account:

* whether the person they care for is near the end of life
* the level of stress the carer is experiencing
* the timing of hospital discharge
* changes to the caring role

any negative impact of delays on the health and wellbeing of the carer.

Recommendation 1.3.11

Discuss with carers the option to combine or link their assessment with the assessment of the person they care for, if they both choose to do this.

Recommendation 1.3.20

If a carer support plan is developed as a result of a carer's assessment, ensure it is monitored and reviewed regularly.

### Current UK practice

[Carers UK State of caring report 2019](https://www.carersuk.org/for-professionals/policy/policy-library/soc-19) (based on a survey of 7525 people currently providing informal care) indicated that 27% of carers in England had had an assessment or a review of their assessment, in the last 12 months. This compares with 31% of carers who received an assessment in 2016. Carers who are providing palliative care and those looking after someone with a mental health condition were slightly more likely to have had an assessment with 31% of each group respectively saying this happened in the previous year. 30% of older carers (aged 65 or over) had received an assessment or review in the last 12 months. Out of all carers who received an assessment in the last year, 80% waited less than six months for this assessment but 20% waited longer than six months.

[A Healthwatch briefing on What is it like to be a carer](https://www.healthwatch.co.uk/report/2018-10-01/whats-it-being-carer-0) indicated that on average carers are waiting 28 days for an assessment from their local authority (based on a freedom of information request to all local authorities in England in 2018. NB. only 25% were able to provide this information).

* + 1. Quality of carers’ assessments

### Summary of suggestions

Stakeholders highlighted the importance of comprehensive carers assessments which include the carers own physical, mental health, wellbeing and social care needs. Assessments should be carried out by professionals with appropriate skills and knowledge. Assessments should result in a plan that makes it clear what support the carer will need.

### Selected recommendations from development source

### Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.3.2

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

details of the assessment are shared with other practitioners and organisations who are involved in the assessment.

Recommendation 1.3.4

The carer's assessment should be jointly produced with the carer and reflect what matters most to the carer and what might help them achieve this.

Recommendation 1.3.15

Discuss education, training and employment with carers during their carer's assessment. Explore the options and the support they need to remain in, start or return to work, training or education. This could include providing replacement care at home.

Recommendation 1.3.18

Ensure there are clearly identified outcomes for the carer after their assessment.

Recommendation 1.3.19

After an assessment:

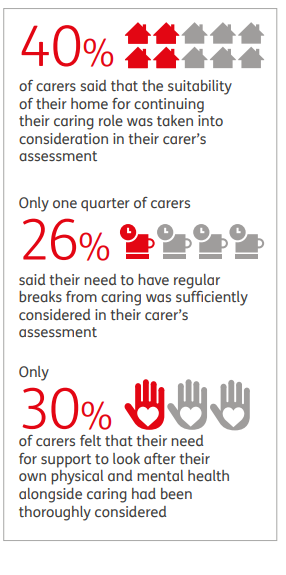
* ensure the carer understands the actions that have been agreed and what the next steps will be and

share information (as appropriate) with other practitioners and organisations involved with the carer and the person they care for.

### Current UK Practice

[Carers UK State of caring report 2019](https://www.carersuk.org/for-professionals/policy/policy-library/soc-19) found that the majority of carers in England who had been assessed / reassessed in the last year felt that their needs were not given sufficient consideration. 25% of carers who were not yet retired and had an assessment in the last year felt that their need to combine paid work and caring was sufficiently considered in their carer’s assessment.

Figure 1: Experience of carers assessments (Carers UK 2019)



### Committee discussion

|  |
| --- |
| For discussion |
| * What is the priority for improvement? * What is the key action that will lead to improvement? * Are there agreed waiting times for a carers’ assessment? * Can we develop a specific, measurable statement? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Supporting carers
     1. Helping carers stay in, enter or return to work, education or training

### Summary of suggestions

Stakeholders suggested that if carers need to give up work in order to care it can have detrimental economic, social and psychological impacts. Helping them to stay in work is a priority because the proportion of carers in paid employment is rising. It was suggested that encouraging employers to support carers through ‘carer friendly’ employment practices (such as flexible working, paid care leave) are a priority that will also benefit employers by improving staff satisfaction and retention. It was suggested that the NHS has a higher risk than other employers of losing valuable staff due to unpaid caring responsibilities. Local authorities and NHS organisations could act as role models to encourage other employers to improve their approach. As women are more likely to take on caring roles this is an important equality issue given the gender pay and pension gap in the UK.

### Selected recommendations from development source

### Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.3.17

Give carers tailored information about community services and support that could help them remain in, start or return to work.

Recommendation 1.4.1

Local authorities should ensure carers have access to tailored advice about balancing work, education or training with caring, including associated benefits and welfare advice.

Recommendation 1.4.4

Workplaces should make information available to their staff about ways in which they can support employees who need to balance caring responsibilities with work. See [NICE's guideline on workplace health](https://www.nice.org.uk/guidance/ng13).

Recommendation 1.4.5

Practitioners should encourage carers to discuss supportive working arrangements with their employers, including adjustments to make caring possible. Examples might include flexible hours, fixed hours or shifts, carers' leave, permission to use a mobile phone, technology to allow flexible working, or providing a private space to take personal phone calls.

Recommendation 1.4.6

Workplaces should offer flexible working arrangements to enable staff to balance caring responsibilities with work, and other initiatives that support mental wellbeing for carers in line with the NICE guidelines on workplace health and mental wellbeing at work.

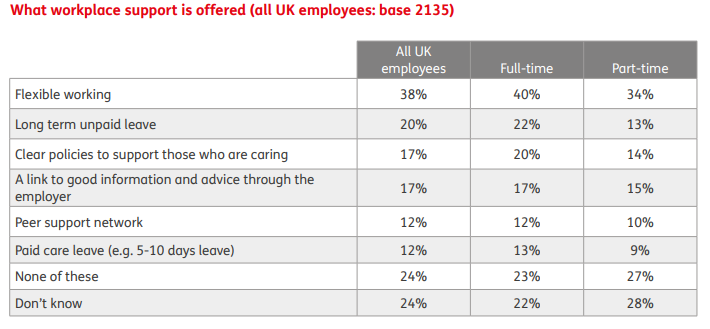
### Current UK practice

[Carers UK Juggling work and unpaid care: a growing issue](https://www.carersuk.org/for-professionals/policy/policy-library/juggling-work-and-unpaid-care) (based on an online YouGov plc survey with 4,254 adults in 2019) indicated that:

* 1 in 7 of all workers in the UK could be juggling work and care (around 4.87 million people)
* 468,000 people have given up work over the past 2 years as a result of caring
* Just over 2 million adults have reduced their working hours in order to care
* 12% of carers said that they had had to take a less qualified job or turned down a promotion to fit around their caring responsibilities
* 7% of adults said unpaid caring had impacted negatively on their paid work

A lower proportion of people were juggling work and care in the private sector (13%) compared to the public sector (19%).

The survey also indicated that part-time and private sector employees were less likely to receive workplace support measures.



[NHS Digital’s Personal Social Services Survey of Adult Carers in England 2018-19](https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19) (based on a survey of 50,800 carers known to Local Authorities) indicated that the number of carers who were not in paid work because of their caring responsibilities increased significantly from 21.0% in 2016-17 to 22.6% in 2018-19. 11% of carers indicated that they were in paid employment and felt supported by their employer, while 3.7% said they were in paid employment but did not feel supported by their employer. The survey also showed that 3.1% of carers had received support to keep them in employment in the last 12 months.

[Chartered Institute of Personnel and Development Creating an enabling future for carers in the workforce](https://www.cipd.co.uk/knowledge/culture/well-being/enabling-carers) (based on a 2016 survey of 554 employers) indicated that:

* 26% of employers had a formal written policy and 8% had an informal, verbal policy aimed at the needs of carers. 38% did not have a policy or plans to develop one.
* The public sector was significantly more likely to have a formal written policy than the private and voluntary sectors and the private sector was significantly more likely than the other sectors to say they did not have a policy or plans to develop one.
* 20% of employers measured how many of their employees had caring responsibilities, 70% didn’t measure this and 10% didn’t know whether they measured this.
* 33% of employers offered paid leave and 59% offered unpaid leave to carers.
* Employers were most likely to support carers by offering: flexible leave arrangements (49%), flexible work arrangements (48%), use of telephone and private time for calls (32%), counselling (22%) and information and advice via employee assistance programmes (22%).
* 13% of organisations provided training to line managers to help them support carers.
  + 1. Social and community support

### Summary of suggestions

Stakeholders indicated that it is important that local social and community support services are available for carers. This should include social activities to prevent social isolation, peer support, health promotion, financial advice, and technology and equipment. Some areas have used social prescribing to meet carers needs for social and community support.

### Selected recommendations from development source

### Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.5.1

Local authorities should ensure carers are kept regularly informed about available community services and other sources of support and advice and how to access them, for example:

* local carer support services
* self-help groups
* community and faith groups
* specialist benefits, financial and legal advice
* financial support
* advice about self-care

where to find reliable information about the health condition of the person they are caring for.

Recommendation 1.5.4

Tell carers about peer support and how to access it locally. Explain that peer support can help reduce a sense of isolation, provide empathy and social and emotional support, and enable them to share information.

### Current UK practice

[Getting Carers Connected research summary carers week 2019](https://www.carersuk.org/for-professionals/policy/policy-library/getting-carers-connected-2) (based on the Office for National Statistics Community Life survey 2016/17 and the Carers UK state of caring survey 2019 (8,096 responses)) indicated that:

* Carers who do not receive any practical support with their caring role are 8 times more likely to say they are always or often lonely compared with the general population (40% compared with 5%).

Over two thirds (69%) of carers said they’d felt lonely because of not having time to participate in social activities.

[NHS Digital’s Personal Social Services Survey of Adult Carers in England 2018-19](https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19) indicated that 31.3% of carers had received support from carers groups or someone to talk to in confidence over the last 12 months.

* + 1. Psychological and emotional support

### Summary of suggestions

Stakeholders highlighted that caring can be very stressful and isolating and can lead to mental health problems. Carers may therefore need psychological and emotional support such as counselling or support groups as well as regular review of how well they are coping. Currently this type of support is limited and may not be available until a crisis occurs.

### Selected recommendations from development source

### Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.7.1

Consider providing carers with psychosocial and psychoeducational support, which should include:

* developing personalised strategies and building carer skills
* advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing

information about emotional support services and psychological therapies for carers and how to access them.

Recommendation 1.7.3

Recognise that psychosocial and psychoeducational support may be needed at different stages of the caring experience and ask carers regularly whether they feel they would benefit from it.

Recommendation 1.7.6

If a carer has an identified mental health problem, consider:

* psychotherapy and counselling interventions in line with existing NICE guidance (see NICE's topic page for mental health and behavioural conditions) or

referral to a GP or mental health professional who can provide interventions in line with existing NICE guidance.

### Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

* + 1. Carers breaks

### Summary of suggestions

Stakeholders suggested that carers should be able to access replacement care (such as overnight, sitting services or day services) so that they can take regular breaks. It is important that these services are high quality so that the carer knows the person they care for is being well-looked after. It was suggested that funding to support carers breaks is currently insufficient and improved access to personal budgets could help carers to choose the break that suits their needs.

### Selected recommendations from development source

### Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.5.2

Health and social care practitioners should regularly discuss with carers the value of having a break from their caring role and explain the options available.

Recommendation 1.5.3

Carers' breaks should:

* meet carers' needs for a break, for example in duration, timing, frequency and type of break

be arranged in a way that provides reliable and consistent support to the carer (such as avoiding last-minute changes that could lead to additional stress for the carer).

### Current UK practice

[Carers UK State of caring report 2019](https://www.carersuk.org/for-professionals/policy/policy-library/soc-19) (based on survey responses from 7,000 carers) indicated that 15% of carers received a break from caring.

[NHS Digital’s Personal Social Services Survey of Adult Carers in England 2018-19](https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19) indicated that:

* 22.6% of carers known to Local Authorities received support or services to allow them to have a rest from caring for between 1 and 24 hours in the last 12 months
* 19.6% of carers (a significant reduction from 20.9% in 2016-17) received support or services to allow them to take a break from caring for more than 24 hours

13.6% of carers (a significant reduction from 14.5% in 2016-17) received support or services allowing them to take a break from caring at short notice or in an emergency.

[Carers UK State of caring 2017](https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-report-2017) (based on a survey of 7,286 carers) indicated that 25% of carers said they hadn’t had a day off from caring for more than five years, while 40% said they hadn’t had a day off for more than a year. 58% of carers reported not having had a weekend off in over a year and 73% not having had a week off for over a year. The most common reasons for not having a break were the costs of paying for or contributing to the cost of a break, or that the person they care for isn’t willing to accept care and support from others.

### Committee discussion

|  |
| --- |
| For discussion |
| * Which, if any, of the themes should be prioritised? * What is the key action that will lead to improvement? * Could we focus on a specific audience or setting? * Is it preferable to have a ‘general’ or ‘focussed’ statement? |
| For decision |
| * Should this area be prioritised for inclusion in the quality standard? |

* 1. Supporting carers at specific times
     1. Support during changes to the caring role

### Summary of suggestions

Stakeholders highlighted the importance of providing carers with information and practical and emotional support when there are changes to their caring role. It was suggested that carers can feel vulnerable and unsupported at transition points such as transfer from hospital to community care, transfer into adult care services, transfer into residential care, transition to becoming a young adult carer and changes following a crisis.

### Selected recommendations from development source

### Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.8.2

Provide information and emotional and practical support to help carers prepare for and adjust to changes in their role, for example if the person they care for:

* becomes an adult
* makes the transition to adult services (see NICE's guideline on transitions from children's to adults' services)
* moves away from home
* has a significant change in their health
* becomes terminally ill or needs end of life care (for recommendations on care near the end of life see NICE's guideline on care of dying adults in the last days of life)

dies unexpectedly.

Recommendation 1.8.3

Provide information and emotional and practical support to carers when their circumstances change, for example when they:

* start or go back to work
* move from being a young carer to an adult carer
* have a change in benefits or financial circumstances
* go through personal changes (such as divorce)
* take on another caring role
* go into hospital
* are bereaved

become less able to care as they get older.

### Statements in existing quality standards

[NICE QS136 Transition between inpatient hospital settings and community or care home settings for adults with social care needs](https://www.nice.org.uk/guidance/qs136) statement 5

Adults with social care needs have family or carers involved in discharge planning if they are providing support after discharge.

* + 1. Current UK practice

No published studies on current practice were highlighted for this suggested area for quality improvement; this area is based on stakeholder’s knowledge and experience.

* + 1. Support for carers during end of life care

### Summary of suggestions

A stakeholder emphasised the importance of supporting the carer during end of life care and after the person dies. It was suggested that carers should be involved in decision making and an end of life care coordinator should provide support including referring the carer to support such as bereavement support, GP, peer support, if needed.

### Selected recommendations from development source

### Recommendations that have been provisionally selected from the development source that may support potential statement development are presented in full below to help inform the committee’s discussion.

NICE NG150

Recommendation 1.9.3

Practitioners should establish early contact with carers involved in providing end of life care. Discuss with carers how best to support them, taking into account that unsatisfactory early contact with health and social care services can have a long-lasting negative impact on carers involved in providing end of life care.

Recommendation 1.9.7

Involve carers in advance care planning if the person being cared for consents to this. For recommendations about involving carers in advance care plans for people who may lack mental capacity, see NICE's guideline on decision making and mental capacity.

Recommendation 1.9.12

Help carers who are providing end of life care at home to access local services that could support them, including from local hospices. This could include:

* replacement care
* palliative home care
* practical support, for example to use equipment and adaptations

additional help in the home.

Recommendation 1.9.14

Give carers of people at the end of life up-to-date and accurate information and advice about financial, legal and logistical issues they need to address when preparing for or following the death of the person they care for.

### Statements in existing quality standards

[NICE QS13 End of life care for adults](https://www.nice.org.uk/guidance/qs13) statement 2

People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

[NICE QS13 End of life care for adults](https://www.nice.org.uk/guidance/qs13) statement 7

Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

[NICE QS13 End of life care for adults](https://www.nice.org.uk/guidance/qs13) statement 14

People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

[NICE QS144 Care of dying adults in the last days of life](https://www.nice.org.uk/guidance/qs144) statement 2

Adults in the last days of life, and the people important to them, are given opportunities to discuss, develop and review an individualised care plan.

### Current UK practice

The [Healthcare Quality Improvement Partnership National Audit of Care at the End of Life 2018/19 report](https://www.hqip.org.uk/resource/national-audit-of-care-at-the-end-of-life-nacel-2019/#.XnjEFYj7Ts0) (based on an organisational audit, a case note review and a quality survey) indicated that:

* The survey results suggested that in around a quarter of cases there was scope for improvement in communication with families and others.
* Most bereaved respondents felt that they, and the dying person, were as involved in decision making as they wanted to be, however, 22% of those responding would like to have been more involved.
* There was documented evidence that the needs of the family were asked about in just over half of cases, a result which is in line with low compliance highlighted in the previous 2016 audit.

Although a high proportion of bereaved respondents felt they were supported after the patient’s death, when asked more specifically about emotional and practical support during the last two or three days, almost one third of those responding felt they did not have enough support.

The [Office for National Statistics National Survey of Bereaved People](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015) (based on a 2015 survey of 22,000 people) found that:

* More than 3 out of 4 bereaved carers (76%) stated that they were involved in decisions about the care provided to the patient as much as they wanted to be.
* The majority (between 74% and 86%) of people responded positively in relation to questions about communication with healthcare professionals in the last 2 days of life.
* More than half of respondents (59%) said that they had definitely been given enough support at the time of the death. A further 27% said that they had to some extent.

When asked whether they had talked to anyone from any support services since the death, most respondents reported that they had not, and did not want to (66%). However, 21% said that they had not, but would have liked to.

### Committee discussion

|  |
| --- |
| For consideration |
| * Do you agree with our suggestion that these areas do not need to be discussed during the meeting? |

* 1. Additional areas

### Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However, they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or need further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 11/8/2020.

### Care coordinator

Stakeholders suggested that it is important that there is a care coordinator or key worker such as a clinical nurse specialist to support the person being cared for and their carers. This area has not been progressed because the focus is on the person being cared for rather than the carer and therefore this area is beyond the scope of this quality standard. In addition, several other quality standards include statements on care coordinators/clinical nurse specialists for people with specific conditions.

### Financial support

There was a suggestion that carers should receive improved financial recognition given the current level of benefits that they receive. This area has not been progressed because quality standards focus on areas for quality improvement that can be addressed by local commissioners. Benefit payments are a national issue and therefore beyond the scope of this quality standard.

### Joined up services

It was suggested that health and care services need to be more joined up so that the carer does not have to keep repeatedly summarising their situation to every professional. This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the organisational structures and relationships that enable the actions to take place. The committee should consider which parts of care and support would be improved by joined up services. Joined up services may be referred to in the audience descriptors.

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# Appendix 1: Review flowchart

Records identified through topic engagement  
[n =161]

Records identified through IS scoping search  
[n =155]

Records identified through ViP searching  
[n = 1846]

Records excluded  
[n =2133]

Records screened  
[n =2162]

Citation searching or snowballing

[n=5]

Full-text papers excluded  
[n =20]

Full-text papers assessed   
[n =34]

Current practice examples included in the briefing paper  
[n =14]

# Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

| ID | Stakeholder | Suggested key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- | --- |
| **Identifying carers** | | | | | |
| 1 | Carers Trust | Key area for quality improvement 1  Identification | Carers will not be able to get the support they need without being identified. The UK Government’s 2018-19 Mandate to NHS England states that “carers should routinely be identified and given access to information and advice about the support available part” | We know that there are at least 5.5 million carers in England alone. We know that the identification of carers is still an ongoing issue. This is recognised by both DHSC and NHS England, both of whom have taken steps since the introduction of the Care Act to try and improve the identification of carers at a local level. | As part of their Commitment to Carers Programme, NHS England released Commissioning for Carers, encouraging commissioners and providers to make sure they identify and support unpaid carers  <https://www.england.nhs.uk/commissioning/comm-carers/principles/principle-7/>  As part of the Carers Action Plan, DHSC set out the need to better identify carers because of the evidence that not enough carers are being identified. Three of the actions (1.1, 1.2 and 1.4) are directly linked to improving the identification of carers.  <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/713781/carers-action-plan-2018-2020.pdf> |
| 2 | Department of Health and Social Care | Carers and potential carers are identified at the earliest opportunity |  |  |  |
| 3 | Mencap | Identification of carers | Carers need to be identified so they can access assessments and support. It is the route to assessments and getting support to meet needs.  This information about numbers and needs is needed to inform planning of local support and services eg. suitable respite.  Important to be able to identify older carers so that there can be appropriate planning ahead and avoid crisis situations.  There is a real 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. | Lack of understanding about ‘who’ carers are as a result many carers are not getting the support they need.  We know many families that are doing a lot of ‘caring’ and support for their loved one who is not living in the family home. It is important the role they are playing is identified and they can access appropriate support for them is developed. | Recommendation from New Forest Mencap research: ‘An integrated system whereby more precise figures of people with learning disabilities and their carers are logged and shared between the local authority and health service, and which are also shared with designated charities such as Mencap - to target those who have health and social care needs.’  <https://www.bath.ac.uk/publications/report-confronting-a-looming-crisis/attachments/Final_AckOnly.pdf> |
| 4 | Newcastle City Council and partners | Key area for quality improvement 2  Identifying carers | Carers need to be identified at the first available opportunity to access appropriate, timely support | All professionals have a responsibility to identify and support the self-identification of carers at the earliest point in their caring journey; caring for someone should be positively promoted to encourage recognition and access to ongoing support |  |
| 5 | Royal College of Nursing | Key area for quality improvement 4  Early identification of carer’s assessment | Early identification of carers leading to a carer’s assessment would be beneficial to facilitate timely support.  Being identified timely will facilitate training and health promotion support to be offered in addition to highlighting the need for robust local carer networks to be set up/early referral into existing groups. | In order to fully support unpaid carers, they need to be identified as early as possible. Investing in support early will have a positive impact on both carer and person being carers for |  |
| 6 | SCM2 | Carer Identification | Carers save health and social care an estimated £132 billion a year. Many people don't identify themselves as carers and will not consider that there might be support available to them. GPs, community health services and hospitals are often the first point of contact for carers so would be natural settings for carers to be identified.  Carers could also be identified by a range of organisations such as employers, faith and other community organisations. | As a result of not being identified carers can miss out on vital support including help for them to maintain their own health and wellbeing.  There is significant scope to improve carer identification at multiple touch points across the breadth of the health and social care system. The benefits to carers of being identified, recognised as partners in the care of the person they are supporting, given consideration around their own needs when accessing services themselves and then offered pathways to support is well evidenced by Carers UK research as well as other studies used in the development of the guideline. | <https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=6866> |
| 7 | SCM3 | Identification of carers | *Not enough carers are likely to be receiving the support they need or are entitled to. One of the main obstacles to carers getting the right support is identification – both self-identification and identification by health professionals. The term carer is problematic as most carers see themselves first as a daughter/son/parent etc* | *NHSE/I state in their Commitment to Carers that 7:10 carers start their caring journey in a health setting and yet only 11% are identified by health professionals and only 7% by GPs. Without identification these carers miss out on timely advice, information and support* | Schonegevel, L. (2013) Macmillan Briefing on Carers Issues (online) Available from: <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/MPs/Commons2ndReadingBriefing.pdf>  Local evidence from Surrey Heartlands on GP Carer Registration  [**http://carersworldradio.ihoststudio.com/useful/Surrey%20GP%20Carers%20Registration%20Survey%20Report%202019.pdf**](http://carersworldradio.ihoststudio.com/useful/Surrey%20GP%20Carers%20Registration%20Survey%20Report%202019.pdf) |
| 8 | SCM3 | Additional developmental areas of emergent practice | *Surrey Heartlands has recently launched an NHS Carers KPI for both primary care and secondary care providers* | The primary purpose of launching a Carer KPI has been to provide a consistent and sustainable approach to identifying, recognising and supporting carers across the Surrey Heartlands system and where possible to include carers within our contractual arrangements and our Quality performance monitoring reports with reference to relevant documents and staff guidance where available.  The Surrey Carers KPI is performance monitored by the Contract, Commissioning and Quality Lead. Providers are working to include Carers within their Annual Quality Account. | <https://www.surreyandsussex.nhs.uk/wp-content/uploads/2019/07/Quality-account-2018_19_Final-reduced.pdf>  <https://www.nhs.uk/Services/Trusts/Overview/DefaultView.aspx?id=1822>  The Surrey Carers KPI was launched 1st July 2019 and since then 21 NHS Provider organisations have met the standard. This includes having their own organisational carers policy based on the [Surrey Carers MoU](https://www.surreycc.gov.uk/__data/assets/pdf_file/0006/152943/Together-for-Carers-support-strategy.pdf) and an action plan to deliver it.  Additionally, Surrey Heartlands GP practices were the testbed for the NHSE GP Quality Markers in 2019. As part of the Primary Care Carer KPI 76 practices participated.  All new service specifications reflect the Surrey Carers KPI. Our recent procurement of a wheelchair service included 95 references to carers.  Link to main report: <http://carersworldradio.ihoststudio.com/useful/Surrey%20GP%20Carers%20Registration%20Survey%20Report%202019.pdf>  Link to QM findings: <https://fs4.formsite.com/res/resultsReportCharts?EParam=PyBo85CFjhGgRrmExFlGxrKYScuASs1owCi9jw02kUT1kF9Ghnpw0fMzhoH04BNxG1E3tQHPlR0%3D> |
| 9 | SCM4 | Key area for quality improvement 1  *Identification of Carers* | Identifying individuals as carers is key to enable them to access information / support to allow them to continue caring. People do not see themselves as a carer as primarily still see themselves as a family member or friend. The term ‘carer’ in a health & social system is often used to describe ‘paid package of care’ which adds to the confusion in identifying and recognising unpaid carers.  *Earlier identification, especially in hospitals when people may become carers for the first time is important for long-term carer confidence, resilience and knowing where and how to access information* | NHSE’s commitment to carers states that 70% of carers come into contact with health professionals yet only 7% of carers are identified. Without NHS staff having a heightened awareness of unpaid carers, or the definition of unpaid carers, identification of carers will always remain a stumbling block which then stops any subsequent access to services.  NHS Long Term Plan also recognises the benefit of identifying carers.   |  | | --- | | 1.19. Carers will benefit from greater recognition  and support. |   There is little appetite to identify carers on NHS health IT systems especially in the acute Trusts. Carers identification and needs are often not prioritised in development of IT systems including NHS electronic referral systems. | <https://www.hertfordshire.gov.uk/media-library/documents/about-the-council/data-and-information/hertfordshire-carers-strategy-2015.pdf>  NHS England (2014) [Commitment to carers](https://www.england.nhs.uk/publication/nhs-englands-commitment-to-carers/)  “Carers are a hugely important asset to the NHS. However, too often carers do not receive the recognition and support that they need and deserve from the NHS. We need to do more to help identify, support and recognise their vital roles.” NHS England (2014) [Commitment to carers](https://www.england.nhs.uk/publication/nhs-englands-commitment-to-carers/) |
| 10 | SCM5 | Key area for quality improvement 1  *Identification of carers* | Many people in a caring role don’t identify themselves as carers; they just see themselves as wife/husband etc and consider that what they are doing is just what they signed up for when they made a commitment to their loved one, or is part and parcel of a long-standing relationship.  There is evidence to suggest that many, perhaps even most carers are unknown (at least in that capacity) to health and social care organisations. We don’t know the true number as, by definition, they are not on anyone’s radar.  Taking active steps to identify carers is featured in the NICE guideline (Section 1.2).  *The guideline committee saw evidence to suggest that primary care settings represent something of a missed opportunity for identifying carers, leading to rec 1.2.3* | Carers can’t be offered any help if nobody knows that they are in a caring role. This is the first essential step to recognising, involving and supporting carers.  There is an inequality at the heart of this issue. Carers UK report points out that women are particularly affected:  “*Caring is still often thought of as being part and parcel of women’s lives and within families, women are still most likely to be providing care and most likely to be providing more hours of care”.*  A key recommendation of the Carers UK snapshot report is to:  *“Increase identification and support through primary care.”*  Primary care organisations are in an ideal place to identify carers as they are a point of universal access. Statutory organisations recognise the central role of primary care in identifying carers, but acknowledge that improvements are needed:  “*The role of the primary care team as the one to which all Carers have access is recognised as being paramount in supporting Carers and maintaining the capacity of Carer to care, if they so choose.*    *There is a need to improve the registration and assessment of Carers, including Young Carers, in primary care so that their needs can be identified more quickly and before their health and wellbeing deteriorates”*    The NHS recognises the benefits to carers’ own health and wellbeing of early identification in primary care:  *“timely identification and registration of carers makes it easier to offer practical things (like health checks and ‘flu jabs) to maintain good physical health*  *early identification of carer health problems can lead to faster treatment and improved health outcomes”*  The NHS also offers a framework to help primary care teams improve their practice. The fact that practical tools already exist means that a quality standard in this area should be able to promote measurable improvements quite quickly. | Local Government Association (2018): Supporting carers: Guidance and case studies  Carers UK (2019): State of caring: a snapshot of unpaid care in the UK  Carers UK (2019): State of caring: a snapshot of unpaid care in the UK  NHS England (2016): An integrated approach to identifying and assessing carer health and wellbeing (para 3.3.1)  NHS England and NHS Improvement (2019): Supporting carers in general practice: a framework of quality markers |
| 11 | SCM6 | *Identification and recognition of carers* | Not enough carers are likely to be receiving the support they need or are entitled to. One of the main obstacles to carers getting the right support is identification – both self-identification and identification by health professionals. The term carer is problematic as there is often confusion about the distinction between paid carers and unpaid care by a family member or friend. Most carers see themselves first as a daughter/son/parent etc  *Carers from vulnerable communities (BAEME, LGBT, very elderly or young adult carers and others) identified in NHS Long Term Plan as priority for early identification to avoid later challenges* | NHSE/I state in their Commitment to Carers that 7:10 carers start their caring journey in a health setting and yet only 11% are identified by health professionals and only 7% by GPs. Without identification these carers miss out on timely advice, information and support  The Carers Action Plan (2019) found that carers placed great emphasis on the importance of early identification, recognition and advice, with very variable reports of how such identification took place and what information and advice followed it. | Schonegevel, L. (2013) Macmillan Briefing on Carers Issues (online) Available from: <http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/MPs/Commons2ndReadingBriefing.pdf>  Carers UK (2019), State of Caring  DHSC (June 2018), Carers Action Plan 2018-2020: Supporting carers today  DHSC (2018) Carers call for evidence 2016 – Summary of Government responses. https:/www.gov.uk/government/consultations/carers-strategy-call-for-evidence  NHS England (2019), The Long Term Plan  <http://carersworldradio.ihoststudio.com/useful/Surrey%20GP%20Carers%20Registration%20Survey%20Report%202019.pdf> |
| 12 | SCM6 | Additional developmental areas of emergent practice | *Surrey Heartlands has recently launched an NHS Carers KPI for both primary care and secondary care providers* | The primary purpose of launching a Carer KPI has been to provide a consistent and sustainable approach to identifying, recognising and supporting carers across the Surrey Heartlands system and where possible to include carers within our contractual arrangements and our Quality performance monitoring reports with reference to relevant documents and staff guidance where available.  The Surrey Carers KPI is performance monitored by the Contract, Commissioning and Quality Lead. Providers are working to include Carers within their Annual Quality Account. | <https://www.surreyandsussex.nhs.uk/wp-content/uploads/2019/07/Quality-account-2018_19_Final-reduced.pdf>  <https://www.nhs.uk/Services/Trusts/Overview/DefaultView.aspx?id=1822>  The Surrey Carers KPI was launched 1st July 2019 and since then 21 NHS Provider organisations have met the standard. This includes having their own organisational carers policy based on the [Surrey Carers MoU](https://www.surreycc.gov.uk/__data/assets/pdf_file/0006/152943/Together-for-Carers-support-strategy.pdf) and an action plan to deliver it.  Additionally, Surrey Heartlands GP practices were the testbed for the NHSE GP Quality Markers in 2019. As part of the Primary Care Carer KPI 76 practices participated.  All new service specifications reflect the Surrey Carers KPI. Our recent procurement of a wheelchair service included 95 references to carers.  Link to main report: <http://carersworldradio.ihoststudio.com/useful/Surrey%20GP%20Carers%20Registration%20Survey%20Report%202019.pdf>  Link to QM findings: <https://fs4.formsite.com/res/resultsReportCharts?EParam=PyBo85CFjhGgRrmExFlGxrKYScuASs1owCi9jw02kUT1kF9Ghnpw0fMzhoH04BNxG1E3tQHPlR0%3D> |
| 13 | SCM7 | Key area for quality improvement 3  *Identification of carers* | *50% of people are likely to become carers but it can take many years for an individual to recognise they are a carer.* | *Identification aids the targeting of resources to support wellbeing and enable people to continue to care. Unidentified carers may miss out on financial support* | Will I care 2019? Carers UK  *Missing out Carers UK 2019* |
| 14 | The Challenging Behaviour Foundation | Key area for quality improvement 5:  *Identification of hidden carers* | *Carers cannot access the right support if their local authorities do not know who and where they are. Working towards identification of carers should be included as an area for quality improvement.* | 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 (4)  *Families are diverse – their individual circumstances vary, so understanding each family context is essential to offering appropriate support. The family carers of people with severe learning disabilities whose behaviour challenges may be particularly isolated, especially in minority groups. (5) Extra efforts need to be taken to reach these hidden groups in order that they can access appropriate support as carers.* | Department for Health, *Valuing People Now: Summary Report March 2009-September 2010,* 2009: <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215891/dh_122387.pdf>  *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- Iriss, Improving support for BME Carers, May 2011:* [***https://www.iriss.org.uk/resources/insights/improving-support-black-minority-ethnic-bme-carers***](https://www.iriss.org.uk/resources/insights/improving-support-black-minority-ethnic-bme-carers)) |
| 15 | Think Local Act Personal | Key area for quality improvement 4  Carer recognition, assessment and support planning | People recognising and being recognised that they are a carer and getting information and advice that they need in order to identify and get the right support | Many carers do not recognise themselves as such and when they do, do not know about their entitlements to support.  There is a direct relationship between carers not getting support and the staid offer of services, which is not always taken up even when carers are identified, get an assessment and an offer of support  Carers have variable experience of assessments (which as envisaged in the Care Act 2014) should be based on constructive discussions about what outcomes the carer wants from his or her life and what would enable these outcomes to be achieved.  Assessment should be seen as dynamic, not ‘one-off’. Care and support planning after assessment should be regularly reviewed. Carers should get a support plan after assessment, the person needing care should get a care and support plan. | State of Caring Carers UK 2019  “Too many are going without the support they need and all too often they are going without any support at all. This year’s survey found that one in five carers (21%) neither buy or receive support with caring. Whilst these figures in this section are largely similar to last year, there is still a large level of unmet need, with many carers struggling without any support at all.”  Many carers are unclear as to whether they have had an assessment and also report that their (carer’s) assessment can sometimes be subsumed into the assessment of the person needing support. TLAP’s development of ‘Making it Real’ and related evidence from carers, users and local authorities, demonstrates the importance of empowering carers to articulate their needs and ambitions and gives useful tools to assessors and providers about genuine communication and future planning. |
| Information and advice | | | | | |
| 16 | Carers Trust | Key area for quality improvement 2  Advice and Information | This is a key duty under the Care Act. Carers still report a lack of advice and information on the support available to them and the person they care for. | Advice and information is a key duty under the Care Act. However, anecdotal evidence and data from national organisations suggest that local authorities are struggling to fulfil this duty. | The annual ADASS Budget survey revealed that directors of adult social care are not confident in fulfilling their duties around advice and information.  Asked how confident they were on fulling these duties:  Information and advice  Prevention and wellbeing, Assessment (carers and people using services),  Personal budgets/services sufficient to meet eligible needs,  Safeguarding (DoLS/LPS) and  Market Sustainability (including National Living Wage).  In 2019/20 35% are fully confident that budgets will be sufficient to meet all these statutory duties in the year, with 59% being partially confident and 6% having no confidence.  The Care Quality Commission 2019 State of Caring report found that: “People using services, their families and their carers are not always aware of what services are available to them and can lack the support they need to navigate the health and social care system.” |
| 17 | Department of Health and Social Care | Carers are directed to appropriate support and information sources relevant to their circumstances |  |  |  |
| 18 | Newcastle City Council and partners | Key area for quality improvement 1  Information and support for carers | Information for carers needs to be accessible | Information for carers should be readily available, accessible, culturally sensitive, easy to understand and meet the needs of the carer at any point in their caring journey; information should be co-produced with carers and promoted and publicised by all professionals; information should be delivered consistently throughout |  |
| 19 | Pennine Care NHS Foundation Trust | Key area for quality improvement 1  The right to information |  |  |  |
| 20 | SCM1 | Identifying carers and assessing their needs | Many carers do not self-identify as such. The provision of carers’ assessments is a vital way to identify and support carers. | Many carers do not realise that they are entitled to a stand-alone assessment of their own support needs. Many front-line staff do not realise this either, leading to provision of incorrect information, for example “you can only have a joint assessment with the person you care for”. There is currently no timescale set out for provision of assessment once requested – it should be carried out within a “reasonable” timescale. | NHS England (2016) An integrated approach to identifying and assessing carer health and wellbeing. |
| 21 | SCM2 | Pathways to carers support across health and social care systems | The health and social care system is complex, unwieldy and often hard to navigate for carers and the people they are supporting. Carers expend significant amounts of energy and time supporting people to access and navigate services. Many carers will not prioritise their own needs or have had poor experiences when trying to access support. | At the moment there is great variation, it will usually depend on whether the department, service, ward or professional has mechanisms at hand to link carers into support.  The system needs to ensure that there are clear pathways to support regardless of;  Which professional the carer comes into contact with  Which department, ward or service the carer comes into contact with  The point in the caring journey  The age, condition, background etc of the person being cared for | "Under the Care Act 2014, local authorities and health bodies in England must work together to identify carers6 and any carer who appears, or is likely to have, needs for support must be identified and offered a Carer’s Assessment. The Social Services & Well-being (Wales) Act 2014 and the Community Care & Health (Scotland) Act 2002 include similar measures to ensure carers are identified and guided to support. In Northern Ireland, the Carers and Direct Payments (NI) Act 2002 states that Health and Social Care Trusts must work to identify carers."  <https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=6866> |
| 22 | SCM4 | Key area for quality improvement 5  Access to carers support services | Early support for carers enables them to feel more confident, resilient and able to cope with their caring role.  Carers should be able to access the right type of support at the right time and this can be in a variety of methods, formal carers assessments, third sector voluntary services, health and through social prescribing. | *Carers’ needs are becoming more complex as we are living longer and with more complex health conditions. A one approach fits all no longer works and to provide comprehensive support requires a more imaginative approach. This requires a multi-agency approach and the development of carer champions in NHS organisations.* | <https://www.england.nhs.uk/personalisedcare/social-prescribing/>  <https://www.carersinherts.org.uk/help-us-help-carers/carers-health-information-for-gps/best-practice> |
| *Working with and involving carers* | | | | | |
| 23 | Department of Health and Social Care | *There are methods to quickly identify carers to enable them to take an appropriate role in conversations about the care of the person they care for* |  |  |  |
| 24 | Department of Health and Social Care | Carers are given an active role in deciding the course of action for the person they care for |  |  |  |
| 25 | Department of Health and Social Care | When deciding action the course of action for a cared for person, the needs and circumstances of the carer are considered |  |  |  |
| 26 | Mencap | Working in partnership with carers | *Carers are best placed to say what support they need – it is vital that health and social care professionals work in partnership with family carers, to ensure barriers to accessing support can be removed and ensure appropriate support is developed.* |  | *Finding from New Forest Mencap research: ‘Transformational change which includes trust-building and co-production between health and social services and carers is needed to improve relationships between the parties. Meaningful partnerships between social workers and carers will reduce the problem of the frequent need of carers to urge social services to provide adequate care and support.’* |
| 27 | Pennine Care NHS Foundation Trust | Key area for quality improvement 2  Working with and involving carers |  |  |  |
| 28 | Pennine Care NHS Foundation Trust | Key area for quality improvement 3  Sharing information with carers |  |  |  |
| 29 | SCM1 | Information and support for carers: sharing information | *Treating the carer as an asset and as a valuable member of the “team around the patient” is beneficial for all involved.* | *Provision of information to carers promotes ownership of and buy in to support plans and care packages and can assist carers in feeling prepared and able to cope.* | *NHS England (2014) Commitment to Carers* |
| 30 | SCM2 | Respecting and Involving Carers as Expert Partners | *Carers are often the one constant in a complex situation where they are supporting an individual with multiple co-morbidities accessing multiple services. Involving carers, respecting their expert knowledge and acknowledging how they can influence and enhance a plan of care is essential to the future effectiveness of the NHS* | Involving carers in care planning is written into the NHS Commitment to Carers and the NHS Mandate.  There is no evidence that I have seen that this happens routinely. There are significant risks to not involving carers including;  Readmission following discharge from hospital  Poor adherence to medication or other plan  Care tasks being undertaken incorrectly  Official complaints as a result of carers not understanding or agreeing with decisions that have been made by professionals  Duplication of work i.e. multiple professionals referring an individual to the same organisation |  |
| 31 | SCM3 | Carer Involvement | Involving carers in care planning provides for better patient outcomes as well as providing an opportunity to recognise and support carers own needs.  *Carers have the potential to contribute a huge amount of expertise, experience and knowledge to the services, and consultations in which they are allowed to be involved* | Involving carers in care planning is written into the NHS Commitment to Carers and the NHS Mandate.  Furthermore, it appears in the NICE Quality Standard 15 Patient Experience  *There is very little evidence to suggest this happens routinely or is recorded in patient care plans.* | <https://www.nice.org.uk/guidance/qs15/resources/patient-experience-in-adult-nhs-services-pdf-2098486990789>  <https://bmcpsychiatry.biomedcentral.com/articles/10.1186/s12888-015-0590-y> |
| 32 | SCM4 | Additional developmental areas of emergent practice  Use of carer passports in Acute Trusts for identification and link for supports. | Hospitals are places where caring often begins, following an accident or a diagnosis, an admission with serious illness.  Recognising and supporting carers as partners in healthcare has been a priority for several years.  ENHT have had a carers passport system in place for 3 years. It aids carer recognition, awareness, links to supports within the Trust and can assist with referral to community supports. | Hospitals are also places where caring can intensify, when the experience and knowledge of carers can help make their loved one’s treatment and stay in the hospital more comfortable.  A carers passport raises awareness of the caring responsibilities someone has in a patients care and NHS staff need to listen, respect and involve then in all decisions.    The use of carers passport is also outlined as part of the NHS Long Term Plan  2.33 …”We will encourage the national adoption of carer's passports, which identify someone as a carer and enable staff to involve them in a patient’s care.” | <https://carerspassports.uk/hospitals>  <https://www.england.nhs.uk/atlas_case_study/demonstrating-a-commitment-to-carers/> |
| 33 | SCM4 | Key area for quality improvement 2  Partnership working with carers | *Equal partnership working for health and social care with unpaid carers. Recognising and taking into account carers’ knowledge, expertise and experience when planning care and treatment interventions.* | Involving carers in care planning is written into the NHS Commitment to Carers and the NHS Mandate.  Partnership working, such as the triangle of care model used in mental health should translate into health care models. Heath care systems work on a more hierarchy approach there and the voice of the carer is not valued greatly.  6 principles should be considered best practise and the basis for improving partnership working with carers.  The six key standards state that:  1) Carers and the essential role they  play are identified at first contact or as  soon as possible thereafter.  2) Staff are ‘carer aware’ and trained  in carer engagement strategies.  3) Policy and practice protocols re:  confidentiality and sharing information,  are in place.  4) Defined post(s) responsible for carers  are in place.  5) A carer introduction to the service  and staff is available, with a relevant  range of information across the  care pathway.  6) A range of carer support services  is available. | <https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health> |
| 34 | SCM5 | Key area for quality improvement 5  *Involve carer as part of team* | The overarching principles of the NICE guideline recommend that:  “Health and social care organisations 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. These approaches should be incorporated into formal policies and processes.  Health and social care practitioners should work in partnership with carers and treat them as a valued member of the care team around the person being cared for, with the person's consent. This should include involving carers in decision making and care planning and keeping them up to date.”  *(1.1.10 and 1.1.11)* | The need to recognise the skills, knowledge, experience and commitment of carers was a theme that the committee heard consistently throughout the evidence that informed the guideline. Hence its place at the front of the guideline as an overarching principle:  “*There was evidence that carers value being recognised and respected as core members of the team around the person they care for and that carers have valuable information to contribute to care planning and assessment. They are often key to understanding the person's needs and preferences, so these recommendations were made to promote their involvement. This approach should be incorporated in formal policies and processes to ensure it is consistent across organisations.”*  The evidence came particularly strongly from carers, who often felt that they were not treated as experts in their own right but regarded as passive recipients of services rather than active partners. This increased their sense of not being valued.  There may be a slight resource implication if professionals need to add a bit of time to their day-to-day work to enact this relationship with carers, but:  *“The committee acknowledged that a little additional time may be needed for practitioners to keep carers up to date and well informed. However, the benefits include ensuring that care planning is based on accurate and detailed information, encouraging the carer in their role and respecting them as a core team member to help sustain the caring arrangement.”*  The Local Government Association identifies a key learning point for councils from their survey is to:  *“Co-produce projects with carers themselves”*  The DHSC Carers Action Plan 2018-2020 acknowledges that:  *“Carers often have extensive contact with the health and social care system. They highlighted the importance of having their expertise recognised by the people they interact with in these services, so that their views are taken into account in decision making.”* | NICE evidence reviews  Local Government Association (2018): Supporting carers: Guidance and case studies  Department of Health and Social Care (2018): Carers action plan 2018-2020: Supporting carers today |
| 35 | SCM6 | *Carer Involvement* | Involving carers as active partners in care provides for better outcomes for both the carer and the person they support.  *Carers have the potential to contribute a huge amount of expertise, experience and knowledge to the services, and consultations in which they are allowed to be involved* | Involving carers in care planning is written into the NHS Commitment to Carers and the NHS Mandate.  Furthermore, it appears in the NICE Quality Standard 15 Patient Experience  *The Care Act 2014 envisages ‘parity of esteem’ between carer and the person cared for, with both seen as active partners in assessment and any subsequent care and support plan.* | <https://www.nice.org.uk/guidance/qs15/resources/patient-experience-in-adult-nhs-services-pdf-2098486990789>  <https://bmcpsychiatry.biomedcentral.com/articles/10.1186/s12888-015-0590-y> |
| 36 | SCM7 | Key area for quality improvement 4  *Sharing information with carers* | *Sharing information and involving the carer in care planning can support both the person with support needs and the carer* | *Both service users and carers should be involved in developing the health and social care plan to ensure it is person-centred and focused on their priorities and outcomes. Ensuring all parties, including the service user and their carers, agree with the health and social care plan will encourage joint ownership of the plan This will help people and their carers to consider whether the plan meets their needs.* | *SCIE Integrated working* |
| 37 | The Challenging Behaviour Foundation | Key area for quality improvement 1:  *Carers valued as part of the workforce* | *Carers for vulnerable adults including people with learning disabilities and/or autism will often have the most in-depth knowledge of their loved one’s care, health, support and communication needs and should be involved in every step of the decision making process about their loved one’s care.* | *People with severe learning disabilities and/or autism are often non-verbal. Family Carers are often best equipped to understand their loved one’s communication. We know that in some circumstances where professionals have not understood challenging behaviour as an indication of unmet need, family carers have not been listened to and reasonable adjustments have not been made. This results in people with learning disabilities and/or autism not always receiving appropriate care and support.* |  |
| 38 | The Relatives & Residents Association | Key area for quality improvement 1:  Involving carers of older people receiving care in decisions / planning | There is evidence (Kings Fund report and Jewish Care study below) that the best care for older people living in care homes happens when the residents’ carers are seen as part of the caring team. As the guidance identifies, carers should be acknowledged as expert partners in care and their skills and knowledge valued.  We welcome the guidance’s reference to continuing to see carers of those living in residential care as such (1.2.4). Just as care may be something that gradually develops, it also rarely cuts off due to a person moving into care. However, this is not commonly understood or reflected in care practice.  *The guidance should be strengthened to encourage providers to recognise, identify and engage with relatives and friends who continue to provide care and support, with the person’s consent (to ensure respect for the person’s autonomy, protected by the right to respect for private life in the Human Rights Act). Where a person is unable to give consent, involving relatives and carers will help to ensure decisions are made in the person’s best interest.* | Many carers continue to care for their relatives after they have moved into a care home. This is particularly the case for people affected by dementia who have become used to their previous carer. This may be the person’s child, spouse/partner or another relative and the person may be more comfortable receiving care from them or find it difficult to accept from care staff.  In addition, relatives often assist in activities and social outings which are beneficial for the person being cared for and may be impossible without the support of a carer.  However, carers are often not seen as expert partners in care and can feel excluded from care decisions / planning. This can add to the disorientation and emotional distress of carers when loved ones move into care.  The failure to identify and involve carers in care planning can lead to vital care information being lost. This can have a negative effect on both the carer and the person they support. There is often no formal means to ensure that knowledge is passed from the carer to staff to incorporate into the care planning. This can include dental information, obtaining or maintaining hearing aids or medical information, both on admission into care or after carers accompany the person to health appointments.  *Preferred levels of involvement will vary from person to person. Some carers may not wish, or be able, to be involved to the same degree when a person they care for moves into a home. However, an individualised, person-centred approach should be taken to discuss the carer’s role and their involvement, with the person’s consent.* | Although there is much guidance on the importance of involving family, carers and friends in care homes (<https://www.skillsforcare.org.uk/Documents/Leadership-and-management/Registered-managers/Your-management-tools/Registered-Managers-Handbook-2016.pdf>) (<https://www.scie.org.uk/person-centred-care/older-people-care-homes/families-carers>), there is a lack of implementation of these guidelines and many people’s experience of transitioning from full time carer to supporting someone in a care home has been one of exclusion and frustration.  The exclusion of relatives who cared for and continue to care for residents from the planning and caring process was one of the reasons our charity was set up and remains a key issue for many callers to the R&RA Helpline today.  When R&RA carried out research for ‘Moving Stories: The impact of admission into a care home on residents’ partners’ (<http://www.relres.org/publications/moving-stories-the-impact-of-admission-into-a-care-home-on-residents-partners/>) we found that many partners felt excluded and even blocked from the care planning process despite the extensive involvement they continued to have with their partners.  A piece in Nursing Times also discussed this anomaly in a carer’s experience and the stress it causes: <https://www.nursingtimes.net/roles/older-people-nurses-roles/carers-needs-when-relatives-go-into-a-care-home-19-11-2007/>  The R&RA Helpline frequently hears from carers who are barred or restricted from visiting relatives due to raising concerns or asking for information about loved ones – a concern we have documented and raised with the Care Quality Commission.  *We also hear providers speak of relatives in negative terms and a problem to be managed rather than caring partners. This is often due to lack of communication between the two parties and no clear understanding of each role.* |
| 39 | Think Local Act Personal | Additional developmental areas of emergent practice  Investing in family leadership  (Partners in policymaking)  Closing the gap between Care Act aspirations and the current experience of people and carers of the Health and Social Care system | This helps families get the right support for the person they care for.  Rights, entitlements, coproduction, choice and control are all being curtailed. This is not helping carers to continue caring for as long as possible | It helps to engage and empower carers and ensure care and support is coproduced.  It can contribute positively to the psychology of supporting another person, particularly parenting a child or an adult with learning disabiltiies/autism.  The quality of interaction between carers and professionals is of paramount importance if carers are to be supported to continue in their caring role with the support they need | Partners in Policymaking In Control  Think Local Act Personal Making It Real  Think Local Act Personal Reimagining Social Care  Think Local Act Personal Gathering the evidence; making personal budgets work for all |
| Training to provide care and support | | | | | |
| 40 | Oxford Health NHS Foundation Trust | Key area for quality improvement 1:  Training to provide care and support | There is a good evidence that relevant educational workshops for carers make a great difference with understanding the mental health condition, the level of support needed by their ‘cared for person’ and enables them to support them better in the community.  This is a great opportunity for carers to network with carers in similar situation and exchanging some coping tips.  Carers often find that their stress gets reduced when applying some strategies they learn in order to support their ‘cared for person’. | By educating the carers we can directly support the ‘cared for person’ to have a better quality of life and take positive steps towards their recovery.  Carer’s Wellbeing is enhanced. They feel a reduction in their stress levels. | We have testimonials and feedback forms from the carers on how they find the workshops beneficial and how they would make changes to the way they care as a result. |
| 41 | Royal College of Nursing | Key area for quality improvement 2  Supporting unpaid adults carers with evidence-based training and relevant skills | Evidence reviewed indicates that education/training for unpaid carers is offered across some parts of the UK, however what training is offered varies and face to face training is limited. However, carers need to know how to access on-line and face to face to face training without relying on the internet because not everyone has access to this or the ability to use it effectively.  NICE guidance considered that supporting unpaid, adult carers access free, evidence-based face to face training and education can develop their skills and knowledge to support them in their role as carer. This will also improve the quality of care and support they deliver, reduce avoidable harm and hospital admissions for the person they are caring for. | Carers may wish to have more of an understanding of health conditions/what to look out for re: early signs of deterioration and prevention of potential health and well-being problems such as urine infections, pressure damage, dehydration and loneliness. | The Carers Trust collates some of the free online training  <https://carers.org/article/free-online-courses-carers>  Scotland offer a comprehensive suite of occupational training courses <https://www.mygov.scot/training-for-carers/>  NICE NG150 <https://www.nice.org.uk/guidance/ng150/chapter/Recommendations#training-to-provide-care-and-support> |
| 42 | SCM7 | Key area for quality improvement 5  Training for carers | Carers can be asked to take on complex care tasks and medicines management with little or no training and may lack confidence to do these tasks safely. | Ensuring carers are able to provide care safely improves both their wellbeing and that of the person they care for. | NHS England Long term Plan 2018 |
| 43 | The Challenging Behaviour Foundation | Key area for quality improvement 2:  *Training for family carers* | Family carers of adults with learning disabilities and/or autism should be able to access the same training as professionals to support their loved one. | It is essential 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. Where training is offered to professionals, families should also be included to ensure consistent support for the individual being cared for. |  |
| Access to carers’ assessments | | | | | |
| 44 | Carers Trust | Key area for quality improvement 3  Assessment | Carers are still not getting the statutory assessments they are entitled to. | Linked to the lack of identification, not enough carers are getting a carer’s assessment. When carers do get an assessment, research suggests the assessment does not always fully consider their needs. | Carers are still not getting the assessment they are entitled to.  Carers UK’s latest State of Caring report showed that:  27% of carers in England reported that they had an assessment, or a review of their assessment, in the last 12 months.  When carers do have an assessment, they often feel their needs were not given sufficient consideration.  carers’ ability and willingness to provide care was only thoroughly considered and reflected in support in 37% of assessments;  only 30% of carers felt that their need for support to look after their own physical and mental health alongside caring had been thoroughly considered;  only one quarter (26%) said their need to have regular breaks from caring was considered  <http://www.carersuk.org/images/News__campaigns/CUK_State_of_Caring_2019_Report.pdf>  The ADASS Budget survey asked councils which statutory duties they felt least confident about being able to meet.  25/150 respondents (17%) were less than confident that they would be able to meet the specific duties on assessments for carers and people using services in 2019/20.  And 32/150 (21%) were less than confident that they would meet this specific duty on 2020/2021. |
| 45 | Department of Health and Social Care | Carers needs and wider circumstances are reviewed at regular and appropriate times |  |  |  |
| 46 | Newcastle City Council and partners | Key area for quality improvement 3  Assessing carers needs | Carers need to know that carers assessments can be formal or informal, either of which may meet a carers needs at a particularly given time | Professionals should recognise that an informal carers assessment through a non-statutory service may meet a carers needs at any given point in time; Professionals should be supported to build relationships with carers and, where appropriate the person they are caring for prior to any formal (statutory) carers assessment, the context of which should be discussed with the carer; a contingency plan should be developed to support and enable carers in crisis situations | Key area for quality improvement 3  Assessing carers needs |
| 47 | Public Health England | Key area for quality improvement 4  Waiting times for carers assessments | Timely carers assessments allow preventative support to be put in place and avoid situations escalating to crisis point for vulnerable people and their carers. | There is no routine data available on waiting times for carers or formal analysis of the impact this has on health outcomes. | The Nuffield Trust has published a guide to help local authorities understand the needs of carers in their area - <https://www.nuffieldtrust.org.uk/resource/understanding-carers-a-guide-for-local-authorities> |
| 48 | SCM2 | Access to high quality Carers Assessment | Evidence used in the development of the guideline showed that a good quality carers assessment is a therapeutic intervention in its own right. There is significant variation in the way that Local Authorities conduct Carers Assessments, many still defaulting to the carers assessment being tagged on the end of the assessment of the person with support needs. | The Care Act 2014 is an excellent piece of legislation for carers but has yet to be fully implemented by most local authorities in terms of its obligations towards carers.  Only 27% of carers who responded to the Carers UK State of Caring Survey in 2019 had an assessment or review in the previous year. Carers are often not given a choice of how that assessment takes place and 20% of carers wait more than six months for an assessment to take place. Please see pages 11 - 13 for comments on how carers felt about their assessment experience.  Portsmouth City Council has radically redesigned its assessment process for carers. There is no form and no bureaucracy making it difficult for carers to access an assessment. Assessments;  Start at first contact meaning the carer has quick access to support and doesn’t need to repeat themselves  Are proportionate, brief and quick if needed or can take place over a longer period of time with multiple contacts if needed  Scalable so support can be scaled up or down as needed  Take place at a time, location and via the chosen method of communication  Reviewed in line with carer need | <https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=6804> |
| 49 | SCM3 | Access to statutory carers assessment and carers support | Macmillan Care identified that only 5% of cancer carers received a Carers Assessment.  At the time of the Care Act is was felt clause 2 needed strengthening to include health services.  If carer care and support needs are not assessed they risk not only their own health and wellbeing, but they may also risk carer breakdown meaning increase hospital admissions for both them and the person they care for. | *The Care Act 2014 was designed to improve support for carers; as were amendments to the Children Act relating to young carers and parent carers. Carers rights to a statutory carers’ assessment based on the appearance of need are yet to be fully realised for a variety of reasons. Carers who receive an assessment are more likely to be able to sustain their caring role, have a life outside of caring and access support to maintain their own health and well being.* | <https://www.theguardian.com/social-care-network/2016/jul/12/the-care-act-is-failing-to-support-carers>  <https://www.communitycare.co.uk/2016/05/26/difference-care-act-can-make-carers-benefit/> |
| 50 | SCM5 | Key area for quality improvement 2  Assessment | Carers are entitled by law to ask for a Carer’s Assessment (Care Act 2014).  *The NICE guideline makes several recommendations in this area, covering preparation, conduct and implementation of assessment.* | Carers UK data suggests that only 27% of carers receive an assessment. This number is going down from an already low base (31% in 2016). I think this is the main area for quality improvement since few of the recommendations can be implemented if there is no assessment to begin with.  Timeliness is an issue for many. The same snapshot showed that 20% of carers who did receive an assessment had to wait for more than six months.  The quality of assessment appears to be patchy. The Carers UK report found that:  *“The experiences that carers have shared suggest that implementation of the Care Act and Children and Families Act is varied across England and they are not realising the benefits that were intended by the legislation. Even for those carers who had a positive experience of the assessment itself, often there is not support available locally following on from it to relieve any of the issues they have raised*.”  Many carers experience poor health:  *“7 in 10 have suffered mental ill health and 6 in 10 physical ill health from caring”*  The Carers UK report shows that only 30% of carers who receive an assessment felt that their own health needs had been adequately considered.  Evidence considered by the Guideline committee also showed that assessments were more commonly focused on the needs of the care recipient rather than on carers’ needs.  Evidence also shows that there are problems with the outcomes of assessments. NICE guideline recommends that  a clear set of outcomes and actions should be established following assessment and that it is important for carers to be helped to understand those actions and what the next steps will be.  that assessors should take responsibility to pass on the outcomes of assessments and where appropriate share information with the relevant services for follow up.  if the outcome of an assessment is the development of a carer’s support plan, the committee agreed about the critical importance of ensuring it monitored regularly and updated given that carer’s needs are likely to change over time. | Carers UK (2019): State of caring: a snapshot of unpaid care in the UK  Local Government Association (2018): Supporting carers: Guidance and case studies  NICE evidence review  *NICE evidence review* |
| 51 | SCM6 | *Access to statutory carers assessment and carers support* | Macmillan Care identified that only 5% of cancer carers received a Carers Assessment.  At the time of the Care Act is was felt clause 2 needed strengthening to include health services.  *If carer care and support needs are not assessed they risk not only their own health and wellbeing, but they may also risk carer breakdown meaning increase hospital admissions for both them and the person they care for. With carers increasingly managing complex care packages, integrated and personalised care and support plans are vital.* | The Care Act 2014 was designed to improve support for carers; as were amendments to the Children Act relating to young carers and parent carers. The Care Act 2014 in theory expects assessment to be holistic, addressing carers’ own aspirations regarding practical and emotional support; their wishes regarding access to education, training and employment and importantly their willingness to continue caring. There is still wide variation in numbers and quality of statutory assessments. But carers who receive an assessment are more likely to be able to plan and sustain their caring role, have a life outside of caring and access support to maintain their own health and well being.  Assessment (including information prior to assessment an subsequent support planning) are critical to carer well-being and the sustainability of the caring relationship but experiences vary widely.  *There are opportunities in the proposals for both health and social care (ie an integrated service) in the Comprehensive Model for Personalised Care, as proposed in the NHS Long term Plan, which will ‘make personalised care business as usual across the health and social care system’,* | <https://www.theguardian.com/social-care-network/2016/jul/12/the-care-act-is-failing-to-support-carers>  <https://www.communitycare.co.uk/2016/05/26/difference-care-act-can-make-carers-benefit/>  <http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=10464>  NHS England (2019), Universal Personalised Care: Implementing the Comprehensive Model ([personalisedcare@england.nhs.uk](mailto:personalisedcare@england.nhs.uk)  ADASS (2019), The Care Act 2014: A guide to efficient and effective interventions for implementing the Care Act 2014 as it applies to carers  Carers UK – a number of different publications. I will supply list if required. However, I single out: <https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment> [note:this guide for LAs and carers is updated annually] . |
| *Quality of carers’ assessments* | | | | | |
| 52 | Carers Trust | Key area for quality improvement 4  *Prevention and wellbeing* | Prevention and wellbeing should be at the heart of services supporting carers.  *Prevention is vital in both stopping support needs from developing and saving money for local authorities.* | *Another key duty under the Care Act where research suggests is not being fulfilled.* | Asked how confident they were on fulling these duties:  Information and advice  Prevention and wellbeing, Assessment (carers and people using services),  Personal budgets/services sufficient to meet eligible needs,  Safeguarding (DoLS/LPS) and  Market Sustainability (including National Living Wage).  In 2019/20 35% are fully confident that budgets will be sufficient to meet all these statutory duties in the year, with 59% being partially confident and 6% having no confidence.  Councils were asked which statutory duties they felt least confident about being able to meet  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.  *Directors see prevention as an important way to save money. However due to the funding crisis, and the lack of confidence in being able to meet other statutory duties, councils are not able to invest in approaches that might reduce future demand. Spend on prevention is set to increase by 5.4% in 2019/20 – although this is only an increase from 8% to 8.4% taken as a percentage spend of the overall adult social care budget.* |
| 53 | Department of Health and Social Care | Carers assessments are undertaken by professionals with the appropriate level of experience and knowledge |  |  |  |
| 54 | Department of Health and Social Care | Carers needs are assessed in a proportionate manner and include mental health, physical health and wellbeing of the carer |  |  |  |
| 55 | Mencap | Assessments (needs assessments and carers assessments), meeting needs, access to information about rights and clarity about LA responsibilities under the Care Act. | 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.  Carers breaks and replacement care should 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. | Too often people with a learning disability are not getting comprehensive needs assessments.  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. | Finding from New Forest Mencap research: ‘The Care Act 2014, despite its laudable goals, is yet to be applied sufficiently well to make a difference to the lives of people with learning disabilities and/or autism or their carers who took part in this study.’  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. As well as ensuring professionals are following the law, 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.  Recommendation from New Forest Mencap research: ‘More emphasis and clear guidance for family members on the duty of the local authority to undertake comprehensive needs assessments (under s5 of the act) – with plans co-produced in terms of a whole family approach. This should include planning for future needs - to pre-empt crises.’ |
| 56 | Mencap | Thinking ahead and planning for the future | Vital to prevent crisis situations. Plan in good time so that the person will be able to access the support they need when a carer is not willing or able to care anymore. This links to identification of carers (including identification of older carers) | We know too often this planning ahead doesn’t happen and people can end up in inappropriate placements and it can be traumatic for individuals and cause a lot of worry and stress for family carers who are not willing or able to care any more. | New Forest Mencap research recognised that all too often this is not happening. Tools have been produced to try to encourage this to happen. See: Thinking Ahead  <https://www.mentalhealth.org.uk/learning-disabilities/our-work/family-friends-community/thinking-ahead> |
| 57 | Oxford Health NHS Foundation Trust | Key area for quality improvement 2: Assessing Carers’ Needs | By offering a holistic carer assessment, we can help carers improve their quality of life that might have been compromised due to their caring responsibilities. | Carers often don’t have the knowledge of what support or services would be appropriate for their own needs, what their rights are and how they can continue supporting their ‘cared for person’ to be independent and live safely in the community. | Carers provide feedback and write thank you notes to say their quality of life has improved after the in-depth carer’s assessment.  However, we don’t have a system to collate this kind of data. It would be beneficial if a system can pick up data to highlight and appreciate ‘quality’. |
| 58 | Public Health England | Key area for quality improvement 1  Caring as a social determinant of health | Carers experience poorer health than the general population, as a result of their caring responsibilities and ‘juggling’ this with their own health need  1 in 8 people (around 6.5million people) are adult carers (Carers UK) | Unpaid carers play a significant role in supporting the social care system in England. Therefore, it is important that further efforts are made to improve the health of carers. | Public Health England’s Fingertips resource includes data on carer’s health and wellbeing: <https://fingertips.phe.org.uk/search/carers#page/0/gid/1/pat/6/par/E12000001/ati/102/are/E06000004>    This report by Carers UK highlights the impact of caring on health - <http://static.carers.org/files/in-poor-health-carers-uk-report-1674.pdf>  NHS England and Improvement has produced a factsheet which explains why investing in carers matters - <https://www.england.nhs.uk/commissioning/comm-carers/carer-facts/> |
| 59 | Public Health England | Key area for quality improvement 5  Adult carers to have their mental health and wellbeing needs assessed. | Looking after a family member with a physical or mental health problem can have a significant impact on a carer’s own mental health. Mental health problem of carers (including emotional stress, depressive symptoms and in some cases clinical depression) are often under-reported by carers and subsequently underdiagnosed and the right support is not provided. Although this can be an issue across all ages, for carers aged 65 and over, where mental health problems generally remain often underdiagnosed or misdiagnosed as a whole, particular care should be taken to provide the appropriate support. | Carers provide invaluable support and help to their family, friends and loved ones, whether this is for physical or mental health problems. The mental health needs of carers is often neglected. Appropriate assessment and support of poor mental wellbeing and early signs of mental ill health, can prevent development of more prolonged mental health. | Department of Health report on Carers at the heart of 21st century families - <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136492/carers_at_the_heart_of_21_century_families.pdf>  Carers UK- State of Caring Report - [file:///C:/Users/livia.dragomir/Downloads/carers-uk-state-of-caring-2015-report-final-web.pdf](file:///C:\Users\livia.dragomir\Downloads\carers-uk-state-of-caring-2015-report-final-web.pdf) |
| 60 | Public Health England | Key area of improvement 7  Falls risk assessment for carers and maintenance of physical activity | More carers are aged 65 and over. | 30% of people aged 65 and over have experienced a fall and about half of those aged 80 and above have had a fall. Evidence from randomized control trials for the National Institute for Health and Care Excellence and Cochrane Review for strength and balance has shown that exercise reduces falls by 30%. | NICE guidance on falls in older people: assessing risk and prevention - <https://www.nice.org.uk/Guidance/CG161>  Cochrane review - Exercise for prevention falls in older people living in the community - <https://www.cochrane.org/CD012424/MUSKINJ_exercise-preventing-falls-older-people-living-community>  Age UK report on older adults left to fill service gaps, 2017 - <https://www.ageuk.org.uk/latest-news/articles/2017/december/older-carers-fill-the-gap/>  The PHE Health Matters Blog - Physical activity, prevention and management of long term conditions - <https://www.gov.uk/government/publications/health-matters-physical-activity/health-matters-physical-activity-prevention-and-management-of-long-term-conditions> |
| 61 | Royal College of Nursing | Key area for quality improvement 1  Assessment of healthcare needs of adult carers | In line with the Care Act 2014, NICE guidance NG150 recommended that local authorities and social care organisations delegated by local authorities should carry out carers' assessments including aspects of health, wellbeing and social care needs of carers. | Adult carers may have their own care needs, for instance due to long term conditions or disability. Sometimes these needs are neglected because the carers are busy caring for others. We would like the healthcare needs of adult carers to be given consideration particularly mental health and access to healthcare to avoid isolation and deterioration of carers’ own health. | [Care Act 2014](http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted)  NG150 - NICE Supporting Adult Carers <https://www.nice.org.uk/guidance/ng150> |
| Helping carers stay in, enter or return to work, education and training | | | | | |
| 62 | Public Health England | Key area for quality improvement 3  Support for carers of people living with dementia | Variability of local services. | In mid-2016, there were 1.6 million people aged 85 years and over (2% of the total population); by mid-2041 this is projected to double to 3.2 million (4% of the population) and by 2066 to treble, by which time there will be 5.1 million people aged 85 years and over making up 7% of the total UK population (ONS - <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglongerhowourpopulationischangingandwhyitmatters/2018-08-13>).  An increasing older population, particularly those over age 85, means more caring is required and this is often provided by family members (carers may need to leave employment to carry out this role) | Carers UK provides advice for carers juggling caring responsibilities and careers - <https://www.carersuk.org/help-and-advice/work-and-career/other-rights-at-work> |
| 63 | SCM1 | Helping carers stay in, enter or return to work, education and training | Many carers have to give up work due to their caring role. This has a massive economic and psychological effect and adds additional pressures. | This is an issue which is growing year on year, and means carers are less likely to be able to contribute economically. | Carers UK (2019) Juggling work and unpaid care: a growing issue |
| 64 | SCM2 | Balancing work and caring | The number of carers in paid employment is rising more quickly than the number of carers overall. This is a vital area for development and improvement particularly in the public sector where one in five workers are also carers. | " 5% of UK adults have given up work to provide care for an ill, disabled or older relative or friend, and 4% said they had reduced their working hours to care. This equates to 2.6 million people giving up work in order to care" from the adjacent Carers UK report.  Evidence from expert witnesses during the development of the guideline showed the significant benefits to employers in terms of staff retention and satisfaction where policies to support carers are in place and well used. Opportunities such as the Carer Confident Employer Scheme and Employers for Carers make this easier than ever to achieve for all employers regardless of size. | <https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=6644>  <https://www.employersforcarers.org/> |
| 65 | SCM3 | Support for staff juggling work with care | New research by Carers UK reveals that 2.6 million have quit their job to care for a loved one who is older, disabled or seriously ill, with nearly half a million (468,000) leaving their job in the last two years alone that equates to more than 600 people a day. In the NHS it is estimated that one in five staff are juggling work with care. The average cost of replacing an employee has been estimated at between 50 to 150% of their salary.  The above research suggests that the NHS is at a greater risk of losing valuable staff because of unpaid caring responsibilities. The research estimates that 72,000 NHS workers have quit their job to care, 60,000 of them women. All this against a backdrop of urgent workforce shortages.  Additionally, there is now a significant body of evidence to demonstrate the emotional, physical and financial impact that caring can have, not only in the here and now but also being stored up for the future. Taking on a caring role should not mean that people have to face financial hardship and social exclusion or give up work to care. Carers who want to work should be enabled to do so and should not be discriminated against. They should be supported in the workplace to maintain their employment status. This is essential to avoid poverty and social exclusion and it is particularly important in the light of the gender pay and pension gap in UK. | The introduction of new rights for carers achieved in the Care Act and through the EU Work Life Balance Directive is part of a wider objective of ensuring a better work life balance across the whole life cycle for working carers. It is guided by the recognition that the current situation is detrimental in terms of quality of life of people trying to combine work and care, gender equality as women tend to take most of the care responsibilities. Supporting the full participation of women on the labour market through an improved work life balance and more equal sharing of care between genders should have a positive impact on our economy. Moreover, work life balance policies are likely to improve occupational health and retain skilled workers, to the benefit of the organisation.  Where organisations have moved toward ‘Carer friendly’ employment practice they have been able to demonstrate strong business benefits such as significant savings made in unplanned absences and improved employee retention.  Therefore, there is both a strong moral and economic imperative to support families and friends who provide unpaid care. | <https://www.carersuk.org/news-and-campaigns/news/more-than-600-people-quit-work-to-look-after-older-and-disabled-relatives-every-day>  <https://www.carersuk.org/news-and-campaigns/press-releases/quarter-of-a-million-nhs-workers-juggle-job-with-caring-unpaid-for-loved-one>  <https://researchportal.bath.ac.uk/en/publications/the-evidence-employee-engagement-task-force-nailing-the-evidence->  <https://www.employersforcarers.org/carer-confident> |
| 66 | SCM4 | Key area for quality improvement 4  Support for staff juggling work with care | Carers UK estimates that 2.6 million have quit their job to care for a loved one who is older, disabled or seriously ill, with nearly a half a million (468,000) people leaving their job in the last two years. In the NHS it is estimated that one in five staff are juggling work and caring responsibilities.  The same research estimates that 72, 000 NHS workers have quit their job to care, 60,000 of them women. There is also the concern of double jeopardy caring burnout, with the stress from caring in work capacity and then the unpaid caring responsibilities.  Carers who want to work should be able to and supported to continue in the workplace and not discriminated against due to their caring responsibilities. | Organisations that have moved toward ‘Carer friendly[[1]](#footnote-1)’ employment practice they have been able to demonstrate strong business benefits such as significant savings made in unplanned absences and improved employee retention.  Some staff carers describe a really positive experience of how a supportive work environment, usually a sympathetic manager, had enabled them to balance working and caring and to stay in work. However we need to recognise that this isn’t a universal experience and there are potential risks around discrimination by association. The vagueness of the carers leave policy and leaving decisions to ‘manger’s discretion’ actually was a source of added stress and anxiety for staff carers.  Organisations should voluntary include ‘carers’ as part of one of the protected categories within the Equality and Diversity framework, thus giving them added protection in the workplace. | <https://www.carersuk.org/news-and-campaigns/news/more-than-600-people-quit-work-to-look-after-older-and-disabled-relatives-every-day>  <https://www.carersuk.org/news-and-campaigns/press-releases/quarter-of-a-million-nhs-workers-juggle-job-with-caring-unpaid-for-loved-one>  <https://www.employersforcarers.org/carer-confident> |
| 67 | SCM5 | Key area for quality improvement 3  *Returning/staying in work* | There is good evidence that the ability to work and/or study carries significant benefits for carer’s health and wellbeing.  The NICE guideline contains several recommendations for health and social care agencies to support carers in work, related to  the timing and content of Carers’ Assessments,  the provision of information (to carers, employers and other welfare advice organisations) and  *these agencies’ responsibilities as major employers.* | Many carers face considerable financial pressures. Even amongst those who receive Carer’s Allowance, 53% struggle to make ends meet. These pressures are clearly worse for those who have to give up or reduce their work as a result of their caring responsibilities.  The non-financial benefits of work for health and wellbeing are well recognised. For carers, going to work may be particularly important to help maintain contact with a world outside their role as carers.  Carers UK report that the top three interventions most helpful to carers are:  a supportive employer/line manager  flexible working  additional paid care leave of between five and ten days  Although Quality Standards can’t talk to all employers, Local Government Association guidance for local authorities recognises the important role that they have in influencing employment practice:  *“Remember many carers work so local employers are important partners. Seek to raise awareness about the needs of carers among employers and support carers to stay in work or get back into work.”*  Local authorities and NHS organisations are themselves major employers and can act as role models and as testing grounds for innovative practice in, for example, harnessing new technology to support flexible working.  They can also support working carers by arranging visits/interviews (e.g. Carer’s Assessment) at suitable times.  Given the wide variety of employers and the even wider disparities in their policies and practices for carers, the most promising area for a quality statement might centre on influencing employers to be carer-friendly. | Carers UK (2019): State of caring: a snapshot of unpaid care in the UK  Carers UK (2019): Juggling work and unpaid care: a growing issue  Local Government Association (2018): Supporting carers: Guidance and case studies  NICE evidence review |
| 68 | SCM6 | *Support for working carers (and recognition of the importance of planning and delivering information, advice and support appropriate for different life stages and the management of any key transitions)* | Carers UK/Employers for Carers demonstrate that 2.6 million have quit their job to care for a loved one who is older, disabled or seriously ill, with nearly half a million (468,000) leaving their job in the last two years alone that equates to more than 600 people a day. In the NHS it is estimated that one in five staff are juggling work with care. The average cost of replacing an employee has been estimated at between 50 to 150% of their salary.  The above research suggests that the NHS is at a greater risk of losing valuable staff because of unpaid caring responsibilities. The research estimates that 72,000 NHS workers have quit their job to care, 60,000 of them women. All this against a backdrop of urgent workforce shortages.  *Additionally, there is now a significant body of evidence to demonstrate the emotional, physical and financial impact that caring can have, not only in the here and now but also being stored up for the future. Taking on a caring role should not mean that people have to face financial hardship and social exclusion or give up work to care. Carers who want to work should be enabled to do so and should not be discriminated against. They should be supported in the workplace to maintain their employment status. This is essential to avoid poverty and social exclusion and it is particularly important in the light of the gender pay and pension gap in UK.* | The introduction of new rights for carers achieved in the Care Act and through the EU Work Life Balance Directive is part of a wider objective of ensuring a better work life balance across the whole life cycle for working carers. It is guided by the recognition that the current situation is detrimental in terms of quality of life of people trying to combine work and care, gender equality as women tend to take most of the care responsibilities. Supporting the full participation of women on the labour market through an improved work life balance and more equal sharing of care between genders should have a positive impact on our economy. Moreover, work life balance policies are likely to improve occupational health and retain skilled workers, to the benefit of the organisation.  Where organisations have moved toward ‘Carer friendly’ employment practice they have been able to demonstrate strong business benefits such as significant savings made in unplanned absences and improved employee retention.  Therefore, there is both a strong moral and economic imperative to support families and friends who provide unpaid care.  *This is also significant because of the UK’s ageing population and the economic arguments for retaining working carers in the workforce.* | <https://www.carersuk.org/news-and-campaigns/news/more-than-600-people-quit-work-to-look-after-older-and-disabled-relatives-every-day>  <https://www.carersuk.org/news-and-campaigns/press-releases/quarter-of-a-million-nhs-workers-juggle-job-with-caring-unpaid-for-loved-one>  <https://researchportal.bath.ac.uk/en/publications/the-evidence-employee-engagement-task-force-nailing-the-evidence->  <https://www.employersforcarers.org/carer-confident> |
| 69 | SCM7 | Key area for quality improvement 2  *Supporting carers to enter or remain in employment* | Carers have identified the positive effects of employment for both their mental wellbeing and financial security | This effects a significant proportion of the workforce and is a problem which is expected to increase with the aging population. | Carers Action Plan 2018-20  Juggling Work and unpaid care Carers UK 2019 |
| 70 | Think Local Act Personal | Key area for quality improvement 3  *Supporting working carers* | Being supported to be able to continue to work, where the carer is of working age. Often this is about the culture of the organisation they work for. | For many carers the organisational culture and awareness of how to support working carers well is poor. The business case to support them well is strong. | Supporting Working Carers: The Benefits to Families, Business and the Economy, HM Govt. and Carers UK 2013  *“If we can get this right, there are substantial gains to be made. Individuals will gain from the health and financial benefits of work and maintaining a life of their own alongside caring; businesses and their clients will gain from retaining talented employees; and the wider economy will gain from growth in the care sector.”* |
| Social and community support | | | | | |
| 71 | Mencap | The right support for carers and the individuals they care for | Vital that there is suitable local support and services to meet the needs of carers and their loved ones eg. suitable respite, Replacement care, Meaningful day opportunities.  There must also be enough suitable housing available. This links to planning ahead as some people with a learning disability may live in the family home now but they will need housing in the future.  There need to be suitably skilled social workers, there must be continuity so that when a familiar social worker leaves information about individuals and families are shared, so families don’t have to start from scratch explaining needs etc. | Too many carers are not getting the support they need.  Too often burden of ‘care management’ is falling on family carers. | Recommendation from New Forest Mencap research: ‘Co-ordinated and appropriate respite, to enable carers to have a ‘night off’ and/or longer stretches of time to rest, and enable life goals to be realised - putting carers on a more equal footing with non-carers who are enjoying retirement’. |
| 72 | Multiple System Atrophy Trust | Key area for quality improvement 4  Provision of social opportunities to help prevent social isolation.  These opportunities need to be backed up by care provision for, or the inclusion of, the people living with MSA and transport. | 80% of Former Carers in our survey (2) reported that social activities and isolation got worse or much worse as a result of caring for somebody with MSA. | Social isolation came up as a major issue in our survey. There is a very real problem when people gradually become distanced from friends and family and the world around them. This can often mean that they are unable to access information by word of mouth, or access other support or respite such as effective palliative care.  This is another area where ongoing support from a care co-ordinator is vital. | See 1 and 2 above |
| 73 | Public Health England | Key area for quality improvement 2  Carers and loneliness | The Government’s loneliness strategy highlighted that certain groups are more likely to experience loneliness. Loneliness can be addressed through social connectedness | Eight out of ten carers felt lonely as a result of their caring role. | To support these claims Carers UK has produced a report on carers loneliness, which is available to view here - <https://www.carersuk.org/images/News__campaigns/The_world_Shrinks_Final.pdf>  The Government Loneliness Strategy - <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/750909/6.4882_DCMS_Loneliness_Strategy_web_Update.pdf>  Public Health England and the National Health Service (NHS) has developed the Every Mind Matters website and the Your Mind Plan quiz offers personalised advice via email - <https://www.nhs.uk/oneyou/every-mind-matters/your-mind-plan-quiz/?WT.tsrc=Search&WT.mc_id=Brand&gclid=Cj0KCQiA7OnxBRCNARIsAIW53B95RnwQsvdArC3ziGdau0K6WZe2Cn47NVg3rxJu6UcXxytU3fjnra0aAoW3EALw_wcB> |
| 74 | Royal College of Nursing | Key area for quality improvement 3  Health promotion | Health Promotion  Unpaid carers save the NHS and social care a significant amount of money and should be a high priority in providing support/signposting to improve their own health. Promoting good health focusing on explaining the benefits of physical activity, good nutrition and stress management are key to support the mental and physical health of unpaid carers. Social Prescribers could also support carers.  Education/events/forums for carers to learn the importance of looking after their own health and well-being. This will improve their own physical/mental health and support them in their role as carer. | It is vital that carers have the insight and opportunity look after their own health and well-being and understand why this is important.  There is significant evidence to indicate that physical activity is good for health in relation to the prevention and management of disease and improvement in mental health and wellbeing. | <https://www.gov.uk/government/publications/physical-activity-guidelines-uk-chief-medical-officers-report> |
| 75 | SCM3 | Access to carers support services | No one should be left to care alone, and it is vital that all unpaid carers feel supported in their caring role, or feel supported to stop caring, if that's what they choose.  We know that when carers access support this can be transformative in terms of their caring role. | There is very little evidence that carers data is routinely collected within NHS setting. (Primary care withstanding) For example carers are not included in the NHS electronic referral system. This makes providing an integrated approach to supporting carers challenging.  If we are not able to identify carers in our systems, we are even less likely to be able to refer them on to the support services available to them and not meet our Care Act duty around well-being and prevention.  Surrey Heartlands have developed stand alone Carers Prescription online referral mechanism to link carers to support services. To date we have dispensed over 32,000 prescriptions through this approach. | <https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/eligibility/how-is-wellbeing-understood.asp>  [www.surreynhscarersprescription.org.uk](http://www.surreynhscarersprescription.org.uk) |
| 76 | SCM5 | Key area for quality improvement 4  Support for carers | The NICE guideline contains recommendations that support be provided for carers in several categories:  social and community support  training to carry out their caring responsibilities  psychological and emotional support  support during changes to the caring role  support during end of life care for the person being cared for  These could be viewed as separate areas for quality improvement or be wrapped up into an overall quality statement relating to support. | Caring can take a toll on people and cut them off from support available in their local community. Evidence suggests that the number of carers experiencing poor health is rising:  *“60.6% of carers reported that caring had caused them feelings of stress, compared with 58.7% in 2016-17. This was a significant increase”*  Other surveys suggest that around a fifth of carers (i.e.more than a million people) receive no support at all.  *“one in five carers (21%) neither buy or receive support with caring.”*  The Carers UK snapshot report shows that only 30% of carers who receive an assessment felt that their own health needs had been adequately considered.  A quality statement might be drafted to the effect that every Carer’s Assessment should produce a clear support plan, but that would exclude the large number of carers who, for whatever reason, do not receive or ask for an assessment.  Evidence presented to the guideline committee emphasised the importance to carers of peer support and integration into their local community via access to local services. The LGA recommend that health and social care agencies:  *“unlock the potential of small charities and groups that may be put off by a formal tendering process”*  The DHSC Carers Action Plan 2018-20 acknowledges that:  *“Many carers have little contact with services for carers and are not receiving formal support in their caring role. It is, therefore, vital that we work with partners beyond government to raise awareness of caring among the wider population to build carer friendly communities.*  *Responses to the Call for Evidence emphasised the importance of working with the voluntary and community sector. Charities were highlighted as a source of information and support for carers. There was also a desire for carer-led and community-led support, with carers saying they would value local action groups, social activities and peer support.”*  *I tend to think that this holds the most potential for a quality statement.* | NHS Digital (2019) Personal social services survey of adult carers in England  Carers UK (2019): State of caring: a snapshot of unpaid care in the UK  Carers UK (2019): State of caring: a snapshot of unpaid care in the UK  NICE evidence review  Local Government Association (2018): Supporting carers: Guidance and case studies  Department of Health and Social Care (2018): Carers action plan 2018-2020: Supporting carers today  Carers UK (2019): State of caring: a snapshot of unpaid care in the UK |
| 77 | SCM6 | *Access to carers support services* | *Support for carers should be individually tailored in line with their assessment and importantly regularly reviewed. Caring is seldom static and many carers will be managing a long-term condition or disability with changes in their own circumstances as well as the person cared for.* | There is very little evidence that carers data is routinely collected within NHS setting. (Primary care withstanding) For example carers are not included in the NHS electronic referral system.  *Access importantly requires accessible information and the use of technology (carer passports, assistive technology offer new possibilities – if the carer is aware of the opportunities. Digital inclusion can also offer training, friendship and support and up-to-date information. It can also combat loneliness.* | <https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/eligibility/how-is-wellbeing-understood.asp>  [www.surreynhscarersprescription.org.uk](http://www.surreynhscarersprescription.org.uk)  <https://www.carersuk.org/for-professionals/carersuk-products/digital-resource-for-carers> |
| 78 | The Brian Tumour Charity | *Need for information about financial support for carers to be offered*. | Evidence for financial pressures of brain tumour on carers and families  For adults affected by a brain tumour diagnosis (Losing My Self The Brain Tumour Charity):- 75% 3 in 4 had their / their partner's working life affected 50% 1 in 2 experience financial difficulty  28% have had to give up work entirely  For parents of children affected by brain tumours (Losing My Place The Reality of Childhood with a Brain Tumour The Brain Tumour Charity):- 83% parents of child with BT said their working life moderately or severely affected by their child's illness 66% 2 in 3 had moderate or severe impact on finances  *For adults affected by a brain tumour diagnosis (The Price you Pay The Brain Tumour Charity):- 81% patients stopped work or reduced hours  69% carers stopped work or reduced hours 65% partly dependent on benefits 33% entirely dependent on benefits 24% had their household income drop below £40k* | For adults affected by a brain tumour diagnosis (*The Price you Pay The Brain Tumour Charity*):-  76% carers didn't receive info about financial help as carer  46% people diagnosed didn't receive info about financial help / benefits after diagnosis (36% high grade, 50% low grade)  44% people diagnosed didn't receive free prescription info  *For adults affected by a brain tumour diagnosis (Unpublished Unmet needs survey The Brain Tumour Charity):-  When asked about their need to “Have enough money to live our life and pursue treatment” there was a 42% gap between those saying this was important and those satisfied their need was met.* | *The Price You Pay: The financial impact of a brain tumour* [*https://www.thebraintumourcharity.org/about-us/our-publications/price-you-pay/*](https://www.thebraintumourcharity.org/about-us/our-publications/price-you-pay/)  *Losing my self: the reality of life with a brain tumour* [*https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/*](https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/)  *Losing my place: the reality of childhood with a brain tumour* [*https://www.thebraintumourcharity.org/about-us/our-publications/losing-my-place-reality-childhood-brain-tumour/*](https://www.thebraintumourcharity.org/about-us/our-publications/losing-my-place-reality-childhood-brain-tumour/)  *TheBrainTumourCharity unpublished unmet need survey 2019 available on request* |
| 79 | Think Local Act Personal | Key area for quality improvement 5  *The use of technology and equipment to improve quality of life and connectivity* | Often providing some equipment to the person needing care and support can greatly assist carers ability to continue to care.  Technological solutions are evolving at pace and offer opportunities to provide care in new and different ways to the past, particularly for remote family members and close friends | There are a wide range of options of equipment and aids to daily life. Good information and advice can assist people to make good choices as can the intervention of Occupational Therapists.  Whilst the opportunity of technology is vast, there are also challenges to carers being able to access and utilise these new forms of support.  Standards of behaviour on the internet are loose and this vulnerable group are at risk of exploitation | State of Caring Carers UK 2019  Carers were asked what type of practical support they receive or buy. The most popular type of support was equipment in the home of the person they care for (like hoists, grab rails or easy-grip handles on taps) with 48% receiving or buying this  Of those carers who use technology, the internet was the most popular type with 88% using it as a source of information and 44% using it as a form of communication or online support.  <https://www.thinklocalactpersonal.org.uk/Latest/TEC-Stories-technology-enabled-care-/>  Person-centred planning has been life changing for Rachel and her sons, Shaun, 28, and Greg, 30, who have learning disabilities and autism. A dynamic approach to how their funding is spent and a creative attitude towards assistive technology have resulted in significant cost savings and increased independence.  Carers UK Passport Scheme Carers UK  “A Carer Passport helps to improve and embed identification, recognition and support for carers in the day-to-day life of an organisation or community.”  The use of Carer Passports in hospitals has been selected as a global Innovative Carer Practice by the International Alliance of Carer Organizations (IACO) and Embracing Carers TM. |
| Psychological and emotional support | | | | | |
| 80 | Mencap | Support for emotional, psychological needs carers | For many carers this can be closely linked with how much they have to fight for their loved ones to get the right support – hugely stressful. Need to make sure their loved ones is able to access the right support. But alongside this need to make sure carers are getting emotional support. | 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. |  |
| 81 | Multiple System Atrophy Trust | Key area for quality improvement 5  Proactive and targeted emotional support for carers | 43% of former carers said their caring responsibilities caused them depression and 56% reported anxiety in our survey (2) | There is a significant yet unmet need for carer counselling for supporting a condition such as Multiple System Atrophy which is progressive, terminal and it’s deterioration, with complexity of symptoms, is rapid.  Requirements may be for counselling, but also for attendance at Support Groups or other activities where emotional support can be found. There are often issues around loss of identity, loss of relationship or fear for the future.  Regular and proactive discussion about how carers are managing emotionally should be integrated into any support. | See 1 and 2 above |
| 82 | Pennine Care NHS Foundation Trust | Key area for quality improvement 4 Emotional and practical support at a time it is needed |  |  |  |
| 83 | Public Health England | Key area of improvement 6  Adult carers to be provided with support to ensure positive mental health and wellbeing |  | Many carers often report to be socially isolated and there is a clear link between social isolation and poor mental health. | GP Patient Data Survey results on the experience of carers- <https://www.ipsos.com/sites/default/files/migrations/en-uk/files/Assets/Docs/Infographics/gpps-carers-infographic-2017.pdf>  The Personal Social Services Survey of adult Carers in England 2018-19- <https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2018-19> |
| 84 | SCM1 | Psychological and emotional support for carers | Caring can have a significant impact on health, with carers often finding that both their mental and physical health are affected. | Wellbeing support for carers varies widely between areas. An exhausted carer may well develop care needs themselves. A preventative approach is what’s needed, but so often support and interventions are not available until the situation has reached crisis point. | Carers UK (2019) State of caring: a snapshot of unpaid care in the UK |
| 85 | SCM7 | Key area for quality improvement 1  Psychological and emotional support for carers | There is long standing evidence that caring can impact on mental health and wellbeing. This affects both the carer and the person receiving care. | There is evidence that carers can benefit from psychological interventions but they are not accessible to all carers | Kishita, Naoko, et al. "Which interventions work for dementia family carers?: an updated systematic review of randomized controlled trials of carer interventions." *International psychogeriatrics* 30.11 (2018): 1679-1696. |
| 86 | The Brian Tumour Charity | *Need for earlier and adequate emotional, mental health and relationships support for carers and families because of the unique impact of brain tumours on quality of life.* | Brain tumours are different to other cancers. They have a high, different and often ‘invisible’ impact on quality of life compared to other cancers. Key differences include fatigue, cognitive function, personality change and emotional and mental health. These factors have a disproportionally large impact on quality of life, affecting the ability to work and maintain family and other relationships  For adults affected by a brain tumour diagnosis *(Losing My Self The Brain Tumour Charity)*:- 91% people said the tumour had affected their emotional and mental health 89% of people with a brain tumour experience ongoing symptoms including personality changes, memory problems and cognitive problems which directly affects their own and their carer’s emotional and mental health and relationship.  2 in 3 have seen a negative impact on relationships with their partner (likely to also be their carer) 72% have had their physical intimacy negatively affected 28% people affected by a brain tumour diagnosis experience personality changes (eg depression, anger, disinhibition, heightened emotions) which then has an added direct and deleterious effect on their relationships with their family and main carer  For parents of children affected by brain tumours *(Losing My Place The Reality of Childhood with a Brain Tumour The Brain Tumour Charity)*:- 99% parents of child with BT affected emotionally 95% parents with more than one child said lives of other children had been affected by their child's tumour, and 73% said the effect was moderate or severe 9 in 10 parents said their child's tumour made them feel at least somewhat lonely, 62% said quite a lot Nearly 3 in 4 parents said their child's brain tumour had a moderate or severe impact on their own mental health, nearly 6 in 10 had severe impact 73% parents with more than one child said lives of other children had been severely or moderately affected by their child's tumour  Impact on relationships of brain tumours and impact of strong relationships on outcomes for brain tumours: Research published in *Cancer Medicine 2018* evidenced that marital status is the most important independent prognostic factor for glioblastomas (1). In addition to marital status, demographic factors, disease progression factors, education and insurance status were also associated with survival in glioblastomas. The most significant is marriage and notably, the protective effect of marriage becomes more and more apparent as time goes on. Sadly though this differs between men and women, with this being more significant for men. Additional research in Australia showed how the increased responsibilities placed on family members can lead to significant strain on their relationship with the person with the brain tumour and, in some cases, relationship breakdown (2). *Carlson* (3) reported that females with brain tumours were nearly 10 times more likely to become divorced or separated during the course of their illness compared to males with a brain tumour. | The impact of having a strong main relationship on the prognosis for a brain tumour: Research published *in Cancer Medicine in 2018* evidenced that marital status is the most important independent prognostic factor for glioblastomas (1). In addition to marital status, demographic factors, disease progression factors, education and insurance status were also associated with survival in glioblastomas. The most significant is marriage and notably, the protective effect of marriage becomes more and more apparent as time goes on. (1)  For adults affected by a brain tumour diagnosis *(Unpublished Unmet needs survey The Brain Tumour Charity)*:-  When asked about their need to “Cope day to day with the emotional and mental health impact” there was a 71% gap between those saying this was important and those satisfied their need was met. | For evidence of the need for earlier and adequate emotional and mental health and relationships support for carers and families please see :  *Jun‐Chao Xie, Shuai Yang, Xue‐Yuan Liu and Yan‐Xin Zhao. Effect of marital status on survival in glioblastoma multiforme by demographics, education, economic factors, and insurance status. Cancer Medicine [internet]. 2018 Aug; 7(8): 3722–3742. Available from:* [*https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6089174/*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6089174/)*,*  *Schubart J, Kinzie M, Farce E. Caring for the brain tumor patient: family caregiver burden and unmet needs. Neuro Oncol (2008) 10:61-72. doi: 10.1215/15228517-2007-040*  *Carlson, R. Study: women with brain tumors have 10 times rate of divorce as men with brain tumours. Oncol Times (2001) 23:63-63, doi:10.1097/01.COT.0000312819.01966.79*  *Losing my self: the reality of life with a brain tumour* [*https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/*](https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/)  *Losing my place: the reality of childhood with a brain tumour* [*https://www.thebraintumourcharity.org/about-us/our-publications/losing-my-place-reality-childhood-brain-tumour/*](https://www.thebraintumourcharity.org/about-us/our-publications/losing-my-place-reality-childhood-brain-tumour/)  *TheBrainTumourCharity unpublished unmet need survey 2019 available on request* |
| 87 | The Challenging Behaviour Foundation | Key area for quality improvement 4:  *Psychological and emotional support for carers* | Family carers should have access to appropriate and timely psychological and emotional support. | There needs to be recognition that families experience trauma too (as well as children, young people and adults with learning disabilities and autism (3)) and the impact on them needs to be acknowledged and addressed.  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. | Children with intellectual disabilities experience a greater number and range of adverse life events- *Hatton & Emerson, 2004* (<http://www.research.lancs.ac.uk/portal/en/publications/the-relationship-between-life-events-and-psychopathology-amongst-children-with-intellectual-disabilities(a39b0426-5d1c-4ab7-b51c-f1f7808d7d62)/export.html>) |
| Carers breaks | | | | | |
| 88 | Multiple System Atrophy Trust | Key area for quality improvement 2  Fully funded, non means tested, respite care. | Respite care provision should cover regular time out each week and regular overnight breaks. This is causing severe problems for carers leading to early care admissions. | One major difficulty is the fact that if the person living with MSA is assessed as needing to pay for the respite care and they are unable/unwilling to do so the carer gets no break. Sleep deprivation and physical exhaustion are common issues raised by carers (80% of former carers reported fatigue and tiredness as a major issue- see 2 above supporting information as reference) | See 1 and 2 above. |
| 89 | SCM5 | Key area for quality improvement 4  Support for carers | The NICE guideline contains recommendations that support be provided for carers in several categories:  • social and community support  • training to carry out their caring responsibilities  • psychological and emotional support  • support during changes to the caring role  • support during end of life care for the person being cared for  These could be viewed as separate areas for quality improvement or be wrapped up into an overall quality statement relating to support. | Another potential statement could be built around the recommendation from Carers UK, consistent with the NICE guideline (1.5.2 1nd 1.5.3), to:  *“Give carers a break: Provide funding and choice of quality services to enable carers to take the breaks they need.*  *Increase and ring-fence funding for carers’ breaks. Funding should also be transparent, so carers know what they are entitled to, and ensure greater consistency in what is available. A choice of appropriate and good quality care must be available, or carers cannot get the breaks they need for their own health and wellbeing.”*  Only 26% of carers who received an assessment reported that their need for regular breaks from caring was considered. |  |
| 90 | Think Local Act Personal | Key area for quality improvement 1  *Services provided to the person to enable the carer to have a break from caring are of high* *quality* | *Carers need peace of mind that the person they care for will be looked after well and as close to the standard they would provide as possible, otherwise they may often experience emotional distress and anxiety* | *Carers breaks usually are enabled through the provision of overnight residential accommodation, sitting type services, and day services or opportunities to the person needing care and support. The critique of the quality of these services is extensive and well established.* | <https://www.scie.org.uk/carers/breaks/evidence>  “Quality of support is vital: it strongly influences whether carers will take a break. A poor experience can put them off. Carers want time to build up trust with the service provider so they can be confident the person they care for will have a good experience.” |
| 91 | Think Local Act Personal | Key area for quality improvement 2  Availability of Personal Budgets or Personal Health Budgets both for the person needing care and support and the carer to enable meaningful breaks | *Carers need choice and control in order to shape breaks that are meaningful to them and the person they care for* | Carers need to be able to flexibly shape the break that they get from caring in order to minimise their emotional distress and anxiety. A set menu of options can lead to premature admission to long-term social or NHS care and a lowering of future aspirations – and an unnecessary assumption that residential care is an inevitability.  *The current offer to carers is all about services, there could be a useful shift in focus using making It Real to have different conversations about what is possible* | <https://www.scie.org.uk/carers/breaks/evidence>  “More choice and control for carers over the type of break they take. Everyone’s needs, preferences and situations are different, so carers want a range of breaks available. Flexibility and a mix of settings are important – residential, in the home, out of the home, day services with good activities, for example.”  Breaks have to work for the person who is cared for to be effective. That might be about doing something they really enjoy. It can also be about support services having the right training and confidence so the carer is not constantly called.  NHS Long Term Plan  1.37. But the NHS also needs a more fundamental shift in how we work alongside patients and individuals to deliver more person-centred care, recognising – as National Voices has championed – the importance of ‘what matters to someone’ is not just ‘what’s the matter with someone’. Since individuals’ values and preferences differ, ensuring choice and sharing control can meaningfully improve care outcomes. |
| Support during changes to the caring role | | | | | |
| 99 | Newcastle City Council and partners | Key area for quality improvement 4  Support during changes to the caring role | *Any type of change to a caring role, if not facilitated in an open and transparent way can have a negative impact on the carer and their caring situation* | All professionals have a responsibility to recognise key points of change in a caring role e.g. planned, crisis, forced, proactive, emergency and provide carers with timely information, emotional and practical support to support that change | Key area for quality improvement 4  Support during changes to the caring role |
| 100 | SCM4 | Key area for quality improvement 3  Support for carers through key transition areas, eg from hospital to community care, young adult carers and as caring situations change. | Carers can often feel vulnerable and unsupported at key transition periods within a caring journey, including End of Life discussions.  *There needs to be a recognition that different information / signposting is required at these points of transition. They can include transition from hospital to home, changes in care environment,* *transition to young adult carer, etc* | Supporting carers in general practise: a framework of quality markers states: “The framework also reinforces *An integrated approach to identifying and assessing carer health and wellbeing* (3), which remains a model of good practice for health and care services to work together in agreeing how they will identify, assess and support carer health and wellbeing.”  It is one of the recommendations in the new NICE supporting adult carers (2020) guidance NG150. | <https://www.nice.org.uk/guidance/ng43>  <https://www.nice.org.uk/guidance/ng31> |
| 101 | SCM4 |  |  |  | Additional evidence  Health and Social Organisations in Hertfordshire work against a 5 step single carer pathway. The steps remain the same  throughout each organisations and what differs are the actions behind each step. This gives consistency for the carer as they transition though all services. Below is the pathway used at ENHT, and the Carers Policy also is linked to this.  Single Carer Pathway  All NHS health services in Hertfordshire are working towards a single carer pathway so that you can feel supported  and valued. The pathway is described below:  *(Carer Pathway co-produced by Hertfordshire Partnership University NHS Foundation Trust – 2016)* |
| 102 | The Challenging Behaviour Foundation | Key area for quality improvement 3:  Supporting adult carers through transition-Maintaining Care packages | *Family Carers should be empowered to care for their loved one while also being able to work, train or be in education with the help of an individual and tailored support package for their loved one.* | Families have told us they do not feel supported through transition into adult services well enough. Once under the provision of adult services family carers of people with learning disabilities and/or autism have experienced losing the right to be involved in decisions about their loved one’s life. Equally, where a care package has been working well to support their loved one, services choose to reduce the package, increasing the burden on family carers. In a climate of cuts, family carers have noticed that respite is one of the first forms of support to disappear (1) meaning it is harder to engage in work, training or education in the ways that NICE scope guidelines indicate (2), and therefore this must be reflected in the quality standards. | *Confronting a Looming Crisis,* Rachel Forrester Jones, University of Bath and Mencap New Forest, 2019 (<https://www.bath.ac.uk/publications/report-confronting-a-looming-crisis/attachments/Final_FullDocument.pdf>)  NICE Guideline Scope: Provision of support for adult carers: <https://www.nice.org.uk/guidance/ng150/documents/final-scope> |
| 103 | The Relatives & Residents Association | Key area for quality improvement 2:  The expectations placed on carers when relatives move into care | The care home sector is heavily reliant on the support of family members, who may have been full time carers until the person moved into the home. This is particularly the case for providers of care to local authority or NHS funded residents. For some carers, there is an expectation from staff that they will continue to provide some level of care.  Care providers and local authorities should consider the well-being of carers (protected by the right to respect for private life in the Human Rights Act) when planning a person’s care. | Examples of this include carers supporting residents to attend external health appointments, such as with audiologists or opticians, outpatient appointments or emergency trips to hospital.  Carers are often called to care homes at short notice to deescalate situations involving their relative. Carers often provide daily support during meal time, activities, or encourage residents with personal care.  There is also rarely back up for carers who, for whatever reason, find they can no longer continue to provide care at that level, leaving residents in a vulnerable position and carers with feelings of guilt or worry.  As stated above, preferred levels of involvement in care will vary from person to person. Some carers may not wish, or be able, to be involved to the same degree when a person they care for moves into a home. However, continued involvement of the carer in helping to provide care is rarely discussed with them and there is often an assumption they will be available to provide a level of support whether they have agreed to or not. | There are a range of reasons why a carer might be unable or unwilling to continue to provide care, including ill health, work commitments, other caring commitments, break-down in relationships etc. Carers often do not know who to speak to about stepping back from their caring role and often their concerns and needs are overlooked.  Below are a few examples from the R&RA Helpline to illustrate this:  A spouse, whose husband is active at night and is prone to accidents, feels she can longer get to the care home and drive him to hospital in the early hours of the morning. She did not know where to go to raise her concerns or find alternative options and felt pressured by the care home management who failed to plan how the resident might be supported if she was unable to support him.  A son who regularly visited his mother to support her during mealtimes as she was more able to accept food from him but still took 45 minutes to an hour to eat her meals. The son had mental health issues, including clinical anxiety, and felt under huge pressure to carry on even when he was exhausted. This was exacerbated when he was told that staff couldn’t spend that time with his mother. Again, there was little support for him and, despite supporting his mother and being supportive to staff, he was considered strange for providing that level of support and often treated by management as being in the way.  A sister of a resident who had been told that if she did not take her brother to his medical appointments, they could not guarantee that they would have staff available to do so.  The Kings Fund report below shows that better engagement with families was an important factor in implementing changes that led to providing enhanced health care for care home residents: <https://www.kingsfund.org.uk/sites/default/files/2017-11/Enhanced_health_care_homes_Kings_Fund_December_2017.pdf> (page 11) |
| 104 | The Relatives & Residents Association | Key area for quality improvement 3:  Support for carers of care home residents | We welcome the inclusion in the guidance of support for carers during difficult times. (1.7, 1.8. 1.9)  However, given that carers of people in care homes are frequently not recognised as such, they often do not receive this support.  Support for carers is particularly needed for those who may have had to give up caring, those who lose their relationship with the person they care for due to illnesses such as dementia, and for end of life care. | People rarely receive support to prepare them to become the carer of an older person – for many people this can happen quite suddenly, or can creep up on them and can take over many years of their life.  Carers can lose a sense of who they are when their loved one moves into care. This is particularly acute when a person moves into care at the end of their life and the carer finds themselves stripped of their role in the eyes of the care provider. This can have lasting effects on the carer’s wellbeing. Where a loved one dies in difficult circumstances, the emotional effect on carers can last a life time. | Our report Moving Stories, referenced above, highlights the impact on carers when those they care for are moved into care homes. As most are no longer seen as care partners, they can often not be privy to important information such as moving a resident on to palliative care, decisions to use medication to control behaviour etc.  We also hear of families being side-lined - by care providers and local authorities - when residents no longer recognise their relationship but remain comforted by their presence. We hear of statements such as ‘your mother doesn’t know who you are, so your relationship with her is no longer relevant’. This can have a significant emotional impact on carers and also fails to recognise how familiar carers can bring comfort to people with illnesses like dementia, long after they know who they are.  Below are a couple of examples from the R&RA Helpline to illustrate this:  A son who cared for his mother for several years found out she was on palliative care when he caught sight of her notes. However, he was prevented from speaking to the palliative care nurse or staff about it.  A spouse became concerned her husband was deteriorating and in pain in his mouth. The care home manager had threatened to ban her if she continued to raise concerns. We supported the spouse to arrange for a domiciliary dentist to visit. The dentist found a sharp broken tooth that he was able to file down while the palliative care team increased his pain relief and he died one week later.  There is evidence that involving carers ensures residents have a better experience and often are able to die in the location of choice, most often the care home, rather than find themselves moved to hospital in the last hours/days of life which can be distressing for all. A study by Jewish Care study in 2012 (<https://www.jewishcare.org/assets/000/000/296/elcad-report_original.pdf?1405347994>) found that by training staff to speak about end of life and plan it with residents and their families, the experience changed dramatically for families who felt supported and involved. It also helped staff to gain confidence in managing end of life care and saw a rise in residents receiving palliative care and dying in the care home. It found that when relatives are well supported through bereavement they experience less stress and the wishes of the resident are better catered for. |
| Support for carers during end of life care | | | | | |
| 105 | Newcastle City Council and partners | Key area for quality improvement 5  Support for carers during end of life care and after the person dies | This caring situation brings totally different stressors to ‘everyday’ caring and needs to be supported sensitively and appropriately | Professionals should involve and include carers at every stage, from diagnosis to death; Professionals should work in partnership with each other and combine discussions with carers around the practicalities of end of life situations e.g. finances, budgeting, additional support; an end of life coordinator should be appointed to support the family and the wishes of the patient; following death, carers should be offered referral to psychological and emotional support, GP intervention, bereavement services, peer support, community support; this offer should be flexible, fluid and not time limited. | Key area for quality improvement 5  Support for carers during end of life care and after the person dies |
| Additional areas – Care coordinator | | | | | |
| 106 | Multiple System Atrophy Trust | Key area for quality improvement 1  A professionally qualified keyworker who is responsible and accountable for co-ordination of support needs. This would include accountability for co- producing a carer plan. | Multiple System Atrophy is a progressive neurological condition which causes autonomic failure and a range of symptoms which need managing before death.  Given the range of issues such as mobility, communication, speech, choking, nutrition, palliative care and extreme fatigue that the person with MSA needs support with, plus the carers needs for support in managing these then there is a need for somebody to co-ordinate such support from different sources. In addition, there is a significant need for anticipatory care and somebody to reflect, plan and organise this before the situation(s) become crises.  This needs therefore, to be long term ongoing engagement. | There needs to be somebody who can support the carer and the person(s) they care for especially where there is help from various sources required. They need to take on a co-ordinating, holistic role, remaining in regular touch over time and not just focused on short term tasks. For people living with MSA this would ideally be a community matron or a rare neurological conditions nurse. This would greatly reduce the carers stress of taking full responsibility for the care related decisions. This is one of the things carers of people with MSA tell us time and again they wish they had. In some areas care navigators are used – these tend not to be professionally qualified and rarely do home visits so tend to be less effective. | <https://www.england.nhs.uk/rightcare/products/pathways/progressive-neurological-conditions-toolkit/>  Multiple System Atrophy survey of Former Carers 2019 currently unpublished due publication 21.2.2020 |
| 107 | The Brian Tumour Charity | Coordinated support by a CNS for everyone with a brain tumour diagnosis and their families, including those with low grade tumour diagnosis. | There is good evidence that coordinated support from a Clinical Nurse Specialist improves quality of life for people diagnosed with a brain tumour and their family.  When people do have access to a clinical nurse specialist, 74% say they are satisfied with the care they provide. However, those without a CNS or other single point of contact were: 1.5 times more likely to report a high symptom burden (43.6% compared with 29.1%); 1.6 times more likely to say that their brain tumour had severely affected their [emotional or mental health](https://www.thebraintumourcharity.org/living-with-a-brain-tumour/health-fitness/mental-health/) (30.7% compared with 19.6%); 2.7 times more likely to disagree they had good access to information on managing symptoms (46.1% compared with 17.1%); 4.7 times more likely to disagree that that the healthcare professionals they dealt with understood brain tumours (44% compared with 9.4%)  *Source: Finding myself in your hands The Brain Tumour Charity* | CNSs are guaranteed for high grade tumour patients but not for low grade tumour patients.  In our report [*Finding Myself in your Hands*](https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/)*: The Reality of Brain Treatment and Care* *(2016)* only 53% of people diagnosed with a [low grade tumour](https://www.thebraintumourcharity.org/brain-tumour-diagnosis-treatment/how-brain-tumours-are-diagnosed/how-brain-tumours-are-graded/) said that they had access to a dedicated keyworker or CNS. This compared to 76% of those diagnosed with a high grade brain tumour.  There are est. 81,000 people living with a low grade brain tumour diagnosis in the UK and est. 6,000 more are newly diagnosed with a low grade tumour each year. However, low grade brain tumour patients are not considered as having cancer. They have a so-called ‘benign’ or ‘non-cancerous’ tumour, although we know that many such tumours progress over time into higher grade malignant tumours, and we know that the symptoms and short- and long-term side effects of the tumour and of the treatment interventions are life changing for low grade tumours. We also know that people with low grade tumours live with this changed and impaired quality of life and cognitive, physical and emotional wellbeing for much longer.  For adults affected by a brain tumour diagnosis *(Unpublished Unmet needs survey The Brain Tumour Charity)*:-  When asked about their need for “Having a coordinated support plan and getting joined up help” there was a 55% gap between those saying this was important and those satisfied their need was met. | For evidence about the critical role of a CNS in coordinating care please see :  *Development of an Integrated Subspecialist Multidisciplinary Neurooncology Service* [*BMJ Qual Improv Rep*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4652738/)*. 2013* [*https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4652738/*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4652738/)  [*Finding Myself in your Hands*](https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/)*: The Reality of Brain Treatment and Care (2016)* [*https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/*](https://www.thebraintumourcharity.org/about-us/our-publications/finding-myself/)  *TheBrainTumourCharity unpublished unmet need survey 2019 (sample 216 people) available on request* |
| Additional areas – Financial support | | | | | |
| 108 | Multiple System Atrophy Trust | Key area for quality improvement 3  Financial recognition | Carers Allowance is £66.15 a week and carers must provide support for at least 35 hours per week. This is way, way below minimum wage and causes huge upset. Many retired people don’t even qualify for this. | Most people with MSA either have to give up work or are retired so are on fixed incomes. Carers will also usually have to give up work if they are in employment due to the significant care needs generated by this progressive neurological condition.  43% of Former Carers reported that they had had financial issues whilst caring for somebody with MSA, with 28% of them saying that they had had ongoing financial issues subsequent to their loved one’s death. (2 above supporting information) | See 1 and 2 above. |
| Additional areas – Joined up services | | | | | |
| 109 | Department of Health and Social Care | Services are joined up to reduce the need for the carer to repeatedly summarise a situation to each health and social care professional |  |  |  |
| Additional evidence identified | | | | | |
| 110 | SCM3 |  |  |  | [GP Patient Survey](https://www.gp-patient.co.uk/) 2019 found that carers were more likely to report having health problems compared with the general public, as was also found in the 2018 survey. Carers are more likely to report having a long-term condition, disability or illness – 63% of carers compared to 51% of non-carers. In addition, 63% of carers reported that their condition led to trouble with day to day activity compared to 58% of non-carers.  This difference was even higher for carers who care for more than 50 hours a week, 71% of whom reported having a long-term condition, disability or illness.  GPs are a key service within the community that many carers will interact with on a regular basis, whether for themselves or the person they care for. Carers responding to the GP Patient Survey were asked about their recent experiences with their own GP practice.  Overall 8 in 10 carers (81%) had a very or fairly good experience at their GP practice, for all patients this was 83% who had a very or fairly good experience. 11% of carers reported a neither good nor poor experience and 8% reported a poor experience.  For some carers, the services offered by their GP are difficult for them to access. Around 6% of carers declined the appointment offered to them by their GP. The most common reason for declining an appointment for both carers and non-carers was that there weren’t any appointments for the time or day they wanted. 26% carers didn’t see or speak to anyone after declining an appointment. 24% decided to contact the practice at another time, 14% got an appointment at a different time and 12% found information online. |
| 111 | SCM6 |  |  |  | [GP Patient Survey](https://www.gp-patient.co.uk/) 2019 found that carers were more likely to report having health problems compared with the general public, as was also found in the 2018 survey. Carers are more likely to report having a long-term condition, disability or illness – 63% of carers compared to 51% of non-carers. In addition, 63% of carers reported that their condition led to trouble with day to day activity compared to 58% of non-carers.  This difference was even higher for carers who care for more than 50 hours a week, 71% of whom reported having a long-term condition, disability or illness.  GPs are a key service within the community that many carers will interact with on a regular basis, whether for themselves or the person they care for. Carers responding to the GP Patient Survey were asked about their recent experiences with their own GP practice.  Overall 8 in 10 carers (81%) had a very or fairly good experience at their GP practice, for all patients this was 83% who had a very or fairly good experience. 11% of carers reported a neither good nor poor experience and 8% reported a poor experience.  For some carers, the services offered by their GP are difficult for them to access. Around 6% of carers declined the appointment offered to them by their GP. The most common reason for declining an appointment for both carers and non-carers was that there weren’t any appointments for the time or day they wanted. 26% carers didn’t see or speak to anyone after declining an appointment. 24% decided to contact the practice at another time, 14% got an appointment at a different time and 12% found information online. |

1. <https://www.employersforcarers.org/carer-confident> [↑](#footnote-ref-1)