

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Social care guidance scope

1 Guidance title

Social care of older people with more than one physical or mental health long-term condition

1.1 *Short title*

Older people with long-term conditions

2 Remit and background

The National Institute for Health and Care Excellence (NICE) has been asked by the Department of Health (DH) to develop social care guidance on older people with long-term conditions.

This guidance will provide action-orientated recommendations for good practice, aimed at improving outcomes for users of social care services and their families or carers. The guidance is based on the best available evidence of effectiveness, including cost effectiveness. It is relevant to service users, carers, communities, care providers (statutory and non-statutory), health and social care practitioners and commissioners (including people who purchase their own care).

This guidance will complement a range of NICE guidance on topics including, for example, dementia, diabetes, hypertension, mental wellbeing and older adults, and Parkinson's disease. For further details see section 5 (related NICE guidance).

3 The need for guidance

3.1 *Key facts and figures*

- 3.1.1 This scope defines a long-term condition as ‘one that cannot currently be cured but can be managed with the use of medication or other therapies. This is in contrast to acute conditions which typically have a finite duration’ (Royal College of General Practitioners 2011, page 9). Long-term conditions may also be known as ‘chronic conditions’ and ‘life limiting conditions’.
- 3.1.2 The prevalence of long-term conditions is strongly linked to ageing. Approximately 14% of people aged under 40 have a long-term condition, compared with 58% of people aged over 60 (DH 2012a). Although the number of people with one long-term condition is projected to be relatively stable in the coming years, the number of people with ‘multiple’ long-term conditions is projected to rise from an estimate of just over 2 million in 2013 to 2.9 million by 2018 (DH 2012b). Disability may be closely related to one or more long-term condition.
- 3.1.3 Rates of long-term conditions such as diagnosed coronary heart disease, diabetes, hypertension and musculoskeletal problems all increase substantially with age. Prevention, delaying onset and slowing the progression of long-term conditions are all important outcomes for older people who may go on to develop one or more long-term condition (DH 2012b). Other important outcomes include quality of life and positive experience related to independence, choice, dignity and control (National Dignity Council 2013).
- 3.1.4 There is an association between prevalence of long-term conditions and socioeconomic status. The least privileged in society have 60% higher prevalence of long-term conditions, and 30% higher severity of conditions than the most privileged (DH 2012b).

- 3.1.5 Having one or more long-term condition places people at greater risk of mental health problems, but services may not identify the need for assessment and treatment. Depression is 7 times more common in people with 2 or more chronic physical conditions than in those without a chronic condition. Depression in later life is strongly linked to physical ill health and disability, but only 10–12% of older people with poor physical health are treated for depression (National Development Team for Inclusion 2011). There is evidence that older people who have had a long-term mental health problem have poorer physical health outcomes than the general population (DH 2011). People are less likely to be able to self-manage a physical health condition if they also experience poor mental health.
- 3.1.6 The DH estimates that the average annual health and social care cost per person per year for a person without a long-term condition is £1000. This rises to £3000 for a person with 1 long-term condition, and to just under £6000 for a person with 2, and approximately £7800 for a person with 3. Around 70% of total health and care spend in England is attributed to caring for people with long-term conditions (DH 2012b).

3.2 Current practice

- 3.2.1 The prevalence of multiple long-term condition increases with age. However, there is evidence that older people can experience inequalities and discrimination when resources are being allocated and in terms of the diagnostic, care and support open to them (Clark 2009).
- 3.2.2 People with one or more long-term condition may have other conditions, including depression, which have not been recognised or treated. The impact and symptoms of long-term conditions, and the circumstances of a person who may need social care or is providing care to a family member, are also likely to fluctuate. Some relatively common and treatable problems, such as urinary

tract infections or incontinence, can result in unnecessary admission to hospital when proactive approaches could have avoided that. The regular assessment and review of care and support needs should help to maximise quality of life and make best use of resources.

- 3.2.3 People who use social care services want joined-up, coordinated services that address their needs holistically (National Voices 2012). However, for people with long-term conditions services can be fragmented, and those who need to rely on them often find that they are hard to access and that there are inadequate links between them (National Collaboration for Integrated Care and Support 2013). Improving the organisation and coordination of services is widely acknowledged as a vital means of improving the experience of patients and carers. For example, the NHS Mandate (DH 2012a, page 11) notes that ‘The challenge is to tackle practical barriers that stop services working together effectively’.
- 3.2.4 If social care and primary and secondary healthcare services work in collaboration with service users and carers they can improve the quality of care and quality of life for people with long-term conditions. However, existing approaches may not be configured to address physical and mental health needs and may not include social care services (National Collaboration for Integrated Care and Support 2013).
- 3.2.5 The typical care home resident is in their mid-80s or older, and has at least one long-term condition. Care homes for older people need strong support from health services, but there is evidence to suggest the support offered can vary considerably (Care Quality Commission 2012). Interviews conducted with care home managers and GPs (English Community Care Association 2008) report problems with access to care services and there is also evidence to suggest that mental health needs in particular are often

not addressed (British Geriatrics Society 2011; National Development Team for Inclusion 2011).

3.2.6 Against a policy background that consistently emphasises integrated and collaborative working, the issue of how health services can work in an integrated way with nursing and care home residents with long-term conditions may have been neglected (British Geriatrics Society 2011; Care Quality Commission 2012). National Voices note that people in care homes want the 'system' to offer 2 things:

- 'knowledge of the patient/service user/carer as a person
- knowledge of the relevant condition and all options to treat or manage ... including knowledge of all available support services' (National Voices 2012, page 2).

3.3 Policy

3.3.1 As well as setting minimum standards, government policy articulates the values that need to underpin care services. The NHS Mandate sets out the DH's ambitions for the health service (DH 2012). The document recognises that too many people with ongoing health problems are treated as a collection of symptoms and not as a person. The need to improve the quality of life of people with long-term conditions is identified as a key priority and the NHS Mandate proposes to support the empowerment of people to manage and make decisions about their own care. The Mandate also specifies a range of objectives, to be achieved by 2015, for improving the coordination and personalisation of care and support, both for people with long-term conditions and their carers.

3.3.2 In 2011 the DH published the national mental health strategy for people of all ages 'No health without mental health' (DH 2011). The strategy notes that depression is the most common mental health problem in older people, and that it is associated with social

isolation, long-term physical health problems, and living in residential care. These problems often go unnoticed and untreated.

3.3.3 Key policy documents relevant to England include:

- [The Adult Social Care Outcomes Framework 2013 to 2014.](#) Department of Health (2013)
- [Caring for Our Future: reforming care and support - white paper.](#) Department of Health (2012)
- [The Mandate: a mandate from the government to the NHS commissioning board April 2013 to March 2015.](#) Department of Health (2012)
- [Fulfilling and rewarding lives: the strategy for adults with autism in England.](#) Department of Health (2011)
- [Living well with dementia: a national dementia strategy.](#) Department of Health (2011)
- [No health without mental health: a cross-government mental health outcomes strategy for people of all ages.](#) Department of Health (2011)
- [A vision for adult social care: capable communities and active citizens.](#) Department of Health (2010)
- [Supporting people to live and die well: a framework for social care at the end of life.](#) National End of Life Care Programme (2010)
- [Raising the profile of long term conditions care: a compendium of information](#) Department of Health (2008)
- [Supporting people with long term conditions – An NHS and social care model to support local innovation and integration.](#) Department of Health (2005)
- [National Service Framework for Long Term Conditions.](#) Department of Health (2005)

3.4 *Legislation, regulation and guidance*

3.4.1 The draft Care and Support Bill (2013–14) incorporates many of the values and aspirations of policy concerning the care and support of people with long-term conditions. This includes the promotion of individual wellbeing, prevention strategies to avoid increasing need for care and support, the centrality of care planning and the need for integrated care services.

3.4.2 There is a range of guidance promoting personalised care of older people across different sectors. The mental health and wellbeing of older people is a particular concern. Evidence suggests that older people may not receive the same range and standard of care available to younger adults (Mental Health Foundation 2009).

3.4.3 Relevant legislation and guidance includes:

- [Commissioning for Carers](#). Royal College of General Practitioners (2013)
- [Dying well at home: the case for integrated working](#). Social Care Institute for Excellence (SCIE) (2013)
- [Making managed personal budgets work for older people](#). Age UK (2013)
- [Draft Care and Support Bill](#). HM Government (2012)
- [Social care and clinical commissioning for people with long-term conditions](#). SCIE (2011)
- [Age equality and age discrimination in social care](#). SCIE (2010)
- [Geriatricians and the management of long-term conditions](#). British Geriatrics Society (2010)
- [Promoting mental health and well-being in later life: a guide for commissioners of older people's services](#). Age UK (2010)
- [Achieving age equality in health and social care](#) Sir Ian Carruthers and Jan Ormondroyd for the Department of Health (2009)

4 What the guidance will cover

Social care guidance will be developed according to the processes and methods outlined in [The social care guidance manual](#). This scope defines exactly what the guidance will (and will not) examine and what the guidance developers will consider. The key areas that will be addressed by the guidance are described in the following sections.

4.1 *Who is the focus?*

4.1.1 **Groups that will be covered**

- Older people with social care needs and more than one long-term condition (including mental health conditions) and their carers.
- Older people who organise and/or fund their own care will be covered, in addition to those where care is organised and/or funded by the local authority.
- Protected characteristics under the Equality Act 2010 will be considered during scoping and guidance development.

4.1.2 **Groups that will not be covered**

- Older people who do not have social care needs.
- Younger adults.
- Children and young people.

4.2 *Setting(s)*

4.2.1 **Settings that will be covered**

- All community-based settings (including sheltered accommodation, extra-care housing and people's own homes).
- All residential and nursing care homes.
- Other settings or services in which a social care package is delivered.

4.2.2 **Settings that will not be covered**

- Inpatient or residential care provided in NHS settings.

4.3 Activities

4.3.1 Key areas that will be covered

- Personalised care and support provided to older people living with long-term conditions to improve quality of life and to sustain dignity and independence. Care that fully supports people and their carers including:
 - access to services and assessment of needs
 - care planning and review
 - support to self-manage their long-term conditions provided as part of a wider package of social care support.
- Integrated health and social care for older people with more than one long-term condition that fully involves service users and carers, for example:
 - interface between physical and mental healthcare
 - different models of inter-professional working that can be shown to improve outcomes for service users and carers
 - care coordination (teams, protocols, navigator roles)
 - multidisciplinary or primary care reviews involving social care practitioners
 - training of care staff to recognise and respond appropriately to common treatable conditions, such as depression, continence problems and urinary tract infections.
- The use of packages of care and support (including those provided by the voluntary and community sector) to promote social participation for older people with long-term conditions.
- Support for carers of older people with social care needs and more than one long-term condition.

4.3.2 Areas that will not be covered

- Clinical teams with no social care element, or no element of joint working with social care staff.
- Efficacy of healthcare interventions.

- The organisation of homecare (or domiciliary care) services (this will be covered in detail in the NICE guidance on homecare that is under development).
- Transitions and transition planning between hospital and community or care home settings (this will be covered in detail in the NICE guidance on transition between health and social care that is under development). However, because transitions between hospital and community or care home settings are an important issue for older people with long-term conditions, we will necessarily cross reference to this topic, ensuring that any overlap is justifiable and consistent.

4.4 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence relate primarily to the experience of older people with more than 1 long-term condition, their carers and families. This will include:

- user and carer experience, views and levels of satisfaction
- choice, control and dignity for service users
- quality and continuity of care
- outcomes relating to maximising independence
- measures of social support and effects on social isolation and loneliness.
- service user quality-of-life outcomes (measured for example by the EQ-5D and ASCOT, and measures of mental wellbeing)
- preventative effects such as delaying the onset of, and slowing the progression of, long-term conditions
- residential care admissions
- hospital admissions including unplanned admissions
- mortality
- safety and adverse effects
- resource use and impact on other services.

4.5 Review questions

Review questions guide a systematic review of the literature. They address only the key issues covered in the scope, and usually relate to interventions,

service delivery or user and carer experience. The review questions will be used to explore evidence to consider how the outcomes which are important to users and carers (listed in section 4.4 above) can be improved. Some possible review questions are:

- What is the experience of people with long-term conditions and their carers of the social care and integrated health and social care they receive? What needs to change?
- Which new or established organisational models of integrated and personalised care offer the best outcomes, including wellbeing, for older people with more than one long-term condition?
- Which approaches to assessment and care planning deliver the best outcomes for service users and carers?
- How effective are different types of support for older people to enable them to self-manage (aspects of) their own conditions?
- How can staff be assisted or trained to recognise and manage common conditions such as depression, incontinence and urinary tract infections?
- How can we support older people with long-term conditions living in the community or in residential care to participate in community, family and social activities, and what is their effect on wellbeing?
- How should services work with and support carers of people with long-term conditions (who may have long-term conditions themselves)?

Please note these are only examples of areas that may be addressed. The review questions will be specified by the Guidance Development Group after consultation on the scope.

4.6 Economic aspects

Developers will take into account cost effectiveness when making recommendations involving a choice between alternative interventions or services. Appropriate economic review questions will be identified. A review of the economic evidence will be undertaken in line with the methods outlined in [The social care guidance manual](#). Economic analysis, if undertaken, will

consider all relevant commissioners, decision-makers, funders, providers, service users and carers that are relevant to the economic review question.

The following cost drivers for long-term conditions will influence the scope and method of economic analysis (Davies and Fernandez 2000; Mottram et al. 2007; Windle et al. 2011; Naylor et al. 2012):

- setting in which care is provided
- severity or complexity of long-term needs as reflected in reduced functioning and impairments
- provision of unpaid care
- social isolation (linked to depression and mortality)
- comorbidity
- potential preventative effects of social care interventions.

There is variation in support offered and service use between individuals. This suggests that the analysis should focus on long-term conditions most associated with the use of social care (such as dementia, depression, musculoskeletal conditions and stroke). There is very limited UK literature that discusses the social care costs of long-term conditions.

We will consider (sets of) interventions which prevent or delay the onset of long-term conditions including earlier diagnoses, as well as those which reduce the negative consequences of living with a long-term condition to the older person, their carers and families. This includes personalised interventions and those that help older people to participate in their communities more actively.

The social care sector is increasingly responsible for the provision of community initiatives that support older people (including those with long-term conditions) to live independently. This area may become the focus of an economic analysis, subject to the availability of appropriate economic evidence, and subject to the economic review questions identified by the Guidance Development Group.

4.7 Status of this document

4.7.1 Scope

This is the consultation draft of the scope. The consultation dates are 15 October to 12 November 2013.

4.7.2 Timing

Following consultation on the draft scope, the final scope will be published on 20 December 2013 and guidance development will then formally commence in January 2014. The final guidance is scheduled to be published in September 2015.

5 Related NICE guidance

5.1 Published guidance

A range of NICE clinical and public health guidance relating to long-term conditions has been published. The selection listed here relate specifically to long-term conditions that occur most frequently among older people (see section 3.1.3).

- [Hypertension](#). NICE clinical guideline 127 (2011)
- [Chronic heart failure: management of chronic heart failure in adults in primary and secondary care](#). NICE clinical guideline 108 (2010)
- [Depression with a chronic physical health problem](#). NICE clinical guideline 91 (2009)
- [Rheumatoid arthritis](#). NICE clinical guideline 79 (2009)
- [Mental wellbeing and older people](#). NICE public health guidance 16 (2008)
- [Type 2 diabetes](#). NICE clinical guideline 66 (partially updated by CG87) (2008)
- [Osteoarthritis](#). NICE clinical guideline 59 (2008)
- [Dementia](#). NICE clinical guideline 42 (2006)
- [Parkinson's disease](#). NICE clinical guideline 35 (2006)

5.2 *Guidance under development*

NICE is currently developing the following related guidance (details available from the NICE website):

- [Homecare](#). NICE social care guidance. Publication expected July 2015.
- [Transition between health and social care](#). NICE social care guidance. Publication expected November 2015.
- [Multimorbidities: system integration to meet population needs](#). NICE public health guidance. (Publication date tbc).

The titles and schedules for the following topics are still to be confirmed:

- Assessment, prioritisation and management of care for people with commonly occurring multi morbidities. NICE clinical guideline. (Publication date tbc).
- Service design of care for people with commonly occurring multi morbidities. NICE clinical guideline. (Publication date tbc).

5.3 *NICE Pathways*

[Mental wellbeing and older people pathway](#).

6 Further information

Information on the guidance development process is provided in [The social care guidance manual](#), available from the NICE website. Information on the progress of the guidance will also be available on the [NICE website](#).

7 References

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Mottram P, Pitkala K, Lees C (2007) [Institutional versus at-home long term care for functionally dependent older people](#). Cochrane Database of Systematic Reviews 2007 issue 4: CD003542

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Naylor J, Galea A, Parsonage M et al. (2012) [Long-term conditions and mental health: the cost of co-morbidities](#). London: The King's Fund

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