

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Carers: provision of support for adult carers

The Department of Health in England has asked NICE to develop a guideline about supporting adult carers.

The guideline will be developed using the methods and processes outlined in [Developing NICE guidelines: the manual](#).

This guideline will also be used to develop the NICE quality standard for supporting adult carers.

1 Why the guideline is needed

Caring for someone can take its toll on a person's health and wellbeing. The 2011 Census indicated that there were around 6.5 million unpaid carers in the UK (with 1.3 million being over 65): this figure is rising.

In the UK, the number of people over 85 (the group most likely to need care) is expected to increase to 1.9 million by 2020 (Office for National Statistics). Carers UK (2015) estimates that the number of people caring for someone will increase to 9 million by 2037. In a survey conducted by Dying Matters, 70% of people expressed a wish to stay in their own home, and to die at home. Guidelines on supporting carers are therefore urgently needed.

According to Carers UK (2015), unpaid care is estimated to be worth about £132 billion in terms of savings to health and social care budgets. However, carers may have to give up paid employment, which affects both their own independence and wellbeing and their economic 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. Support from paid care workers at home can ease this pressure, but it may not always be appropriate or affordable.

The amount and quality of support available to unpaid carers varies widely across the UK. High quality and consistent care and support benefits 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 facilitate timely discharge.

Many carers do not think of themselves as carers, or are not identified by health and social care professionals as such (so called 'hidden carers') and do not know about the support available.

The [Care Act 2014](#) has substantially strengthened the rights and recognition of adult carers within the social care system. It defines a carer as an adult, aged 18 or over, who provides, or intends to provide, care for another adult who needs care. It excludes those who provide paid care or do so as voluntary work.

The Care Act 2014 gives unpaid carers specific rights to personal budgets, direct payments, information and advice, assessment and support to maintain their health and wellbeing. However, only a small proportion (in one area estimated as 7%) are identified as unpaid carers by social care and health bodies, and so many are missing out on help and support.

This guideline will provide action-oriented recommendations for good practice, aimed at improving outcomes for adult carers. It will identify good practice in providing support that enhances the wellbeing, resilience and life experience of adult carers.

The guideline will be based on the best available evidence of effectiveness, including cost effectiveness. It will refer to other relevant NICE guidelines (including those on end of life care), the [Children and Families Act 2014](#), NHS England's [Carers' toolkit](#), the latest National Carers' Strategy, the Department of Health's [Care and Support Statutory guidance](#) (issued under the Care Act 2014).

NICE guidelines provide recommendations on what works. This may include details on who should carry out interventions and where. NICE guidelines do not routinely describe how services are funded or commissioned, unless this has been formally requested by the Department of Health.

2 Who the guideline is for

This guideline is for:

- Adult carers aged 18 years or over of people aged over 16 years, with ongoing health and social care needs
- Local authorities and clinical commissioning groups that provide or commission support and information for adult carers and people receiving care
- People responsible for assessing and planning local services
- Providers of health and social care services that support and give information to adult carers and people receiving care, including:
 - Primary care (including GPs)
 - Secondary and tertiary care (including acute and mental health trusts and residential care)
 - Emergency services
 - Community and voluntary organisations supporting adult carers
- Social care and health practitioners (including personal assistants) working with adult carers.

It will also be relevant to:

- People using health and social care services

- Families of adult carers
- Advocates of people using health and social care services
Practitioners working in other related services, including employers of carers, education, housing, leisure, job centres and welfare advice services.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#).

Equality considerations

NICE has carried out [an equality impact assessment](#) during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will consider inequalities relating to gender, older carers (including frail elderly), young adult carers (aged 18 to 25), lesbian, gay, bisexual and transgender (LGBT) carers, carers from black, Asian and minority ethnic groups, carers who are disabled and carers with long-term health conditions.

3 What the guideline will cover

3.1 Who is the focus?

Groups that will be covered

Adult carers, aged 18 or over, who provide unpaid care for 1 or more people aged 16 years or over with health and social care needs

Specific consideration will also be given to the following carers:

- older carers (including frail elderly)
- those caring for more than 1 person

- those who are also receiving care from the person they are caring for (mutual caring)
- those caring at a distance or not living with the person they are caring for (remote carers).

Groups that will not be covered

- People paid for providing care.
- People providing care as part of voluntary work.
- Young carers (aged 17 or under), except in relation to whole family assessments.
- Adults who care for children under 16 with health and social care needs, except in relation to whole family assessments.

3.2 Settings

Settings that will be covered

People's own homes and health and social care settings in which adult carers provide unpaid care and support to 1 or more adults with health and social care needs.

3.3 Activities, services or aspects of care

Key areas that will be covered

- 1 Identifying carers as defined by the Care Act 2014 (including hidden carers).
- 2 Providing information and advice for carers (for example, about personal budgeting, housing, planning and coordinating care, looking after their own health and self-care).
- 3 Assessment of carers as defined by the Care Act 2014, including whole family assessments and planning for the caring role (including planning in a crisis).
- 4 Support and advice to help adult carers to enter, remain in or return to work, education or training.
- 5 Training carers to provide practical support to the person receiving care (including, training in managing medicines, personal care, moving and

- handling, use of aids and adaptations, use of digital and assistive technology).
- 6 Providing practical social and community support interventions for carers, including supporting communication with health and social care professionals; providing respite care and breaks from caring responsibilities; supporting access to local carers' groups and networks.
 - 7 Providing psychological and emotional support and interventions for carers.
 - 8 Providing support for carers who are caring for people at the end of life.
 - 9 Supporting carers during changes to the caring role, when caring needs fluctuate, when a person moves to another setting, or when a younger person being cared for enters adulthood.

Related NICE guidance

Published

- [Care of dying adults in the last days of life](#) (2015) NICE guideline 31
- [End of life care for adults](#) (2017) NICE quality standard 13
- [Mental health problems in people with learning disabilities: prevention, assessment and management](#) (2016) NICE guideline 54
- [Social care for older people with multiple long-term conditions](#) (2016) NICE quality standard 132
- [Transition between inpatient mental health settings and community or care home settings](#) (2016) NICE guideline 53
- [Older people: independence and mental wellbeing](#) (2015) NICE guideline 32
- [Older people with social care needs and multiple long-term conditions](#) (2015) NICE guideline 22
- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs](#) (2015) NICE guideline 27
- [Dementia: supporting people with dementia and their carers in health and social care](#) (2006) NICE guideline CG42

In development

- People's experience in adult social care services: improving the experience of care for people using adult social care services. NICE guideline. Publication expected February 2018
- [Dementia: assessment, management and support for people living with dementia and their carers](#). NICE guideline. Publication expected June 2018
- [Decision making and mental capacity](#). NICE guideline. Publication expected July 2018
- [End of life care for adults in the last year of life: service delivery. NICE guideline](#). Publication expected July 2018. NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to supporting adult carers:

- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- [Service user experience in adult mental health](#) (2011) NICE guideline CG136
- [Medicines adherence](#) (2009) NICE guideline CG76
- [Medicines optimisation](#) (2015) NICE guideline NG5

3.4 *Economic aspects*

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS, an individual or societal perspective, as appropriate.

3.5 *Key issues and draft questions*

- 1 Identifying carers as defined by the Care Act 2014 (including hidden carers).

- 1.1 What interventions, tools and approaches are effective and cost effective for identifying carers?
- 2 Providing information and advice for carers (for example, about personal budgeting, housing, planning and coordinating care, looking after their own health or self-care).
 - 2.1 What are the views and experiences of adult carers and of health, social care and other practitioners regarding how information and advice is provided?
- 3 Assessment of carers as defined by the Care Act 2014, including whole family assessments and planning for the caring role (including planning in a crisis)
 - 3.1 What interventions, tools and approaches are effective and cost effective for carrying out carers' assessments, for planning and for record keeping?
 - 3.2 What assessments and reviews are helpful for developing and reviewing carer support plans?
- 4 Support and advice to help adult carers to enter, remain in and return to work, education or training
 - 4.1 What interventions, tools and approaches are effective and cost effective in supporting adult carers to enter, remain in and return to work, education or training?
- 5 Training carers to provide practical support to the person receiving care (including, training in managing medicines, personal care, moving and handling, use of aids and adaptations, use of digital and assistive technology).
 - 5.1 What interventions (including educational interventions) are effective and cost effective for training adult carers to provide practical support to the person receiving care, including:
 - managing medicines,
 - personal care,
 - moving and handling,
 - use of aids and adaptations,
 - use of digital and assistive technology.

- 5.2 What are the views and experiences of both adult carers, health, social care and other practitioners regarding the types of training for practical support that are useful in relation to the caring role?
- 6 Providing practical, social and community support for carers, including communication with health and social care professionals; providing respite care and breaks from caring responsibilities; supporting access to local carers' groups and networks.
- 6.1 What are the most effective and cost effective forms of social and community support interventions for adult carers that include:
- effective communication with health and social care professionals
 - types of respite care and breaks
 - how to access local carers' groups and networks
 - how to improve their health and wellbeing.
- 6.2 What are the views and experiences of adult carers and health, social care and other practitioners regarding the forms of practical, social and community support interventions (including respite care) that are useful?
- 7 Providing psychological and emotional support and interventions for carers.
- 7.1 What psychological interventions are effective and cost effective for maintaining resilience and improving the health and wellbeing of adult carers?
- 7.2 What are the views and experiences of adult carers and health, social care and other practitioners regarding the forms of psychological and emotional support that are useful?
- 8 Providing support for carers who are caring for people at the end of life
- 8.1 What are the needs of adult carers who are caring for people at the end of life, and after the person dies?
- 9 Supporting carers during changes to the caring role, when caring needs fluctuate, when a person moves to another setting, or when a younger person being cared for enters adulthood.

9.1 What is the effectiveness and cost effectiveness of specific interventions for preparing and supporting adult carers during changes to the caring role?

3.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

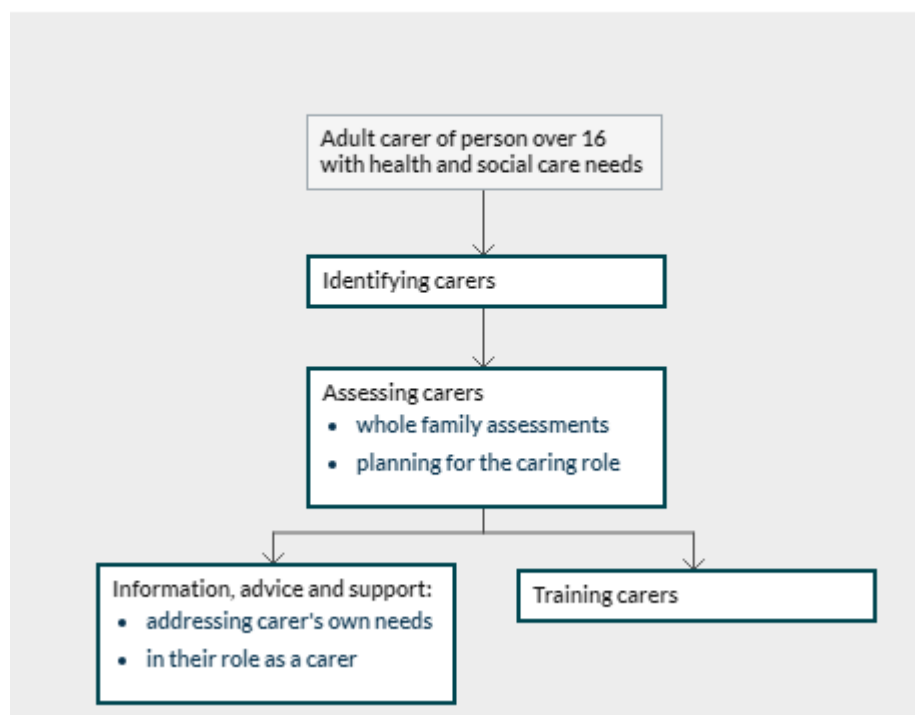
- 1 Impact of caring on the carer (including the physical, psychological, emotional, social and financial stresses that carers experience). This can be measured using validated measures of impact.
- 2 Carer skills (including coping strategies, response to disruptive behaviour and knowledge of caring).
- 3 Carer mental health (including psychological wellbeing, depression and anxiety).
- 4 Morbidity related to caring (including measures of safety and adverse events).
- 5 Quality of life of the carer, including maintaining healthy relationships. This can be measured using Adult Social Care Outcomes Toolkit (ASCOT) or other suitable quality of life measures.
- 6 The impact of place of care on the carer's health and wellbeing.
- 7 Carer experience, views and levels of satisfaction.
- 8 Economic outcomes (including resource use and impact on other services).

4 NICE quality standards and NICE Pathways

[NICE Pathways](#) bring together everything we have said on a topic in an interactive flowchart. When this guideline is published, the recommendations will be included in the NICE Pathway on adult carers (in development).

An outline based on this scope is included below. It will be adapted and more detail added as the recommendations are written during guideline development.

Adult carers overview



5 Further information

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in July 2019.

You can follow progress of the [guideline](#).

Our website has information about how [NICE guidelines](#) are developed.