

# 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**

The 2011 Census indicated that there were around 6.5 million unpaid carers in the UK (with 1.3 million being over 65); the figure is rising. Caring for a loved one, although often acknowledged as a privilege, can take its toll on health and wellbeing.

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 estimates that the number of carers needed 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 their independence and wellbeing, but also reduces payment of taxes and may affect the productivity of their former employers.

28 Carers may also give up other activities and may face isolation. Unpaid carers  
29 report feelings of depression and a reduced quality of life. Professional (paid)  
30 support at home can ease this pressure, but may not always be appropriate.

31 The amount and quality of support available to unpaid carers varies widely  
32 across the UK. A high quality accessible and consistent service benefits the  
33 health, wellbeing and resilience of unpaid carers. It can also enhance the life  
34 of the person being supported and help to reduce admissions to hospital and  
35 facilitate timely discharge. Supporting unpaid carers can also reduce  
36 dependence on professional social care and health services.

37 Many carers do not identify themselves as being in a caring role ('hidden  
38 carers') and do not know about the support available. This can have a  
39 negative impact on their physical and mental wellbeing.

40 The [Care Act 2014](#) has strengthened the rights and recognition of carers  
41 within the social care system. It describes a carer as an adult, aged 18 or  
42 over, who provides or intends to provide care for another adult needing care.  
43 This excludes people providing paid care or people providing care as  
44 voluntary work.

45 Although the Care Act 2014 gives unpaid carers specific rights to assessment  
46 and support of their own needs, only a small proportion (in one area estimated  
47 as 7%) are identified as carers by social care and health bodies, and so many  
48 are missing out on services.

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

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

57 of Health's [Care and Support Statutory guidance](#) (issued under the Care Act  
58 2014).

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

## 63 **2 Who the guideline is for**

64 This guideline is for:

- 65 • Adult carers of people with health and social care needs.
- 66 • Local authorities and clinical commissioning groups that provide or  
67 commission support and information for adult carers and people receiving  
68 care.
- 69 • People responsible for assessing and planning local services.
- 70 • Providers of health and social care services that support and give  
71 information to adult carers and people receiving care, including:
  - 72 – Primary care (including GPs)
  - 73 – Secondary care (including acute and mental health trusts)
  - 74 – Emergency services
  - 75 – Community and voluntary organisations supporting adult carers
- 76 • Social care and health practitioners (including personal assistants) working  
77 with adult carers

78 It will also be relevant to:

- 79 • People using health and social care services
- 80 • Families of adult carers
- 81 • Advocates of people using health and social care services
- 82 • Practitioners working in other related services, including:
  - 83 – employers of carers, education, housing, leisure, job centres and welfare  
84 advice services.

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

## 88 ***Equality considerations***

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

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

93 The guideline will look at inequalities relating to gender, older carers, young  
94 adult carers (aged 18 to 25), lesbian, gay, bisexual and transgender (LGBT)  
95 carers, carers from black, Asian and minority ethnic groups, carers who are  
96 disabled and carers with long-term health conditions.

## 97 **3 What the guideline will cover**

### 98 **3.1 Who is the focus?**

#### 99 **Groups that will be covered**

100 Adult carers, aged 18 or over, who provide unpaid care for 1 or more adults  
101 with health and social care needs.

102 Specific consideration will be given to those caring for more than one person  
103 and to those who are also receiving care from the person they are caring for  
104 (mutual caring).

#### 105 **People receiving care**

106 Adults with health and social care needs, including people with sensory,  
107 cognitive or physical impairments, mental health conditions, substance  
108 misuse, learning disability, dementia and other complex, long-term conditions,  
109 and people at the end of life.

110 Young people aged 16 or over who need continuing care from an adult carer.

## 111 **Groups that will not be covered**

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

## 118 **3.2 Settings**

### 119 **Settings that will be covered**

120 All health and social care settings (including people's own homes) in which  
121 adult carers provide unpaid care and support to 1 or more adults with health  
122 and social care needs.

## 123 **3.3 Activities, services or aspects of care**

### 124 **Key areas that will be covered**

- 125 1 Identifying carers as defined by the Care Act 2014 (including hidden  
126 carers).
- 127 2 Providing information and advice for carers (for example, about planning  
128 and coordinating care).
- 129 3 Assessment of carers as defined by the Care Act 2014, including whole  
130 family assessments and planning for the caring role (including planning  
131 in a crisis).
- 132 4 Support and advice to help adult carers to enter or to remain in work,  
133 education or training.
- 134 5 Training carers to provide practical support to the person receiving care  
135 (for example, training in personal care, moving and handling).
- 136 6 Providing practical support and interventions for carers, including aids  
137 and adaptations; supporting communication with health and social care  
138 professionals; providing respite care and breaks from caring  
139 responsibilities.

- 140 7 Providing social and community support interventions for carers,  
141 including support through local carers' groups and networks.
- 142 8 Providing psychological and emotional support and interventions for  
143 carers.
- 144 9 Providing support for carers who are caring for people at end of life.
- 145 10 Supporting carers during transitions (e.g. during admission to hospital,  
146 relocation to a care home, transition to adulthood), when caring  
147 requirements fluctuate and after caring has finished.
- 148

## 149 **Related NICE guidance**

### 150 ***Published***

- 151 • [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31
- 152 • [End of life care for adults](#) (2017) NICE quality standard 13
- 153 • [Mental health problems in people with learning disabilities: prevention,](#)  
154 [assessment and management](#) (2016) NICE guideline 54
- 155 • [Social care for older people with multiple long-term conditions](#) (2016) NICE  
156 quality standard 132
- 157 • [Transition between inpatient mental health settings and community or care](#)  
158 [home settings](#) (2016) NICE guideline 53
- 159 • [Older people: independence and mental wellbeing](#) (2015) NICE guideline  
160 32
- 161 • [Older people with social care needs and multiple long-term conditions](#)  
162 (2015) NICE guideline 22
- 163 • [Transition between inpatient hospital settings and community or care home](#)  
164 [settings for adults with social care needs](#) (2015) NICE guideline 27
- 165 • [Dementia: supporting people with dementia and their carers in health and](#)  
166 [social care](#) (2006) NICE guideline CG42

### 167 ***In development***

- 168 • People's experience in adult social care services: improving the experience  
169 of care for people using adult social care services. NICE guideline.  
170 Publication expected February 2018

- 171 • [Dementia: assessment, management and support for people living with](#)  
172 [dementia and their carers](#). NICE guideline. Publication expected June  
173 2018.
- 174 • [Decision making and mental capacity](#). NICE guideline. Publication  
175 expected July 2018

### 176 **NICE guidance about the experience of people using NHS services**

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

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

### 185 **3.4 Economic aspects**

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

### 192 **3.5 Key issues and draft questions**

- 193 1 Identifying carers as defined by the Care Act 2014 (including hidden  
194 carers).
- 195 1.1 What interventions, tools and approaches are effective and cost  
196 effective for identifying carers?
- 197 2 Providing information and advice for carers (for example, about planning  
198 and coordinating care).

- 199 2.1 What are the views and experiences of adult carers and of health,  
200 social care and other practitioners about how information and advice is  
201 provided?
- 202 3 Assessment of carers as defined by the Care Act 2014, including whole  
203 family assessments and planning for the caring role (including planning  
204 in a crisis)
- 205 3.1 What interventions, tools and approaches are effective and cost  
206 effective for carrying out carers' assessments and for planning?
- 207 3.2 What assessments are helpful for developing and reviewing a carer's  
208 plan?
- 209 4 Support and advice to help adult carers to enter or remain in work,  
210 education or training
- 211 4.2 What interventions, tools and approaches are effective and cost  
212 effective in supporting adult carers to enter or remain in work, education  
213 or training?
- 214 5 Training carers to provide practical support to the person receiving care  
215 (for example, training in personal care, moving and handling).
- 216 5.1 What interventions (including educational interventions) are effective  
217 and cost effective for training adult carers to provide practical support to  
218 the person receiving care (for example, personal care, moving and  
219 handling)?
- 220 6 Providing practical support for carers.
- 221 6.1 What is the most effective and cost effective form of delivering  
222 respite care, to provide flexible carer breaks and respond to the  
223 individual needs of adult carers and the people they are caring for?
- 224 6.2 What are the views and experiences of adult carers and of health,  
225 social care and other practitioners about the forms of practical support  
226 that are useful?
- 227 7 Providing social and community support for carers, including support  
228 through local carers' groups and networks.
- 229 7.1 What social and community support interventions are effective and  
230 cost effective for improving the health and wellbeing of adult carers?



- 231 7.2 What are the views and experiences of adult carers and of health,  
232 social care and other practitioners about the forms of social and  
233 community support that are useful?
- 234 8 Providing psychological and emotional support for carers.  
235 8.1 What psychological interventions are effective and cost effective for  
236 improving health and wellbeing of adult carers?  
237 8.2 What are the views and experiences of adult carers and of health,  
238 social care and other practitioners about the forms of psychological and  
239 emotional support that are useful?
- 240 9 Providing support for carers who are caring for people at the end of life  
241 9.1 What are the needs of adult carers who are caring for people at the  
242 end of life, and after the person dies?
- 243 10 Supporting carers during transitions, when caring requirements fluctuate  
244 and after caring has finished.  
245 10.1 What is the effectiveness and cost effectiveness of specific  
246 interventions for preparing and supporting adult carers during transitions,  
247 when caring needs fluctuate, when person moves to another setting or  
248 when younger person or carer enters adulthood?

### 249 **3.6 Main outcomes**

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

- 252 1 Impact of caring on the carer (including the physical, psychological,  
253 emotional, social and financial stresses that carers experience). This can  
254 be measured using the Burden Inventory, the Caregiver Burden  
255 Inventory and other validated burden measures.
- 256 2 Carer competency (including coping strategies, response to disruptive  
257 behaviour and knowledge of caring).
- 258 3 Carer mental health (including psychological wellbeing, depression and  
259 anxiety).
- 260 4 Morbidity related to caring (including measures of safety and adverse  
261 events).

- 262 5 Quality of life of the carer, including maintaining healthy relationships.  
263 This can be measured using the Adult Social Care Outcomes Toolkit  
264 (ASCOT) or the Adult Social Care Outcomes Framework (ASCOF).  
265 6 The person receiving care staying in their preferred place of care.  
266 7 Carer experience, views and levels of satisfaction.  
267 8 Economic outcomes (including resource use and impact on other  
268 services).

#### 269 **4 NICE quality standards and NICE Pathways**

270 There are no NICE quality standards or NICE pathways identified at scoping  
271 to be updated

#### 272 **5 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 25 April to 24 May 2017.

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.

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