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# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Guideline

### Supporting adult carers

Draft for consultation, August 2019

**This guideline covers** support for adults (aged 18 or over) who provide unpaid care for anyone aged over 16 with health and social care needs. It aims to help people recognise themselves as a carer and understand their right to information and support. It covers identifying and assessing carers, as well as providing information and practical, emotional and social support and training. It includes support during end of life care.

This guideline covers principles that apply to all adult carers. Recommendations about supporting carers who are caring for people with specific health needs can be found in NICE guidance on those topics.

#### Who is it for?

- Local authorities, clinical commissioning groups and other organisations that assess, plan, and commission local services or provide support and information for adult carers and people receiving care
- Providers of health and social care services, including:
  - Social care providers
  - Primary care (including GPs)
  - Hospital and community care (including acute and mental health trusts and residential care)
  - Emergency services
  - Community and voluntary organisations

- Health and social care practitioners (including personal assistants) working with adult carers
- Adults who provide unpaid care for one or more people aged 16 or over with health and social care needs
- People using health and social care services and members of the public

This draft guideline contains:

- the draft recommendations
- recommendations for research
- rationale and impact sections that explain why the committee made the recommendations and how they might affect practice.
- the guideline context.

Information about how the guideline was developed is on the [guideline's page](#) on the NICE website. This includes the evidence reviews, the scope, and details of the committee and any declarations of interest.

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## 1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

### 2 **1.1 Information and advice**

3 1.1.1 Local authorities must provide information to [carers](#) to support them in  
4 their caring role, in line with the [Care Act 2014](#).

5 1.1.2 Practitioners in health and social care (including healthcare professionals  
6 in primary and secondary care, social care practitioners, care and support  
7 workers and personal assistants) should use every opportunity to tell  
8 carers they have a right to information and support, explain what services  
9 are available and how to access them.

10 1.1.3 Information should be up to date and cover a wide range of services and  
11 advice, for example:

- 12 • statutory [carers' assessments](#)
- 13 • breaks from caring
- 14 • support for the carer's own health and wellbeing, including self-care
- 15 • caring and wider family relationships
- 16 • financial, benefits and legal issues
- 17 • caring and employment, including how to request flexible working  
18 patterns
- 19 • caring and education
- 20 • advocacy for carers
- 21 • planning the future care for the person they care for

- 1           • practical support such as equipment and adaptations at home, and help  
2           with transport
- 3           • planning for an emergency
- 4           • where to find social and emotional support, for example support groups  
5           and carer forums.
- 6   1.1.4    Tell carers where they can find local carer services, for example carer  
7           information centres or community voluntary sector organisations. Also  
8           explain that carer groups and forums can be a valuable source of  
9           information and support.
- 10   1.1.5    Work closely with carers and treat them as a valued member of the care  
11           team for the person they care for.
- 12   1.1.6    When discussing with carers the health condition, disability or needs of  
13           the person they are caring for:
- 14           • share specific information that carers need to be able to provide care  
15           while respecting confidentiality
- 16           • explain to carers the constraints of confidentiality
- 17           • take into account the mental capacity of the person being cared for and  
18           their wishes around confidentiality (see NICE's guideline on [decision](#)  
19           [making and mental capacity](#)).

To find out why the committee made the recommendations on information and advice and how they might affect practice see [rationale and impact](#).

## 20   **How to provide information and advice**

- 21   1.1.7    Take into account that carers' information needs will change over time  
22           and whenever their circumstances or caring role change. Provide  
23           information and advice that addresses the carer's individual needs at the  
24           time when they need it and that helps them plan and prepare.

- 1 1.1.8 Provide the same information to a carer several times if needed, for  
2 example if the information is complicated, the carer is experiencing  
3 emotional stress or if they request it.
- 4 1.1.9 Tailor information to carers' individual needs and preferences, including  
5 their communication needs, cultural preferences, how they prefer to  
6 receive information (for example, in particular formats or other languages)  
7 or if there are any accessibility considerations (for example, how to have  
8 discussions if they have difficulty attending face-to-face appointments).
- 9 1.1.10 For further guidance about making information accessible, see NICE's  
10 guideline on [people's experience in adult social care services](#)
- 11 1.1.11 Give information to carers in person along with written material to take  
12 away. When providing information:
- 13 • ensure it is plainly worded, clearly presented and free of jargon
  - 14 • be aware that smaller, more manageable chunks of information are  
15 easier to remember and that visual aids or pictures can be useful
  - 16 • give the carer opportunities to ask questions
  - 17 • ensure that information is consistent and coherent.
- 18 1.1.12 Practitioners responsible for providing and discussing information with  
19 carers should have the knowledge, time and communication skills to do  
20 so.
- 21 1.1.13 Communicate openly and honestly with carers about the health condition,  
22 disability or needs of the person they care for (with the person's consent)  
23 to help them plan and prepare for any future changes.
- 24 1.1.14 Primary care providers should explore ways of offering and promoting  
25 services to carers, including through partnership working (for example  
26 with carer support services). This could include, for example, GP  
27 surgeries offering carers follow-up appointments with a surgery-based  
28 'carer champion', to offer referral and signposting for carer support.

To find out why the committee made the recommendations on how to provide information and advice and how they might affect practice see [rationale and impact](#).

## 1 **1.2 Identifying carers**

### 2 **Recommendations for health and social care practitioners**

3 1.2.1 Recognise that many [carers](#) do not know about their right to support and  
4 that every attempt must be made (in line with the [Care Act 2014](#)) to:

- 5 • identify when someone is a carer
- 6 • ensure the carer is aware of their right to a [carer's assessment](#)
- 7 • ensure the carer knows how to obtain a carer's assessment.

8 1.2.2 Recognise the benefits of identifying carers, both for:

- 9 • the carer because their role can be recognised and their contribution  
10 acknowledged, **and**
- 11 • the person being cared for because their carer's knowledge and  
12 experience of them can be shared with practitioners (with their  
13 consent).

14 1.2.3 Be aware that people do not always recognise themselves as carers  
15 because:

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

- 1 1.2.4 At every opportunity, encourage people who provide care to recognise  
2 themselves as carers, and explain how they could benefit from support.  
3 Opportunities include GP appointments, home visits, outpatient  
4 appointments, and admissions and discharge planning meetings.
- 5 1.2.5 Be aware that carers may not ask for support from certain professionals,  
6 for example GPs, because they may not view support for carers as being  
7 part of that professional's role.
- 8 1.2.6 Ask people with care and support needs whether anyone gives them help  
9 or support, apart from paid practitioners. Take into account that other  
10 people offering help or support may not be family members or may not  
11 live with the person and that there may be more than one person involved  
12 in caring.
- 13 1.2.7 Practitioners involved in transferring people to and from hospital should  
14 seek to identify carers and refer them to appropriate services. Follow  
15 recommendations on [involving carers](#) in NICE's guideline on transition  
16 between inpatient hospital settings and community or care home settings  
17 for adults with social care needs.
- 18 1.2.8 Practitioners carrying out care assessments, discharge assessments and  
19 other needs assessments should actively seek to identify carers and  
20 record details about them (with the carer's consent).
- 21 1.2.9 Offer carers the opportunity to have conversations about their own needs  
22 as carers separately from the person they are supporting.

23 ***Mutual caring***

- 24 1.2.10 If a person who has care and support needs also has caring  
25 responsibilities, their care and support needs assessment should take  
26 account of this. In line with the Care Act 2014, they must also be offered a  
27 separate carer's assessment to identify their needs as a carer.



To find out why the committee made the recommendations for health and social care practitioners on identifying carers and how they might affect practice see [rationale and impact](#).

## 1 **Recommendations for service providers and organisations**

2 1.2.11 Health and social care organisations should encourage people to  
3 recognise their role and rights as carers by using:

- 4 • local publicity campaigns
- 5 • posters
- 6 • leaflets
- 7 • community services, such as libraries, pharmacies
- 8 • partnerships with local community organisations.

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

11 1.2.12 Health and social care organisations should consider nominating a ‘carer  
12 champion’ to implement the recommendations in this guideline and Care  
13 Act 2014 requirements in relation to identifying carers

14 1.2.13 Health and social care organisations should ensure their policies and  
15 systems encourage the identification of carers, including by developing  
16 formal processes to help them do so.

17 1.2.14 Ensure that all staff likely to come into contact with carers understand  
18 their responsibilities under the Care Act 2014 in relation to identifying  
19 carers.

To find out why the committee made the recommendations for service providers and organisations on identifying carers and how they might affect practice see [rationale and impact](#).

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## 1 **1.3 Assessing carers' needs**

### 2 **Carers' assessments**

3 1.3.1 Local authorities, and social care organisations delegated by local  
4 authorities to carry out [carers' assessments](#), should make arrangements  
5 for assessments in accordance with statutory guidance in the [Care Act](#)  
6 [2014](#).

7 1.3.2 Local authorities and delegated social care organisations should ensure  
8 that there are clear agreed arrangements for carrying out carers'  
9 assessments in cooperation with health and other social care  
10 organisations, in line with the Care Act 2014.

11 1.3.3 Practitioners from health and social care carrying out or contributing to  
12 carers' assessments should work together to ensure that:

- 13 • the assessment covers all relevant aspects of health and social care,  
14 **and**
- 15 • details of the assessment are shared with other practitioners and  
16 organisations who are involved in the assessment.

17 1.3.4 Health and social care organisations should ensure that practitioners who  
18 carry out or contribute to carers' assessments have training and skills in  
19 that role.

20 1.3.5 Be aware that a well-conducted carer's assessment may in itself be a  
21 therapeutic intervention or a means of preventing future problems.

To find out why the committee made the recommendations on carers' assessments and how they might affect practice see [rationale and impact](#).

### 22 **Preparing for and carrying out carers' assessments**

23 1.3.6 As soon as possible after a carer is identified, tell them about their right to  
24 a carer's assessment and explain what this involves and how to arrange  
25 one.

- 1 1.3.7 The carer's assessment should reflect the carer's needs in the context of  
2 their support environment and family environment and can be linked to the  
3 assessment of the person they care for (with consent).
- 4 1.3.8 Arrange the timing of assessment around the carer's needs and  
5 preferences, for example taking into account:
- 6 • whether the person they care for is near the end of life
  - 7 • the level of stress the carer is experiencing
  - 8 • the timing of hospital discharge
  - 9 • changes to the caring role
  - 10 • any negative impact of delays on the carer.
- 11 1.3.9 Provide flexibility in the timing and location of carers' assessments for  
12 carers who work.
- 13 1.3.10 Ensure that the assessment process is accessible, easy to navigate and  
14 complete, and tailored to individual needs, with information provided in a  
15 format that carers can understand.
- 16 1.3.11 Carers' assessments should be carer-led and jointly produced by the  
17 carer and the practitioner.
- 18 1.3.12 If a carer's needs have been identified during a hospital-based  
19 assessment:
- 20 • inform the local authority or a delegated care organisation that a carer's  
21 needs have been identified
  - 22 • ensure an effective process is in place to link the hospital-based carer's  
23 assessment with completion of the community-based statutory  
24 assessment so that meaningful support for carers is provided during  
25 transfer from hospital (including during a crisis).
- 26 1.3.13 Ensure there are clearly identified outcomes for the carer following  
27 assessment, for example:

- 1 • arrangements for [replacement care](#) to allow the carer to work or attend
- 2 education or training
- 3 • a carer's break
- 4 • a one-off direct payment
- 5 • a carer's support plan
- 6 • carer training
- 7 • further information and advice.

To find out why the committee made the recommendations on preparing for and carrying out carers' assessments and how they might affect practice see [rationale and impact](#).

## 8 **Carers' assessments: work, education and training**

- 9 1.3.14 Discuss education, training and employment with carers during their
- 10 carer's assessment. Explore the options and the support they need to
- 11 remain in, start or return to work, training or education. This could include
- 12 providing replacement care at home.
  
- 13 1.3.15 Ensure that practitioners carrying out carers' assessments have the
- 14 necessary skills, knowledge and understanding of potential opportunities
- 15 for returning to, or remaining in work, education and training.
  
- 16 1.3.16 Give carers tailored information about community services and support
- 17 that could help them remain in, start or return to work.

To find out why the committee made the recommendations on work, education and training during carers' assessments and how they might affect practice see [rationale and impact](#).

1 **1.4** ***Helping carers stay in, enter or return to work, education***  
2 ***and training***

3 **Advice and support**

4 1.4.1 Local authorities should ensure [carers](#) have access to tailored advice  
5 about balancing work, education or training with caring, including  
6 associated benefits advice.

7 1.4.2 Services providing welfare rights advice or back-to-work or education  
8 training should develop an understanding of carer needs, for example by  
9 appointing a named ‘carer champion’ who can provide knowledgeable,  
10 tailored advice.

11 1.4.3 Services providing welfare rights advice or back-to-work or education  
12 training should help carers recognise that the skills they have gained  
13 through caring are transferable and support them to describe their skills in  
14 a way that will appeal to employers.

15 1.4.4 Workplaces should make information available to their staff about ways in  
16 which they can support employees who need to balance caring  
17 responsibilities with work. See NICE’s guideline on [workplace health](#).

To find out why the committee made the recommendations on work, education and training for carers and how they might affect practice see <a href="#">rationale and impact</a> .
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18 **Flexibilities to support employment**

19 1.4.5 Practitioners should encourage carers to discuss supportive working  
20 arrangements with their employers, including adjustments to make caring  
21 possible. Examples might include flexible hours, use of a mobile phone to  
22 keep in touch with the person they care for, or providing a private space to  
23 take personal phone calls.

24 1.4.6 Workplaces should offer flexible working arrangements to enable staff to  
25 balance caring responsibilities with work and other initiatives which

1 support mental wellbeing for carers in line with the NICE guidelines on  
2 [workplace health](#) and [mental wellbeing at work](#).

3 1.4.7 Workplaces should ensure that staff with caring responsibilities have  
4 equal access to career development.

5 1.4.8 Health and social care organisations should offer flexibility when arranging  
6 appointments for working carers. Examples include workplace surgeries  
7 and carer appointments outside of office hours.

8 1.4.9 Carer support services should work closely with employee assistance  
9 programmes to make advice and information for carers available within  
10 the workplace.

To find out why the committee made the recommendations on flexibilities to support employment and how they might affect practice see [rationale and impact](#).

## 11 **Replacement care**

12 1.4.10 Ensure that [replacement care](#) is discussed as part of [carers' assessments](#)  
13 when helping carers who want to stay in, enter or return to work,  
14 education or training.

15 1.4.11 Commissioners should ensure that replacement care services are  
16 available locally for carers who need to access them to stay in, enter or  
17 return to work, education or training, including those who fund their own  
18 support.

19 1.4.12 Commissioners should be aware of the benefits of replacement care for  
20 supporting carers to remain in and return to education and employment  
21 when designing and delivering support services for carers.

22 1.4.13 Ensure that replacement care is flexible and provides a choice of options  
23 to meet all levels of carers' needs, for example including those who care  
24 for more than one person or who care for over 20 hours a week.

25 1.4.14 Review replacement care often enough to respond to changes in people's  
26 working patterns and career development.

To find out why the committee made the recommendations on replacement care and how they might affect practice see [rationale and impact](#).

## 1 **1.5 Social and community support for carers**

### 2 **Community information, advice and support**

3 1.5.1 Local authorities should keep [carers](#) regularly informed about community  
4 services and other sources of support and advice, for example:

- 5 • local carer support services
- 6 • self-help groups
- 7 • financial assistance
- 8 • advice about self-care
- 9 • where to find reliable information about the health condition of the  
10 person they are caring for.

To find out why the committee made the recommendation on community information, advice and support and how it might affect practice see [rationale and impact](#).

### 11 **Carers' breaks**

12 1.5.2 Health and social care practitioners should regularly discuss with carers  
13 options for having a break from their caring role.

14 1.5.3 Ensure that carers have choice and control when accessing [carers'](#)  
15 [breaks](#) and that breaks meet the specific needs of each carer, for example  
16 in their duration, timing, frequency and type of break.

17 1.5.4 Ensure that carers' breaks are arranged in a way that provides reliable  
18 and consistent support to the carer (such as avoiding last minute changes  
19 that could lead to additional stress for the carer).

To find out why the committee made the recommendations on carers' breaks and how they might affect practice see [rationale and impact](#).

1 **Volunteer and peer support**

2 1.5.5 Tell carers about peer support and how to access it locally. Explain that  
3 peer support can help reduce a sense of isolation, provide empathy and  
4 social and emotional support, and enable them to share information.

5 **Support for former carers**

6 1.5.6 Consider extending support services for people when their caring role is  
7 finished, including through peer support groups.

To find out why the committee made the recommendations on volunteer support and support for former carers and how they might affect practice see [rationale and impact](#).

8 **Advocacy**

9 1.5.7 Local authorities must provide information to carers about how to access  
10 advocacy support services, in line with the [Care Act 2014](#).

11 1.5.8 If carers choose to have an advocate or representative to support them,  
12 health and social care practitioners should recognise this person's  
13 contribution and include them in discussions.

To find out why the committee made the recommendations on advocacy and how they might affect practice see [rationale and impact](#).

14 **1.6 Training in providing care and support**

15 1.6.1 Commissioners and those involved in planning local [carer](#) support  
16 services should ensure that the provision of carer training meets local  
17 needs.

18 1.6.2 Offer training to enable carers to provide care safely. It should be tailored  
19 to meet each carer's individual needs. Training could include structured  
20 programmes or one-to-one guidance from a practitioner.

21 **Carer training programmes**

22 1.6.3 Offer carer training programmes that are:



- 1           • designed specifically for carers, aiming to improve their knowledge and  
2            coping skills
- 3           • accessible and available in a variety of formats, including printed or  
4            online materials or face to face
- 5           • relevant to carers' circumstances, including the health condition,  
6            disability or needs of the person they care for.
- 7   1.6.4   Training programmes for carers should include the following components,  
8            as relevant:
- 9           • self-care
- 10          • communication skills
- 11          • education about the health condition, disability or needs of the person  
12          they care for
- 13          • information about relevant services
- 14          • psychosocial support
- 15          • future planning, including preparing for transitions.
- 16   1.6.5   Consider including the following in carer training programmes, as relevant:
- 17          • managing medicines
- 18          • providing personal care
- 19          • use of digital and assistive technology.
- 20   1.6.6   Consider incorporating peer support as part of training programmes for  
21          carers.
- 22   1.6.7   Ensure that training programmes for carers are inclusive and address the  
23          needs and preferences of diverse groups, such as lesbian, gay, bisexual  
24          and transgender carers, and carers from diverse ethnic, religious and  
25          cultural backgrounds.
- 26   1.6.8   Training programmes for carers should provide a balance between  
27          learning, enjoyment and a chance to meet other carers.

- 1 1.6.9 Consider enabling opportunities for carers to keep in touch with each  
2 other following a training programme.

To find out why the committee made the recommendations on carer training programmes and how they might affect practice see [rationale and impact](#).

### 3 **Use of equipment and adaptations, and moving and handling**

- 4 1.6.10 Health and social care practitioners should involve carers during  
5 assessments for equipment and adaptations.

- 6 1.6.11 Health and social care practitioners should ensure carers have access to  
7 advice and guidance about appropriate use of equipment and  
8 adaptations, and safe moving and handling techniques.

To find out why the committee made the recommendations on use of equipment and adaptations and how they might affect practice see [rationale and impact](#).

## 9 **1.7 *Psychological and emotional support for carers***

### 10 **Psychosocial and psychoeducational interventions**

- 11 1.7.1 Consider providing [carers](#) with psychosocial and psychoeducational  
12 support, which should include:

- 13 • general education about the health condition, disability or needs of the  
14 person they care for, for example any symptoms and how they are  
15 likely to progress
- 16 • developing personalised strategies and building carer skills
- 17 • training to help them provide care, including how to understand and  
18 respond to changes in mood and behaviour
- 19 • training in communication skills to improve interactions with the person  
20 they care for
- 21 • advice on how to look after their own physical and mental health, and  
22 their emotional and spiritual wellbeing
- 23 • advice on planning enjoyable and meaningful activities with the person  
24 they care for

- 1           • information about relevant services (including support services and  
2           psychological therapies for carers) and how to access them  
3           • advice on planning for the future.
- 4   1.7.2    Ensure that the range of psychosocial and psychoeducational support  
5           offered to carers includes group-based options.
- 6   1.7.3    Arrange the timing of psychosocial or psychoeducational support to suit  
7           each carer's circumstances, taking into account, for example:
- 8           • how long they have been caring  
9           • any other commitments, such as work or other caring responsibilities.
- 10  1.7.4    When providing psychosocial or psychoeducational support to carers,  
11           take into account:
- 12           • the carer's preferred location  
13           • whether they need support to attend (for example a practitioner to go  
14           with them)  
15           • physical accessibility (such as help needed with transport)  
16           • if [replacement care](#) is needed  
17           • the carer's preferred format  
18           • the cultural appropriateness of the intervention  
19           • what follow-up will be needed.

To find out why the committee made the recommendations on psychosocial and psychoeducational interventions and how they might affect practice see [rationale and impact](#).

## 20 **Psychotherapy and counselling**

- 21  1.7.5    If a carer has an identified mental health problem, consider:
- 22           • interventions in line with [existing NICE guidelines](#) or  
23           • referral to a mental health professional who can provide interventions in  
24           line with existing NICE guidelines.

To find out why the committee made the recommendation on psychotherapy and counselling and how it might affect practice see [rationale and impact](#).

1 **1.8 Support during changes to the caring role**

2 1.8.1 Be aware that caring responsibilities may not end when the person being  
3 cared for moves away from home, for example into a residential care  
4 home.

5 1.8.2 Provide information and emotional and practical support to help [carers](#)  
6 prepare for and adjust to changes in their caring role when the person  
7 they care for:

- 8 • becomes an adult
- 9 • makes the transition to adult services (see NICE's guideline on  
10 [transitions from children's to adults' services](#))
- 11 • moves away from home
- 12 • has a significant change in their health.

13 1.8.3 Provide information and emotional and practical support to carers when  
14 their circumstances change – for example when they go back to work,  
15 have a change in benefits or financial circumstances, go through personal  
16 changes (such as divorce), take on another caring role or go into hospital.

17 1.8.4 For recommendations about support and training for carers during  
18 transitions between hospital and home, see NICE's guideline on transition  
19 between inpatient hospital settings and community or care home settings  
20 for adults with social care needs, in particular:

- 21 • recommendations 1.5.7 to 1.5.9 on [communication and information](#)  
22 [sharing](#), and
- 23 • recommendations 1.5.32 to 1.5.35 on [support and training for carers](#).

To find out why the committee made the recommendations on support during changes to the caring role and how they might affect practice see [rationale and impact](#).

1 **1.9 Support for carers during end of life care and after the**  
2 **person dies**

3 **Information and support**

- 4 1.9.1 Offer [carers](#) frequent opportunities for discussion and help them to  
5 understand information about the diagnosis and prognosis of the person  
6 they care for (with the person's consent). Use a sensitive manner during  
7 these discussions and avoid jargon.
- 8 1.9.2 Health and social care practitioners involved in providing end of life care  
9 should be competent to have conversations with carers about death and  
10 dying.
- 11 1.9.3 Practitioners should establish early contact with carers involved in  
12 providing end of life care. Discuss with carers how best to support them,  
13 taking into account that unsatisfactory early contact with health and social  
14 care services can have a long-lasting negative impact on carers involved  
15 in providing end of life care.
- 16 1.9.4 Health and social care practitioners, including home care workers, should  
17 recognise that carers can find it hard to accept help at home when they  
18 are providing end of life and can find it invasive.
- 19 1.9.5 Provide continuity during end of life care with the same professional care  
20 staff wherever possible, so that the carer and the person they care for can  
21 build a relationship with the staff supporting them.
- 22 1.9.6 Encourage carers who are caring for someone near the end of their life to  
23 think about ways they can get support from their family, friends and wider  
24 social network.

1 **Advance care planning**

2 1.9.7 Involve carers in advance care planning if the person being cared for  
3 consents to this. For recommendations about involving carers in advance  
4 care plans for people who may lack mental capacity, see NICE's guideline  
5 on [decision making and mental capacity](#).

6 1.9.8 When making an advance care plan that includes responsibilities for  
7 carers, health and social care practitioners should consider the wishes of  
8 any current or future carers who have been named in the plan.

9 1.9.9 If the person has given consent for carers, family and friends or advocates  
10 to be involved in discussions about advance care planning, take  
11 reasonable steps to include them.

12 1.9.10 Share any advance care plans in a clear and simple format with everyone  
13 involved in the person's care, if the person has given consent.

14 **Providing care at the end of life**

15 1.9.11 When managing medication at the end of life, follow the principles of  
16 involving carers and the dying person, as described in NICE's guideline  
17 on [care of dying adults in the last days of life](#).

18 1.9.12 During a structured medication review, as described in NICE's guideline  
19 on [medicines optimisation](#), take into account:

- 20
- 21 • the person's, and their family members or carers where appropriate,  
views and understanding about their medicines
  - 22 • the person's, and their family members' or carers' where appropriate,  
23 concerns, questions or problems with the medicines.

24 1.9.13 Help carers who are providing end of life care at home to access local  
25 services that could support them. This could include:

- 26
- 27 • [replacement care](#)
  - 28 • domestic help
  - palliative home care

- 1                   • practical support, for example to use equipment and adaptations.
- 2 1.9.14       Provide privacy and dignity for people dying in hospital and their carers.
- 3                   This could include offering them a private room, but if this is not possible
- 4                   offer alternatives such as:
- 5                   • private space
- 6                   • flexible visiting times
- 7                   • comfortable seating for the carer
- 8                   • access to refreshments.
- 9 1.9.15       Give carers of people at the end of life up-to-date and accurate
- 10                  information and advice about legal and logistical issues they need to
- 11                  address when preparing for or following the death of the person.
- 12 1.9.16       Take account of the changing information and support needs of carers in
- 13                  planning for their own future when the person they care for dies.

To find out why the committee made the recommendations on support at the end of life and after the person dies and how they might affect practice see [rationale and impact](#)

14

## 15 ***Terms used in this guideline***

### 16 **Carer**

17 A carer is anyone who provides unpaid care and support to a family member, partner

18 or friend due to their disability, health condition, frailty, mental health problem,

19 addiction or other health or social care needs.

### 20 **Carer's assessment**

21 Anyone who is an unpaid carer for a family member or friend has the right to discuss

22 their own needs with their local council, separate to the needs of the person they

23 care for. This is a statutory requirement under the Care Act 2014. Carers can

24 discuss anything they think would help with their own health and wellbeing or with

1 managing other aspects of their life, including their caring role. The council uses this  
2 information to decide what help it can offer.

### 3 **Carers' breaks**

4 Also known as respite care, this service gives carers a break by providing short-term  
5 care for the person with care needs in their own home or in a residential setting. It  
6 can mean a few hours during the day or evening, overnight, or a longer-term break.  
7 It can also benefit the person with care needs by giving them the chance to try new  
8 activities and meet new people.

### 9 **Replacement care**

10 Care that replaces the care normally given by a regular carer. It may be needed  
11 either on a planned basis or in an emergency. Replacement care may be offered by  
12 the local council, if the person needing care has had an assessment and is entitled  
13 to care and support services, or if the carer is entitled to help. Otherwise, people may  
14 have to pay for it.

15 These definitions are based on Think Local, Act Personal's [care and support jargon](#)  
16 [buster](#). See the jargon buster for other social care terms used in this guideline.

## 17 **Recommendations for research**

18 The guideline committee has made the following recommendations for research.

### 19 ***Key recommendations for research***

#### 20 **1 Whole family approach to carer's assessment**

21 What is the effectiveness, cost effectiveness and acceptability of the whole family  
22 approach to carers' assessments?

23 To find out why the committee made the research recommendation on whole family  
24 approach to carers' assessment see [rationale and impact](#).

#### 25 **2 Support for carers to return to work, employment or training**

26 What is the effectiveness of personal health and social care budgets in supporting  
27 carers to return to work, education or training?



1 To find out why the committee made the research recommendation about support for  
2 carers to return to work, employment or training see [rationale and impact](#).

### 3 **3 Training for carers to reduce caring-related incidents**

4 What training, support or interventions help to reduce caring-related accidents or  
5 incidents?

6 To find out why the committee made the research recommendation about training for  
7 carers to reduce caring-related incidents see [rationale and impact](#).

### 8 **4 Practical support through carer passport schemes**

9 What is the effectiveness, cost effectiveness and acceptability of carer passport  
10 schemes?

11 To find out why the committee made the research recommendation about practical  
12 support through carer passport schemes see [rationale and impact](#).

### 13 **5 Practical support for carers through social prescribing**

14 What is the effectiveness, cost effectiveness and acceptability of social prescribing  
15 for carers?

16 To find out why the committee made the research recommendation about practical  
17 support for carers through social prescribing see [rationale and impact](#).

## 18 **Rationale and impact**

19 These sections briefly explain why the committee made the recommendations and  
20 how they might affect practice. They link to details of the evidence and a full  
21 description of the committee's discussion.

### 22 ***Information and advice***

23 Recommendations [1.1.1 to 1.1.6](#)

### 24 **Why the committee made the recommendations**

25 The committee used qualitative themes from the evidence and also drew on  
26 examples of information for carers recommended by other NICE guidelines to build  
27 on statutory guidance about providing information and advice. Under the Care Act

1 2014, carers already have a right to know about the support available in their area,  
2 but many are unaware of the advice and services available, or they may not have  
3 time to search for them. The committee used the evidence to make  
4 recommendations about information and services that local authorities could  
5 promote to carers. Health and social care practitioners should also pass these on  
6 whenever the opportunity arises.

7 The evidence also showed that to provide effective care, carers need sufficient  
8 information about the person they are caring for. However, in many cases the health  
9 condition, disability or needs of the person, or the nature of the relationship with their  
10 carer, may mean that providing this information can clash with the person's right to  
11 confidentiality. The committee made a recommendation to address this issue and  
12 balance the different concerns.

### 13 **How the recommendations might affect practice**

14 Current information provision varies, so in some areas additional training and review  
15 of current information provision may be needed. Providing information is a statutory  
16 requirement, and giving carers the right information and advice at the right time can  
17 help them continue caring while managing other aspects of their lives. Any costs  
18 would be outweighed by the benefits of helping to avoid crisis situations such as  
19 unplanned hospital admissions and carer health problems.

20 Full details of the evidence and the committee's discussion are in [evidence review B:  
21 providing information and advice about caring to carers in the UK](#).

22 [Return to recommendations](#)

### 23 ***How to provide information and advice***

24 Recommendations [1.1.7 to 1.1.14](#)

### 25 **Why the committee made the recommendations**

26 There was good quality evidence from carers about how information giving could be  
27 improved. This evidence guided recommendations about the way in which  
28 information should be delivered, including its format, style and timing of delivery and  
29 how to tailor it to what each carer needs and prefers.

1 There was strong evidence that carers value being kept up to date even with difficult  
2 news about the condition of the person they care for because they prefer to have  
3 time to prepare than be left unaware. Another strong theme suggested that carers  
4 often receive information from multiple sources around the same time, emphasising  
5 the importance of professionals in different services working together to make sure  
6 they are giving consistent advice.

7 There was some limited evidence that primary care practitioners would like to  
8 promote care services to carers and are interested in formalising ways to do it.  
9 However only one example was identified for how this might be done. The committee  
10 discussed this and reached the consensus that developing partnerships with other  
11 services, and designating a carer 'champion' within their team, are two ways they  
12 could do this.

### 13 **How the recommendations might affect practice**

14 Following these recommendations would make information easier for carers to  
15 understand and retain, improve their experience and wellbeing, and their ability to  
16 give effective care. They may call for refinements to existing practice but do not  
17 imply any costly changes or radical new provision.

18 Details of the evidence and the committee's discussion are in [evidence review B:  
19 providing information and advice about caring to carers in the UK](#) and [evidence  
20 review D: supporting adult carers to enter, remain in or return to work, education and  
21 training](#). Other supporting evidence and discussion can be found in [evidence review  
22 A: identifying carers as defined by the Care Act 2014](#), [evidence review B: identifying  
23 carers](#), and [evidence review F: providing practical support for adult carers](#).

24 [Return to recommendations](#)

### 25 ***Identifying carers: recommendations for health and social care 26 practitioners, and mutual caring***

27 Recommendations [1.2.1 to 1.2.10](#)

1 **Why the committee made the recommendations**

2 It is a requirement of the Care Act 2014 to seek to identify people in a caring role and  
3 explain the advice and support available to them. The quality of the evidence was  
4 fairly low but it found specific barriers to identifying carers, so the committee drew on  
5 these along with their own expertise to recommend how to improve identification of  
6 carers.

7 In the committee's experience, even if people recognise they are in a carer role, they  
8 are still more likely to see their primary role in relation to that person as a family  
9 member or friend and practitioners should take this into account in the way they  
10 communicate with carers.

11 The evidence suggested that carers value discussions with practitioners where their  
12 caring is recognised and they are offered support. However, it can be challenging to  
13 have open conversations with carers about their own needs, especially with the  
14 person receiving the support present.

15 There may be more than one person involved in a person's care and support, and  
16 the committee agreed that it is important that health and social care practitioners  
17 seek to identify all carers and to understand the context of their caring situation. This  
18 enables advice, support and assessments to be more likely to meet each carer's  
19 needs.

20 The committee agreed that recording information about carers as part of routine  
21 assessments can help to identify carers, especially when this information is shared  
22 with other health and social care practitioners, and there was evidence to support  
23 this.

24 **How the recommendations might affect practice**

25 The committee agreed the recommendations should have limited cost implications  
26 because they involve using existing opportunities to help identify carers. There may  
27 be some costs associated with improving how information about carers is recorded  
28 and used to improve identification and support.

29 Full details of the evidence and the committee's discussion are in [evidence review A:](#)  
30 [identifying carers as defined by the Care Act 2014 \(including hidden carers\)](#). Other

1 supporting evidence and discussion is in [evidence review H: support needs for end](#)  
2 [of life](#) and [evidence review I: supporting carers during changes to the caring role](#).

3 [Return to recommendations](#)

#### 4 ***Identifying carers: recommendations for service providers and*** 5 ***organisations***

6 Recommendations [1.2.11 to 1.2.14](#)

#### 7 **Why the committee made the recommendations**

8 The committee agreed that organisations need to be proactive about promoting  
9 carers' roles and rights to help more people to self-identify as carers and seek  
10 support – this would help them meet Care Act 2014 requirements. There was little  
11 evidence to support the recommendations, but in the committee's own experience,  
12 people would be more likely to identify as carers if they are presented with images  
13 and language that are directly relatable to their changing perceptions of themselves  
14 and their own needs as carers.

15 Qualitative evidence showed that practitioners welcomed both informal and formal  
16 systems and processes to help them better identify and subsequently support carers  
17 and the committee agreed that carers were likely to benefit from these initiatives.

18 Practitioners coming into contact with carers need to have good knowledge of their  
19 responsibilities under the Care Act 2014 in relation to identifying carers. By  
20 consensus, the committee agreed that an efficient way to achieve this was for  
21 organisations to nominate 'carer champions' within their workforce to help other staff  
22 understand their responsibilities in this area.

#### 23 **How the recommendations might affect practice**

24 The recommendations could result in more carers seeking advice and support, which  
25 could lead to a higher demand for carers' support services. But they may also  
26 improve coordination between local authorities and local health and social care  
27 organisations in identifying carers and giving them support, leading to better care in  
28 turn for the person they care for.

1 Full details of the evidence and the committee's discussion are in [evidence review A:](#)  
2 [Identifying carers as defined by the Care Act 2014 \(including hidden carers\).](#)

3 [Return to recommendations](#)

#### 4 **Carers' assessments**

5 Recommendations [1.3.1 to 1.3.5](#)

#### 6 **Why the committee made the recommendations**

7 The recommendations were underpinned by evidence but in some areas the quality  
8 was variable. The evidence was most limited on collaborative working and on carers'  
9 assessments as a therapeutic intervention, so for these recommendations the  
10 committee supplemented the evidence with their own experience and expertise. The  
11 main findings from the evidence were:

- 12 • carers find out about carers' assessments from various sources, but still have  
13 trouble understanding the process and getting an assessment
- 14 • a lack of coordination across multiple services (for example between hospitals and  
15 community services) is an obstacle to the assessment process
- 16 • practitioners from teams across health and social care need to work together on  
17 carers' assessments, but they do not always have the relevant skills and training
- 18 • properly conducted, a carer's assessment provides carers with psychosocial and  
19 emotional benefits and may be thought of as a therapeutic intervention in itself.

20 There was no evidence on ways to improve the assessment process, or on whether  
21 using the lead professional approach or the whole family approach can make  
22 collaborative working easier and more effective. So the committee made  
23 recommendations that aimed to address the problems reported in the evidence.

24 The committee also agreed to make a research recommendation on the whole family  
25 approach to carers' assessments.

#### 26 **How the recommendations might affect practice**

27 The impact of the recommendations is likely to vary depending on how much local  
28 services already collaborate with each other and train their staff to take the initiative  
29 with assessments. Additional training or reviewing of service coordination may be

1 needed in some areas, but because such assessments are statutory requirements  
2 they should not introduce additional financial implications.

3 Full details of the evidence and the committee's discussion are in [evidence review C:  
4 assessment of carers as defined by the Care Act 2014](#).

5 [Return to recommendations](#)

## 6 ***Preparing for and carrying out carers' assessments***

7 Recommendations [1.3.6 to 1.3.13](#)

### 8 **Why the committee made the recommendations**

9 The quality of the evidence was mixed, so the committee supplemented the  
10 evidence with their own knowledge and experience.

11 According to the evidence, reports from some carers suggested that they found the  
12 assessment process difficult to follow. Some carers also struggled to understand  
13 what being 'entitled to an assessment' actually meant. Sometimes carers'  
14 assessments are carried out in conjunction with those of the person they care for,  
15 which in some cases can mean the carer's own needs are not separately assessed.  
16 The committee agreed that practitioners need to give carers a clear explanation of  
17 what a carer's assessment involves and make sure it is considered independently  
18 from the cared-for person's assessments.

19 The evidence suggested possible ways to make assessments more positive for  
20 carers, including improving their timing and format to make them more accessible  
21 and person-centred. Practitioners should always make sure an assessment leads to  
22 clear outcomes for the carer and practical benefits. If an assessment is done in  
23 hospital, it needs to be forward-looking and connected to the completion of a  
24 statutory assessment by community staff. This helps to ensure meaningful support  
25 for carers during transfer from hospital, as the evidence showed that assessments  
26 by different services can be fragmented.

### 27 **How the recommendations might affect practice**

28 Carers' assessments are already statutory, so the implementation of these  
29 recommendations may only involve minor changes to existing practice. Some costs

1 may be associated with re-training, or with implementing more flexible and  
2 individualised assessments, but the committee agreed these were implicit to what is  
3 an adequate assessment as required by the Care Act 2014.

4 Full details of the evidence and the committee's discussion are in [evidence review C:  
5 assessment of carers as defined by the Care Act 2014](#), and [evidence review D:  
6 work, education and training](#).

7 [Return to recommendations](#)

## 8 ***Carers' assessments: work, education and training***

9 Recommendations [1.3.14 to 1.3.16](#)

### 10 **Why the committee made the recommendations**

11 Although there was no high-quality evidence, the committee was able to make  
12 recommendations in areas where the lower-quality evidence aligned with their own  
13 experiences and expertise. Some qualitative evidence showed that carers valued  
14 being offered services, practical support and financial support to stay in work,  
15 education and training. Evidence also suggested there may not be enough  
16 opportunities presented during carers' assessments to encourage their use and  
17 uptake. This chimed with the committee's concern that practitioners carrying out  
18 assessments often overlook carers' wishes about work, education and training. They  
19 agreed that it was important for assessing practitioners to have good local  
20 knowledge about these types of opportunities for carers, as well as the community  
21 support options available (such as replacement care) to help carers take up these  
22 opportunities if they wish.

### 23 **How the recommendations might affect practice**

24 The recommendations might involve some changes to existing training and practice  
25 for practitioners carrying out assessments to make sure that work, education and  
26 training is covered routinely. They could also lead to changes in the levels of support  
27 needed by carers, and greater demand for services like replacement care. However,  
28 access to this support is a statutory right under the Care Act 2014, and any costs  
29 would be offset by the economic benefits to carers and wider society.



1 Full details of the evidence and the committee's discussion are in [evidence review D:](#)  
2 [work, education and training](#).

3 [Return to recommendations](#)

#### 4 ***Helping carers stay in, enter or return to work, education and*** 5 ***training: advice and support***

6 Recommendations [1.4.1 to 1.4.4](#)

#### 7 **Why the committee made the recommendations**

8 The Care Act 2014 mandates providing information for carers on work, education  
9 and training, and the committee used a combination of evidence and expert  
10 consensus to build on that legal requirement. There was some evidence that a lack  
11 of information and advice, combined with the fragmented nature of local support  
12 services, often acted as barriers to carers remaining in, returning to or entering work,  
13 education and training. The committee agreed it was important to make widely  
14 available person-centred advice and information specifically for carers. This was  
15 supported by evidence that carers welcomed advice and information from  
16 practitioners who understood the particular challenges they face in combining work  
17 and caring.

18 There was some limited evidence showing the disadvantages experienced by young  
19 adult carers striving to balance work or education with caring. The quality of the  
20 evidence was low but the committee added to this from their own expertise. They  
21 agreed that carers may lack confidence about finding work, especially if they have  
22 spent years caring at the expense of education or training. They agreed, by  
23 consensus, that it was relevant for all carers to be encouraged to recognise their  
24 value to employers using the skills they have built up during caring.

25 There was a lack of evidence about the effectiveness of particular tools or  
26 approaches for supporting carers to return to work, education or training. Supported  
27 by expert testimony, the committee agreed that there was potential in further  
28 exploring whether the use of personal budgets, either for the person being cared for  
29 or the carer in their own right, might have positive outcomes for the carer. So the  
30 committee agreed to make a research recommendation about the effectiveness of

1 personal health and social care budgets in supporting carers to return to work,  
2 education or training.

### 3 **How the recommendations might affect practice**

4 These recommendations reinforce legislation and should help to improve the  
5 consistency of best practice. Changes needed to current practice will depend on the  
6 availability of carers' work-related support services in each area. Providing tailored  
7 advice of this kind may require some additional local investment, but this would be  
8 offset by substantial benefits for carers from being supported to continue working or  
9 learning alongside caring, leading to cost savings in the long term.

10 Full details of the evidence and the committee's discussion are in [evidence review D:  
11 supporting adult carers to enter, remain in or return to work, education and training](#).

12 Other supporting evidence and discussion can be found in [evidence review A:  
13 identifying carers as defined by the Care Act 2014](#).

14 [Return to recommendations](#)

### 15 ***Flexibilities to support employment***

16 Recommendations [1.4.5 to 1.4.9](#)

### 17 **Why the committee made the recommendations**

18 There was evidence that even small adjustments to working practices can have  
19 positive benefits for carers balancing paid work with caring responsibilities. Carers  
20 also reported that they often avoid discussing caring-related problems with  
21 employers for fear of negative attitudes from managers, feeling a burden, or being  
22 excluded from opportunities to develop their careers.

23 The committee agreed it was important for employers to actively promote a positive  
24 culture towards people with caring responsibilities, including by promoting  
25 opportunities for flexible working practices and use of employee assistance  
26 programmes that can provide advice and support for working carers. Using expert  
27 witness testimony, the committee also incorporated some specific examples of  
28 adjustments in the workplace that would benefit carers.

1 **How the recommendations might affect practice**

2 The recommendations reinforce carers' statutory rights and best current practice.  
3 Changes needed to current practice will depend on the availability of carers' work-  
4 related support services in each area.

5 Providing flexibility for working carers may incur additional costs for employers (for  
6 example, if it's not possible to reorganise work among other staff) and for policy-  
7 makers and commissioners (for example, costs of enforcing legislation).

8 Full details of the evidence and the committee's discussion are in [evidence review D:  
9 supporting adult carers to enter, remain in or return to work, education and training](#).

10 [Return to recommendations](#)

11 ***Replacement care***

12 Recommendations [1.4.10 to 1.4.14](#)

13 **Why the committee made the recommendations**

14 Some limited evidence showed that carers valued being able to use replacement  
15 care locally so they could work or take part in education or training, and the  
16 committee's own expertise supported this. Furthermore, economic evidence  
17 suggested that the gains from increased labour market participation could outweigh  
18 the costs of replacement care. Those gains would come in the form of increased  
19 taxation receipts, reduced social welfare payments and higher economic output.

20 The recommendations are consistent with the Care Act 2014, which includes a duty  
21 for local authorities to promote individual wellbeing through participation in work or  
22 education.

23 The committee agreed that replacement care should be responsive and flexible and  
24 provide a choice of options. Providing choice would benefit the person being cared  
25 for as well as the carer themselves. This was supported by evidence suggesting that  
26 the attitude of the person being cared for could sometimes discourage carers from  
27 pursuing opportunities for work and education because of concerns about the quality  
28 of their replacement care, especially when their care and support needs were  
29 complex.

1 **How the recommendations might affect practice**

2 The recommendations reinforce carers' statutory rights and best current practice.  
3 Changes needed to practice will depend on whether replacement care services are  
4 available in each area. The recommendations should encourage commissioners to  
5 develop local markets so that replacement care is available to purchase, through  
6 either local authority or self-funding.

7 Providing working carers with replacement care will help them to remain in work, so  
8 the additional costs of replacement care would be offset by the benefits of keeping  
9 carers in the workforce.

10 Full details of the evidence and the committee's discussion are in [evidence review D:  
11 supporting adult carers to enter, remain in or return to work, education and training](#).

12 [Return to recommendations](#)

13 ***Community information, advice and support***

14 Recommendation [1.5.1](#)

15 **Why the committee made the recommendation**

16 The committee used the evidence along with their own experience to complement  
17 the legal requirements of the Care Act 2014 about providing information about  
18 community services to carers.

19 The committee suggested the kinds of information that carers would find useful,  
20 based on the evidence. They also wanted to emphasise that information giving  
21 should be ongoing to meet the changing circumstances of carers. This echoes  
22 recommendations elsewhere that carers' information and support needs should be  
23 revisited frequently (see the section on [information and advice](#) about providing  
24 tailored information for carers).

25 **How the recommendation might affect practice**

26 Providing information to carers is mandated by the Care Act 2014 so this  
27 recommendation should not have a significant impact on practice, other than to  
28 improve the consistency of implementation of legislative requirements.

1 Full details of the evidence and the committee's discussion are in [evidence review F:  
2 providing practical support for adult carers.](#)

3 [Return to recommendations](#)

#### 4 ***Carers' breaks***

5 Recommendations [1.5.2 to 1.5.4](#)

#### 6 **Why the committee made the recommendations**

7 There was a lack of evidence on effectiveness or cost effectiveness to support a  
8 recommendation to offer carers' breaks. Instead, the committee based their  
9 recommendations on qualitative evidence showing that many carers struggle to  
10 maintain their own wellbeing and often overlook their own needs, making it important  
11 for practitioners to remind them regularly of the value of taking a break.

12 Despite the need for services to provide carers' breaks, the evidence showed they  
13 were often limited in nature, availability, quality and flexibility, so the committee  
14 drafted additional recommendations to improve how breaks are provided.

15 No evidence was found about carers' passports as a means of improving support for  
16 carers, so the committee prioritised this for future research to establish their  
17 effectiveness and to understand people's views and lived experiences about them.

#### 18 **How the recommendations might affect practice**

19 The committee did not anticipate that these recommendations would have a  
20 significant impact on practice or resource implications. However, it is not consistent  
21 practice for practitioners to discuss carers' breaks with carers so this  
22 recommendation could have a positive effect and may represent a change to the  
23 quality of discussions between practitioners and carers.

24 Full details of the evidence and the committee's discussion are in [evidence review F:  
25 providing practical support for adult carers.](#)

26 [Return to recommendations](#)

1 ***Volunteer and peer support and support for former carers***

2 Recommendations [1.5.5 and 1.5.6](#)

3 **Why the committee made the recommendations**

4 There was some evidence suggesting the benefits of volunteer and peer support for  
5 carers, either through individual befriending arrangements or support groups. These  
6 include reducing social isolation and providing empathy and mutual emotional  
7 support. The benefits described in the studies resonated with the committee's own  
8 experiences, so they used this evidence to recommend encouraging carers to use  
9 this support and explaining why it can be helpful.

10 This evidence also showed that carers perceive certain barriers to attending  
11 volunteer and peer support – including timing and location – so the committee  
12 agreed it needed to be easily accessible and clear about its aims and purpose.

13 Based on evidence about the perceived benefits of support for former carers (for  
14 example, reducing social isolation) the committee also recommended considering  
15 extending support services to people after their caring role had ended.

16 The committee agreed that signposting and social prescribing could potentially  
17 promote better access to volunteer support for carers, but there was no evidence so  
18 they could not recommend them. Evidence is emerging about the effectiveness of  
19 social prescribing more generally, so the committee recommended research about  
20 its effectiveness and acceptability specifically for carers.

21 **How the recommendations might affect practice**

22 Volunteer support for carers is available but may be configured differently in different  
23 places. There may be an increased demand for and uptake of volunteer and peer  
24 support locally, which may affect coordination and training costs for voluntary  
25 services. The committee did not think that continuing to offer support to former  
26 carers would have resource implications because for most carers this support would  
27 only be needed for a short time after their caring role ended.

28 Full details of the evidence and the committee's discussion are in [evidence review F:  
29 providing practical support for adult carers](#).

1 [Return to recommendations](#)

## 2 **Advocacy**

3 Recommendations [1.5.7 and 1.5.8](#)

### 4 **Why the committee made the recommendations**

5 There was no evidence in this area, but there is a legal responsibility on local  
6 authorities to inform carers about their right to support from advocacy services and  
7 the circumstances in which they would apply. To build on this and ensure that  
8 advocates (or other representatives) can give meaningful support to carers, the  
9 committee agreed that practitioners should recognise the voice and role of  
10 advocates. They felt that this does not always happen in current practice.

### 11 **How the recommendations might affect practice**

12 These recommendations should not impact on practice other than underlining  
13 existing legal requirements.

14 Full details of the evidence and the committee's discussion are in [evidence review F:  
15 providing practical support for adult carers](#).

16 [Return to recommendations](#)

## 17 ***Training in providing care and support: carer training programmes***

18 Recommendations [1.6.1 to 1.6.9](#)

### 19 **Why the committee made the recommendations**

20 Qualitative evidence suggested that carers often lacked confidence or felt  
21 overwhelmed in their caring role. There was also a wide range of good evidence  
22 suggesting that training containing a variety of components can improve carers' skills  
23 and confidence in caring, and their understanding of the health condition, disability or  
24 needs of the person they care for, so they recommended carer-specific training  
25 programmes be offered routinely.

26 The committee used the evidence to pinpoint the common features of effective, cost-  
27 effective and acceptable carers' training programmes. Tailoring programmes means

1 their exact content would depend on the training needs of different carers but, based  
2 on the evidence, the committee recommended some core components to include.

3 By consensus, the committee also agreed to add some additional components in  
4 recommendation 1.6.5 that they felt were valuable based on their knowledge and  
5 experience, but which did not have specific support from the evidence.

6 The recommendation on peer support provided as part of training programmes was  
7 supported by several studies showing positive feedback from carers that training  
8 programmes reduced their sense of isolation, helped them interact with each other,  
9 discuss and resolve issues they are facing and provide informal emotional support.  
10 Also, there was positive feedback about the non-discriminatory support provided by  
11 the training sessions. Therefore, the committee agreed to make a recommendation  
12 to consider peer support as a key component of any carers' training programme and  
13 to ensure that training programmes were designed with a particular focus on  
14 supporting diverse groups.

15 From the evidence it was clear that many carers value the chance during training to  
16 meet other carers with similar experiences or circumstances, as well as the  
17 opportunity to have a break from caring. Based on this evidence and their own  
18 expertise, the committee agreed that training programmes should provide a balance  
19 between learning and social and emotional support and that carers may value the  
20 opportunity to keep in touch with other carers after the training.

21 There was no evidence on the impact of training for carers on caring-related  
22 accidents or incidents (involving either the carer or the person they care for),  
23 including failure to take prescribed medicine and falls. The committee therefore  
24 made a research recommendation to better identify what training, support or other  
25 interventions aimed at carers help to reduce caring-related accidents or incidents.

## 26 **How the recommendations might affect practice**

27 The recommendations reinforce best practice. The way services deliver carer  
28 training programmes varies across the UK, so the recommendations will help to  
29 improve consistency.



1 Providing multicomponent training programmes may involve initial additional costs.  
2 First, there may be an increase in the number of requests for training. Training may  
3 also be needed for practitioners to deliver the training. However, the components in  
4 recommendation [1.6.4](#) were based on the elements of the START (Strategies for  
5 Relatives) training programme. The economic evidence suggested that START was  
6 cost effective for carers of people with dementia and the committee agreed that it  
7 was reasonable to extrapolate this to all carers. Therefore, any additional costs of  
8 providing the programmes would be worth the benefits in carers' wellbeing and  
9 quality of life.

10 Full details of the evidence and the committee's discussion are in [evidence review E:  
11 training for carers to provide practical support](#)

12 [Return to recommendations](#)

### 13 ***Use of equipment and adaptations, and moving and handling***

14 Recommendations [1.6.10 and 1.6.11](#)

#### 15 **Why the committee made the recommendations**

16 The quality of evidence was mixed but, based on both the evidence and their own  
17 expertise, the committee agreed that involving carers in needs assessments for  
18 equipment and adaptations would help the carer understand the options available  
19 and how they can help the person they care for. To address challenges in using  
20 equipment that were reported in the qualitative evidence, carers should also be  
21 offered advice and guidance in using it safely and confidently.

22 No evidence was identified about the effectiveness and acceptability of training for  
23 carers in moving and handling. However, the committee agreed this was an  
24 important area for carers' own safety and wellbeing as well as for the person they  
25 care for. This is in line with current NHS and social care practice.

#### 26 **How the recommendations might affect practice**

27 The recommendations reinforce legislation and should improve consistency of best  
28 practice. The way services support carers with moving and handling is variable, and  
29 changes to practice will depend on the availability of services in each area. Providing

1 advice and guidance for carers in using equipment and adaptations and in moving  
2 and handling could involve additional costs. There may be an increase in the number  
3 of carers seeking this advice or guidance, and training may be needed for the  
4 practitioners who are delivering it.

5 Full details of the evidence and the committee's discussion are in [evidence review E:  
6 training for carers to provide practical support](#).

7 [Return to recommendations](#)

## 8 ***Psychosocial and psychoeducational interventions***

9 Recommendations [1.7.1 to 1.7.4](#)

### 10 **Why the committee made the recommendations**

11 The evidence suggested that psychosocial and psychoeducational support was  
12 important to carers, and helped improve their knowledge, skills and confidence about  
13 caring as well as improving emotional support, mental wellbeing and stress  
14 management. Overall, the quality of the quantitative evidence was low so the  
15 committee agreed that provision of psychosocial and psychoeducational support  
16 should be considered for carers. They also used the qualitative evidence and their  
17 own expertise to agree the important elements which should be included as part of  
18 this support.

19 The evidence for group interventions was more convincing than for one-to-one  
20 interventions. Group-based opportunities, where people had a chance to meet other  
21 carers and share experiences were particularly valuable in building self-esteem,  
22 understanding and expectations of the caring role.

23 The committee adapted a recommendation on psychological support for carers from  
24 the NICE dementia guideline because they agreed it was in line with the evidence  
25 they looked at. They used the qualitative evidence to set out the important elements  
26 to include in any psychoeducational support package. The committee also adapted  
27 the recommendation so that it could apply to anybody in a caring role.

28 The committee agreed by consensus that it was important for practitioners to think  
29 about the way in which such support was provided. This might determine whether

1 carers choose (or are able) to take up this intervention, so they included some  
2 factors to consider.

### 3 **How the recommendations might affect practice**

4 There is considerable regional variation in the psychosocial and psychoeducational  
5 support available for carers, so these recommendations may lead to an increase in  
6 demand from carers. In most cases, funding for support of this kind would only be  
7 considered as part of an assessment of the carer's needs by the local authority.

8 These programmes are likely to help reduce mental health problems in the carer that  
9 could otherwise significantly impact on the person's ability to continue caring and on  
10 the health and wellbeing of the person being cared for, as well as on demand for  
11 mental health services.

12 Full details of the evidence and the committee's discussion are in [evidence review G:  
13 providing psychological and emotional support to adult carers](#).

14 [Return to recommendations](#)

### 15 ***Psychotherapy and counselling***

16 Recommendation [1.7.5](#)

#### 17 **Why the committee made the recommendation**

18 The evidence on the effectiveness of psychotherapy and counselling was conflicting  
19 and was limited to cognitive behavioural therapy for carers of people living with  
20 dementia. There was not enough evidence to recommend these interventions for  
21 carers generally but the committee agreed on the importance of providing emotional  
22 support for carers with mental health problems, in line with existing NICE guidance  
23 on [mental health and behavioural conditions](#).

#### 24 **How the recommendation might affect practice**

25 Since the provision of emotional support to people with mental health problems is in  
26 line with existing NICE guidelines, the recommendation should not have a marked  
27 impact on practice except to highlight the importance of providing this support to  
28 adult carers.

1 Full details of the evidence and the committee's discussion are in [evidence review G:  
2 providing psychological and emotional support to adult carers](#).

3 [Return to recommendations](#)

#### 4 ***Support during changes to the caring role***

5 Recommendations [1.8.1 to 1.8.4](#)

#### 6 **Why the committee made the recommendations**

7 Although there was no strong evidence in this area, the committee was able to use  
8 their own experiences to support studies in some areas, and make  
9 recommendations by consensus in other areas that they felt were too important to be  
10 overlooked.

11 When a cared-for person moves out of their home it can be a difficult time that  
12 leaves carers in need of emotional support. The evidence was specific to transitions  
13 to a care home, but the committee decided that another important change was  
14 during the transition to adulthood. By consensus, the committee agreed to also  
15 highlight the support needed when the carer's own life changes, and how it's  
16 important for practitioners to recognise that caring might not necessarily finish when  
17 the person leaves home.

18 The committee used evidence from the information and advice section of the  
19 guideline to support recommending that carers need information and support when  
20 their needs and circumstances evolve, as they do at times of transition.

#### 21 **How the recommendations might affect practice**

22 Some services and practitioners will need to adjust their practice to improve their  
23 information and consideration of carers during times of transition, but any changes  
24 would fit into existing routines of providing care so should not have any significant  
25 cost implications.

26 Full details of the evidence and the committee's discussion are in [evidence review I:  
27 supporting carers during changes to the caring role](#).

28 [Return to recommendations](#)

1 ***Support for carers during end of life care and after the person dies***

2 Recommendations [1.9.1 to 1.9.16](#)

3 **Why the committee made the recommendations**

4 There was a great deal of variation in the quality of the evidence, but it helped the  
5 committee to highlight the information needs that carers have when they are caring  
6 for someone near the end of life. This included the need to be kept informed about  
7 the person's developing condition, and to be given information to meet their own  
8 practical and emotional needs.

9 The committee agreed with the finding that all practitioners (including non-specialist  
10 staff) need to know how to communicate sensitively with carers. Failing to do this  
11 can add to the carer's distress and may even put them off from seeking support from  
12 services in future.

13 There was good evidence that carers can find it very difficult to accept help at home  
14 and may rearrange their lives to avoid this. The committee agreed that practitioners  
15 going into carers' homes need to know that carers might find outside help invasive  
16 so they can incorporate this into their approach to working with the carer.

17 The committee drew on the evidence to suggest important considerations for  
18 practitioners supporting carers at home at the end of life, as well as how to improve  
19 carers' experiences in hospitals or care units. There was strong qualitative evidence  
20 showing how much carers value good quality care and support when they're  
21 providing end of life care at home, so the committee suggested examples of the  
22 support that would benefit them. Recognising that some hospitals might struggle to  
23 always provide private rooms, the committee added some alternative adaptations.

24 **How the recommendations might affect practice**

25 The recommendations on information provision and communication will help to  
26 improve consistency of best practice and should not have significant implications for  
27 training or cost. The way that care at home is provided, and the amount of resources  
28 allocated to make it accessible, varies from region to region. Recommendation  
29 1.9.13 was intended to improve the consistency of good support for people who are  
30 caring from someone at home so that they know about and can use local services.

1 The recommendation on dignity and privacy for people dying in hospitals or care  
2 units and their carers should promote and reinforce good practice without adding any  
3 significant resource impact. The committee provided a range of suggestions to  
4 improve patients' and carers' experiences even if space or resources are scarce.

5 Full details of the evidence and the committee's discussion are in [evidence review H:  
6 support needs for end of life](#).

7 [Return to recommendations](#)

## 8 **Context**

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

12 In the UK, the number of people over 85 (the group most likely to need care) is  
13 expected to increase to 1.9 million by 2020 (Office for National Statistics). Carers UK  
14 (2015) estimates that the number of people caring for someone will increase to 9  
15 million by 2037. In a survey conducted by Dying Matters, 70% of people expressed a  
16 wish to stay in their own home, and to die at home. Guidelines on supporting carers  
17 are therefore urgently needed.

18 According to Carers UK (2015), unpaid care is estimated to be worth about £132  
19 billion in terms of savings to health and social care budgets. However, carers may  
20 have to give up paid employment, which affects both their own independence and  
21 wellbeing and their economic contribution to the economy.

22 This may also have a substantial effect on their former employers' productivity and  
23 lead to high costs in recruitment and training.

24 Carers may also give up other activities and may face isolation; they may report  
25 feelings of depression and a reduced quality of life. Support from paid care workers  
26 at home can ease this pressure, but it may not always be appropriate or affordable.

27 The amount and quality of support available to unpaid carers varies widely across  
28 the UK. High quality and consistent care and support benefits the health, wellbeing

1 and resilience of unpaid carers. It can also enhance the life of the person being  
2 supported and help to reduce admissions to hospital and facilitate timely discharge.

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

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

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

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

18 The guideline is based on the best available evidence of effectiveness, including cost  
19 effectiveness. It takes account of other relevant NICE guidelines (including those on  
20 end of life care), the Children and Families Act 2014, NHS England's Carers' toolkit,  
21 the latest National Carers' Strategy, the Department of Health's Care and Support  
22 Statutory guidance (issued under the Care Act 2014).

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

## 27 **Finding more information and resources**

28 To find out what NICE has said on topics related to this guideline, see our web page  
29 on [carers](#)

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