Supporting adult carers

NICE guideline
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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

Overview

This guideline covers support for adults (aged 18 and over) who provide unpaid care for anyone aged 16 or over with health or social care needs. It aims to improve the lives of carers by helping health and social care practitioners identify people who are caring for someone and give them the right information and support. It covers carers' assessments, practical, emotional and social support and training, and support for carers providing end of life care.

This guideline covers general principles that apply to all adult carers. Recommendations about supporting carers of people with specific health needs can be found in NICE guidance on those conditions.

This guideline should be read together with the Care and support statutory guidance under the Care Act 2014 and the Children and Families Act 2014.

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 pharmacists and 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 1 or more people aged 16 or over with health and social care needs

Context

The 2011 Census indicated that there were around 6.5 million unpaid carers in the UK, with 1.3 million being over 65. Most carers were aged between 50 and 64 but people aged 65 and over made up a higher proportion of carers (19%) than in the population as a whole.

Carers UK (2015) estimated that the number of carers will increase to 9 million by 2037. This rise is linked with a number of factors, not least the increasing number of people aged over 85 (the group most likely to need care and support), which is expected to increase to 1.9 million by 2020 (Office for National Statistics). Other pressures include the continued closure of care and nursing homes and the increased use of care at home (The state of health care and adult social care in England 2018/19, Care Quality Commission). In addition, according to a survey conducted by Dying Matters, 70% of people expressed a wish to stay in their own home, and to die at home rather than in hospital or a nursing home. This is likely to further increase reliance on family members and friends.

Despite the recognised pressures, both Carers UK's State of caring report 2019 and the Government response to the 2016 carers call for evidence (in advance of the Carers action plan 2018 to 2020) report clear evidence that many carers did not feel adequately supported and that although caring can be immensely rewarding, many found that they did not feel respected, valued and supported for the contribution they made. Guidelines on supporting carers are therefore urgently needed.

The need for the guideline

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

Carers may also give up other activities and may face isolation; they may report feelings of depression and a reduced quality of life. Good quality, consistent support helps to address this, providing benefits for the health, wellbeing and resilience of unpaid carers. It can also enhance the life of the person being supported and help to reduce admissions to hospital and support earlier discharge. However, the amount and quality of support available to unpaid carers varies widely across the UK. Even where it is available, it may be neither appropriate nor affordable and complex local systems can be difficult to navigate with little guidance and direction (Government response to the 2016 carers call for evidence).

A key barrier to the provision of appropriate support to carers is that they are often not identified. Many carers do not think of themselves as carers or are not identified by health and social care practitioners as such (so called 'hidden carers') and do not know about the support available. The Care Act 2014 and Department of Health and Social Care's Care and support statutory guidance attempted to address this, substantially strengthening the rights and recognition of adult carers within the social care system. The Act entitles carers to assessment in their own right, together with information and advice to help them make the best choices about support for their own health and wellbeing. The Care Act defines a carer as an adult, aged 18 or over, who provides, or intends to provide, care for another adult who needs care because of a disability, health condition, frailty, mental health problem, addiction or other health or care needs. It excludes those who provide paid care or do so as voluntary work.

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

The purpose of this guideline

This guideline provides action-orientated recommendations for good practice, aimed at improving outcomes for adult carers. The guideline is based on the best available evidence of effectiveness, including cost effectiveness, as well as evidence on the views and experiences of carers, people using services and practitioners. It identifies good practice in providing support that enhances the wellbeing, resilience and life experience of adult carers.

The guideline covers information and support for carers; identifying carers and assessing their needs; helping carers stay in, enter or return to employment and training; providing community support, training, psychological and emotional support for carers; and providing support during changes to the caring role and during the end of life period of the cared-for person.

How it relates to legislation and other NICE guidelines

The guideline complements statutory duties and good practice as set out in relevant legislation and guidance. The recommendations cross-refer to legislation and other guidance where appropriate. In particular, the guideline takes account of the relationship between the Children and Families Act 2014 and the Care Act 2014, recognising that many young carers will transition into adult caring roles and that many parent carers will similarly transition into caring roles for their adult children. It also takes account of NHS England's Carers toolkit, the latest National carers strategy and the Carers action plan 2018 to 2020, and the Care and support statutory guidance.

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

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

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.

1.1 Information and support for carers: overarching principles

The right to information and support

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

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

1.1.3 Information for carers should be up to date and cover:

- the range of support and advice recommended in this guideline
- how to access social and community support for carers (see section 1.5)
- useful further sources of information and support such as carer groups and forums.

For a short explanation of why the committee made the recommendations on the right to information and support and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review B: providing information and advice about caring to carers in the UK.

Sharing information with carers

1.1.4 Discuss information with carers as well as giving them written materials. When providing information:

- ensure it is plainly worded, clearly presented and free of jargon
- be aware that smaller, more manageable chunks of information are easier to remember, and that visual aids or pictures can be useful
- encourage the carer to ask questions
- ensure that information is consistent.

1.1.5 Make information available in a range of formats to meet carers' needs and preferences, for example written leaflets, links to online and digital resources (including local and national websites and forums and social media) and information in accessible formats or different languages. For more about accessible communication see NHS England's Accessible Information Standard.

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

1.1.7 Offer to revisit discussions or provide the same information several times if needed, for example if there is a lot of complicated information to digest or the carer is experiencing emotional stress.

1.1.8 Practitioners responsible for providing and discussing information with carers should have the knowledge, time and communication skills to do so.

1.1.9 Primary care providers and primary care networks should explore ways of offering and promoting services to carers, including through partnership working (for example, working with local carer support services or nominating carer champions).

For a short explanation of why the committee made the recommendations on sharing information with carers and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review B: providing information and advice about caring to carers in the UK and evidence review D: work, education and training. Other supporting evidence and discussion can be found in evidence review A: identifying carers as defined by the Care Act 2014 and evidence review F: providing practical support for adult carers.

Working with and involving carers

1.1.10 Health and social care organisations should promote ways of working with carers that acknowledge them as expert partners in care and value their skills and knowledge about the person they care for. These approaches should be incorporated into formal policies and processes.

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

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

- take into account the mental capacity of the person being cared for and their wishes around confidentiality (see NICE's guideline on decision making and mental capacity)
- share with carers the information they need to provide care effectively and safely while respecting confidentiality (explain to them the constraints of confidentiality).

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

For a short explanation of why the committee made the recommendations on working with and involving carers and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review A: identifying carers as defined by the Care Act 2014 and evidence review B: providing information and advice about caring to carers in the UK.

1.2 Identifying carers

Recommendations for health and social care practitioners

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

- about their right to a carer's assessment, what this is and the benefits of having one
- how to obtain a carer's assessment
- that some support may be means tested
- that they can still access community support without formal assessment.

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

1.2.3 Take into account that carers themselves may not ask for support from certain professionals, for example GPs, because they may not view support for carers as being part of that professional's role.

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

- becoming a carer can be a gradual process, and carers may not recognise the changing nature of their relationship with the person they support
- carers may prefer to continue identifying primarily as a husband, wife, partner, sibling, parent, child or friend rather than as a carer
- carers often become engulfed by competing demands, including working and caring, and as a result may overlook their own needs as a carer and may not seek support
- the person being supported may not accept that they have care and support needs
- the carer does not live with the person or the person has moved away from home, for example into supported living or residential care.

1.2.5 Encourage carers to recognise their caring role and seek support, explaining the benefits for both them and the person they care for, including:

- the carer's role and contribution can be acknowledged and their support needs addressed and
- carers can share valuable knowledge about the person they care for, which helps practitioners provide the right care and support.

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

- other people offering help or support may not be family members or may not live with the person
- there may be more than 1 person involved in caring.

1.2.7 Practitioners involved in transferring people to and from hospital should seek to identify carers and refer them to appropriate services.

- Follow recommendations on support for families, parents and carers throughout admission in NICE's guideline on transition between inpatient mental health settings and community or care home settingsand
- Follow recommendations on discharge from hospital in NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

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

1.2.9 If a person who has care and support needs is also identified as having caring responsibilities, their care and support needs assessment should take account of this. They should also be offered a carer's assessment to identify their needs as a carer. Assessments must meet the requirements of the Care Act 2014.

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

For a short explanation of 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.

Full details of the evidence and the committee's discussion are in evidence review A: identifying carers as defined by the Care Act 2014. Other supporting evidence and discussion is in evidence review H: support needs of adult carers who are caring for people at the end of life and evidence review I: supporting carers during changes to the caring rolev.

Recommendations for health and social care organisations

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

- publicity campaigns involving local community services, for example posters and leaflets in GP surgeries, libraries and pharmacies
- digital communications, social media and online forums that engage with carers
- partnerships with community pharmacies, local carer support organisations and carer groups, for example in hospital settings
- partnerships with local community organisations who can help disseminate information more widely, such as further education colleges, sports centres and supermarkets.

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

1.2.12 Consider nominating a carer champion to help implement the recommendations in this guideline and Care Act 2014 requirements in relation to identifying carers.

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

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

For a short explanation of why the committee made the recommendations for health and social care organisations on identifying carers and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review A: identifying carers as defined by the Care Act 2014.

1.3 Assessing carers' needs

Carers' assessments

1.3.1 Local authorities, and social care organisations delegated by local authorities to carry out carers' assessments, should make arrangements for and carry out assessments in cooperation with other relevant health and social care organisations (in accordance with the Care Act 2014 and associated Care and support statutory guidance and the Children and Families Act 2014).

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

- the assessment covers all relevant aspects of health, wellbeing and social care needs and
- details of the assessment are shared with other practitioners and organisations who are involved in the assessment.

1.3.3 Health and social care organisations should ensure that practitioners who carry out or contribute to carers' assessments have training and skills in that role and access to specialist advice.

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

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

For a short explanation of why the committee made the recommendations on carers' assessments and how they might affect practice, see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review C: assessment of carers as defined by the Care Act 2014.

Preparing for and carrying out a carer's assessment

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

- whether the person they care for is near the end of life
- the level of stress the carer is experiencing
- the timing of hospital discharge
- changes to the caring role
- any negative impact of delays on the health and wellbeing of the carer.

1.3.7 Provide flexibility in how, when and where carers' assessments are carried out, taking into account individual preferences and accommodating their caring responsibilities, working patterns and other circumstances.

1.3.8 Ensure that the assessment process is accessible, easy to navigate and complete, and tailored to individual needs, with information provided in a format that carers can understand.

1.3.9 Before a carer's assessment takes place, share information with the carer that helps them prepare.

1.3.10 Discuss caring in the context of the carer's own family and support networks, for example whether they share caring responsibilities with other people and whether they care for more than 1 person.

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

1.3.12 Do not make assumptions about the willingness and the ability of carers to carry out caring tasks when completing assessments for the carer or the person they care for.

1.3.13 If a carer's needs have been identified during a hospital-based assessment:

- inform the local authority (and/or any delegated care organisation) that a carer's needs have been identified
- ensure an effective process is in place to link the hospital-based carer's assessment with the community-based statutory assessment, to avoid duplication and so that meaningful support for carers is provided during transfer from hospital (including during a crisis).

1.3.14 Ensure that replacement care is discussed as part of carers' assessments, including planning for any emergency replacement care that might be needed, for example if the carer becomes suddenly unwell.

For a short explanation of why the committee made the recommendations on preparing for and carrying out a carer's assessment and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review C: assessment of carers as defined by the Care Act 2014 and evidence review D: work, education and training.

Work, education and training

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

1.3.16 Ensure that practitioners carrying out carers' assessments have the necessary skills, knowledge and understanding of potential opportunities for returning to, or remaining in work, education and training.

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

For a short explanation of why the committee made the recommendations on work, education and training and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review D: work, education and training.

After a carer's assessment

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

1.3.19 After an assessment:

- ensure the carer understands the actions that have been agreed and what the next steps will be and
- share information (as appropriate) with other practitioners and organisations involved with the carer and the person they care for.

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

For a short explanation of why the committee made the recommendations on after a carer's assessment and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review C: assessment of carers as defined by the Care Act 2014 and evidence review D: work, education and training.

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

Advice and support

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

1.4.2 Services providing welfare rights advice or back-to-work or education training should develop a good understanding of carer needs, for example by appointing a named carer champion who can provide knowledgeable, expert advice and train other practitioners in the service.

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

1.4.4 Workplaces should make information available to their staff about ways in which they can support employees who need to balance caring responsibilities with work. See NICE's guideline on workplace health.

For a short explanation of why the committee made the recommendations on advice and support for helping carers stay in, enter or return to work, education and training and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review D: work, education and training. Other supporting evidence and discussion can be found in evidence review A: identifying carers as defined by the Care Act 2014.

Flexibilities to support employment

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

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

1.4.7 Workplaces should ensure that staff with caring responsibilities have equal access to career development. At a minimum, workplaces must meet the requirements set out in the Equality Act 2010 in relation to people with caring responsibilities.

1.4.8 Health and social care organisations should offer flexibility when arranging appointments for working carers and the person they care for. Examples include workplace surgeries, carer appointments outside of office hours, digital access and telephone appointments.

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

For a short explanation of why the committee made the recommendations on flexibilities to support employment and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review D: work, education and training.

Replacement care

1.4.10 Commissioners should be aware of the benefits of replacement care for supporting carers to stay in, enter or return to work, education and training when designing and delivering support services for carers.

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

1.4.12 Ensure that replacement care is flexible and provides a choice of options to meet all levels of carer need, including for those who care for more than 1 person or who care for over 20 hours a week.

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

For a short explanation of why the committee made the recommendations on replacement care and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review D: work, education and training.

1.5 Social and community support for carers

Community information, advice and support

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

- local carer support services
- self-help groups
- community and faith groups
- specialist benefits, financial and legal advice
- financial support
- advice about self-care
- where to find reliable information about the health condition of the person they are caring for.

For a short explanation of why the committee made the recommendation on community information, advice and support and how it might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review F: providing practical support for adult carers.

Carers' breaks

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

1.5.3 Carers' breaks should:

- meet carers' needs for a break, for example in duration, timing, frequency and type of break
- be arranged in a way that provides reliable and consistent support to the carer (such as avoiding last-minute changes that could lead to additional stress for the carer).

For a short explanation of why the committee made the recommendations on carers' breaks and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review F: providing practical support for adult carers.

Peer support

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

Support for former carers

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

For a short explanation of why the committee made the recommendations on peer support and support for former carers and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review F: providing practical support for adult carers.

Advocacy

1.5.6 Local authorities should provide information to carers about how to access advocacy support services. Access to advocacy services should meet the requirements of the Care Act 2014 and the Mental Capacity Act 2005.

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

For a short explanation of why the committee made the recommendations on advocacy and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review F: providing practical support for adult carers.

1.6 Training to provide care and support

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

1.6.2 Commissioners and those involved in planning local carer support services should ensure that the provision of carer training meets local needs.

1.6.3 Involve carers in the design and delivery of carer training to ensure it covers skills and expertise relevant to them.

Carer training programmes

1.6.4 Offer carer training programmes that are:

- designed to improve carers' knowledge and coping skills
- accessible and available in a variety of formats, including printed or online materials or face to face
- tailored to the needs of carers
- delivered by practitioners with relevant knowledge and skills.

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

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

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

- managing medicines
- managing diet and nutrition
- maintaining personal hygiene
- managing behaviour that challenges
- use of digital and assistive technology
- specific information that carers need to enable them to remain safe in their caring role.

1.6.7 Ensure that training programmes for carers are inclusive and address the needs and preferences of diverse groups, such as lesbian, gay, bisexual and transgender carers, and carers from diverse ethnic, religious and cultural backgrounds.

1.6.8 Training programmes for carers should provide a balance between learning, enjoyment, a chance to meet other carers and opportunities for peer support.

1.6.9 Encourage carers to keep in touch with each other after they have attended a training programme and suggest ways they could do this.

For a short explanation of why the committee made the recommendations on training to provide care and support, including carer training programmes, and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review E: providing training for carers to provide practical support.

Use of equipment and adaptations, and moving and handling

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

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

For a short explanation of why the committee made the recommendations on use of equipment and adaptations, and moving and handling, and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review E: providing training for carers to provide practical support.

1.7 Psychological and emotional support for carers

Psychosocial and psychoeducational support

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

- developing personalised strategies and building carer skills
- advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing
- information about emotional support services and psychological therapies for carers and how to access them.

1.7.2 Ensure that the range of psychosocial and psychoeducational support offered to carers includes group-based options.

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

1.7.4 Arrange the timing of psychosocial or psychoeducational support to suit carers' circumstances, taking into account other commitments such as work or other caring and family responsibilities.

1.7.5 When providing psychosocial or psychoeducational support to carers, take into account:

- the carer's preferred location
- whether they need support to attend (for example a practitioner to go with them)
- physical accessibility (such as help needed with transport)

- if replacement care is needed
- the carer's preferred format
- the cultural appropriateness of the intervention
- what follow-up will be needed.

For a short explanation of why the committee made the recommendations on psychosocial and psychoeducational support for carers and how they might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review G: providing psychological and emotional support to adult carers.

Psychotherapy and counselling

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

- psychotherapy and counselling interventions in line with existing NICE guidance (see NICE's topic page for mental health and behavioural conditions) or
- referral to a GP or mental health professional who can provide interventions in line with existing NICE guidance.

For a short explanation of why the committee made the recommendation on psychotherapy and counselling and how it might affect practice see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review G: providing psychological and emotional support to adult carers.

1.8 Support during changes to the caring role

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

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

- becomes an adult

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

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

- start or go back to work
- move from being a young carer to an adult carer
- have a change in benefits or financial circumstances
- go through personal changes (such as divorce)
- take on another caring role
- go into hospital
- are bereaved
- become less able to care as they get older.

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

- recommendations on communication and information sharingand
- recommendations on support and training for carers.

For a short explanation of why the committee made the recommendations on support during changes to the caring role and how they might affect practice, see rationale and impact.

Full details of the evidence and the committee's discussion are in evidence review I: supporting carers during changes to the caring rolev.

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

Information and support

1.9.1 Offer carers frequent opportunities for discussion and help them to understand information about the diagnosis and prognosis of the person they care for (with the person's consent). Use a sensitive manner during these discussions and avoid jargon.

1.9.2 Health and social care practitioners involved in providing end of life care should be competent to have conversations with carers about death and dying.

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

1.9.4 Health and social care practitioners, including home care workers, should recognise that carers can find it hard to accept help at home when they are providing end of life care and can find it invasive.

1.9.5 Provide continuity during end of life care with the same professional care staff wherever possible, so that the carer and the person they care for can build a relationship with the staff supporting them.

1.9.6 Encourage carers who are caring for someone near the end of their life to think about ways they can get support from their family, friends, employer and wider social network.

Advance care planning

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

1.9.8 When making an advance care plan that includes responsibilities for carers, consider the wishes of any current or future carers who have been named in the plan.

1.9.9 Ensure the carer has a clear understanding of their role as part of the advance care plan. Share advance care plans in a clear and simple format with everyone involved in the person's care.

Providing care at the end of life

1.9.10 When managing medication and other care at the end of life, follow the principles of involving carers and the dying person described in NICE's guideline on care of dying adults in the last days of life.

1.9.11 During a structured medication review, as described in NICE's guideline on medicines optimisation, take into account:

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

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

- replacement care
- palliative home care
- practical support, for example to use equipment and adaptations
- additional help in the home.

1.9.13 Provide privacy and dignity for people dying in hospital and their carers. This could include offering them a private room or, if this is not possible, alternatives such as:

- private space
- space to keep personal possessions from home
- flexible visiting times and tailored arrangements for carers
- comfortable seating for the carer
- access to refreshments.

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

1.9.15 Take account of the changing information and support needs of carers in planning for their own future when the person they care for dies. This should include discussing with carers how to address their own support needs after the death of a mutual carer.

For a short explanation of why the committee made the recommendations on support for carers during end of life care and after the person dies and how they might affect practice see rationale and impact

Full details of the evidence and the committee's discussion are in evidence review H: support needs of adult carers who are caring for people at the end of lifev.

Terms used in this guideline

Carers

In this guideline, a carer is an adult (aged 18 or over) who provides unpaid care and support to a family member, partner or friend (aged 16 or over) because of a disability, health condition, frailty, mental health problem, addiction or other health or social care need.

Carer champion

A designated member of staff (for example in a GP surgery, hospital, workplace, leisure or similar setting) who is given the task of supporting and speaking up for carers. They can act as a key contact for carer information and advice in that setting, providing knowledgeable, expert advice as well as training other practitioners working within the service.

Carer support plan

If a carer is identified as having eligible needs following an assessment under the Care Act 2014, the local authority must provide a support plan that sets out how those needs will be met. The support plan must be developed in partnership with the carer and should set out the outcomes the carer hopes to achieve, including their wishes around providing care and accessing work, education and leisure. The support plan must be regularly reviewed.

Carer's assessment

Anyone who is an unpaid carer for a family member or friend has the right to discuss their own needs with their local authority, separate to the needs of the person they care for. This is a statutory requirement under the Care Act 2014. Carers can discuss anything they think would help with their own health and wellbeing or with managing other aspects of their life, including their caring role. The local authority uses this information to decide what help it can offer.

Carers' breaks

These services, which would include respite care, give carers a break by providing short-term care for the person with care needs in their own home or in a residential setting. This can mean a few hours during the day or evening, overnight, or a longer-term break. Carers' breaks may be one-off or more regular arrangements. They can also benefit the person with care needs by giving them the chance to try new activities and meet new people.

Peer support

Peer support involves carers sharing experiences, practical advice and emotional support and improving their understanding of the options available to them and the person they care for. Peer support can take a number of different forms, including one-to-one friendships and support based on lived experience and contact through third sector organisations, support groups or online networks. Peer support is often but not always provided by volunteers, for example volunteer befrienders.

Replacement care

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

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

Recommendations for research

The guideline committee has made the following recommendations for research.

Key recommendations for research

1 Whole family approach to carer's assessment

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

For a short explanation of why the committee made the research recommendation on whole family approach to carers' assessment see rationale and impact.

Full details of the research recommendation are in evidence review C: assessment of carers as defined by the Care Act 2014.

2 Support for carers to return to work, employment or training

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

For a short explanation of why the committee made the research recommendation about support for carers to return to work, employment or training see rationale and impact.

Full details of the research recommendation are in evidence review D: work, education and training.

3 Training for carers to reduce caring-related incidents

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

For a short explanation of why the committee made the research recommendation about training for carers to reduce caring-related incidents see rationale and impact.

Full details of the research recommendation are in evidence review E: providing training for carers to provide practical support.

4 Practical support through carer passport schemes

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

For a short explanation of why the committee made the research recommendation about practical support through carer passport schemes see rationale and impact.

Full details of the research recommendation are in evidence review F: providing practical support for adult carers.

5 Practical support for carers through social prescribing

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

For a short explanation of why the committee made the research recommendation about practical support for carers through social prescribing see rationale and impact.

Full details of the research recommendation are in evidence review F: providing practical support for adult carers.

Rationale and impact

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

The right to information and support

Recommendations 1.1.1 to 1.1.3

Why the committee made the recommendations

The committee used themes in the qualitative evidence to build on statutory guidance about the key principles of providing information and support to carers. Under the Care Act 2014, local authorities must establish and maintain a service for providing people with information and advice relating to support for carers. However, many carers are unaware of the advice and services available, or they may not have time to search for them. The committee wanted to emphasise the importance of signposting carers to useful local services and up-to-date sources of information and that health and social care practitioners should pass this information to carers whenever they get the chance.

How the recommendations might affect practice

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

Full details of the evidence and the committee's discussion are in evidence review B: providing information and advice about caring to carers in the UK.

Return to recommendations

Sharing information with carers

Recommendations 1.1.4 to 1.1.9

Why the committee made the recommendations

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

One strong theme suggested that carers often receive information from multiple sources around the same time, emphasising the importance of professionals in different services working together to make sure they are giving consistent advice.

There was some limited evidence that primary care practitioners would like to promote care services to carers and are interested in formalising ways to do it. However only 1 example was identified for how this might be done within GP surgeries. The committee discussed this and reached the consensus that developing partnerships with other carer-related services and using carer 'champions' within teams are 2 ways they could do this.

How the recommendations might affect practice

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

Details of the evidence and the committee's discussion are in evidence review B: providing information and advice about caring to carers in the UK and evidence review D: work, education and training. Other supporting evidence and discussion can be found in evidence review A: identifying carers as defined by the Care Act 2014 and evidence review F: providing practical support for adult carers.

Return to recommendations

Working with and involving carers

Recommendations 1.1.10 to 1.1.13

Why the committee made the recommendations

There was evidence that carers value being recognised and respected as core members of the team around the person they care for and that carers have valuable information to contribute to care planning and assessment. They are often key to understanding the person's needs and preferences, so these recommendations were made to promote their involvement. This approach should be incorporated in formal policies and processes to ensure it is consistent across organisations.

The evidence showed that to provide effective care, carers need sufficient information about the person they are caring for. However, in many cases this can clash with the person's right to confidentiality. The committee made a recommendation to address this issue and balance the different concerns.

There was strong evidence that carers value being kept up to date, even with difficult news about the condition of the person they care for. However, the evidence suggested that professionals are sometimes vague, euphemistic or evasive with difficult news, which carers don't find helpful. They prefer to have time to process and understand any new information, and to properly prepare for possible changes to their caring role in the future.

How the recommendations might affect practice

The committee acknowledged that a little additional time may be needed for practitioners to keep carers up to date and well informed. However, the benefits include ensuring that care planning is based on accurate and detailed information, encouraging the carer in their role and respecting them as a core team member to help sustain the caring arrangement.

Details of the evidence and the committee's discussion are in evidence review A: identifying carers as defined by the Care Act 2014 and evidence review B: providing information and advice about caring to carers in the UK.

Return to the recommendations

Identifying carers: recommendations for health and social care practitioners

Recommendations 1.2.1 to 1.2.10

Why the committee made the recommendations

It is a requirement of the Care Act 2014 for local authorities to have due regard to the importance of identifying carers who may have support needs and explain the advice and support available to them. The quality of the evidence was fairly low but it found specific barriers to identifying carers, so the committee drew on these along with their own experience to recommend how to improve identification of carers. This included setting out a range of potential opportunities for practitioners to identify carers and record details about them – providing the carer gives consent.

In the committee's experience, there are many reasons why people may not identify as a carer and, even if people recognise they are in a caring role, they are still more likely to see their primary role in relation to that person as a family member or friend. Practitioners should take this into account in the way they communicate and work with carers.

There may be more than 1 person involved in a person's care and support, and the committee agreed that it is important that health and social care practitioners seek to identify all carers and to understand the context of their caring situation. This enables advice, support and assessments to be more likely to meet each carer's needs.

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

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

Carers may also have care needs of their own due to long-term health conditions or disability. Where this is the case, an assessment of both their own care and support needs and their carer support needs should take place in line with the requirements of the Care Act 2014.

Finally, the committee agreed that not all carers would want or need a formal statutory carers assessment, for example if they were managing well at that time, so it was important to give those carers information about how and where to access carer support services if they need them.

How the recommendations might affect practice

The recommendations should have limited cost implications because they involve using existing opportunities to help identify carers. There may be some costs associated with improving how information about carers is recorded and used to improve identification and support. The committee recognised that as more people identify as carers and seek information and support, local authorities, together with partner organisations in health and social care, will need to consider how resources are best used to benefit as many carers as possible, as well as those most in need.

Full details of the evidence and the committee's discussion are in evidence review A: identifying carers as defined by the Care Act 2014. Other supporting evidence and discussion is in evidence review H: support needs of adult carers who are caring for people at the end of life and evidence review I: supporting carers during changes to the caring rolev.

Return to recommendations

Identifying carers: recommendations for health and social care organisations

Recommendations 1.2.11 to 1.2.14

Why the committee made the recommendations

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

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

Practitioners coming into contact with carers need to have good knowledge of their responsibilities under the Care Act 2014 in relation to identifying carers. By consensus, the committee agreed that one possible way to achieve this was for organisations to consider nominating 'carer champions' within their workforce to help other staff understand their responsibilities in this area.

How the recommendations might affect practice

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

Full details of the evidence and the committee's discussion are in evidence review A: identifying carers as defined by the Care Act 2014.

Return to recommendations

Carers' assessments

Recommendations 1.3.1 to 1.3.5

Why the committee made the recommendations

Recommendations were drafted to complement the Care Act 2014, other associated care and support statutory guidance, and the Children and Families Act 2014. These set out legal duties for local authorities, or social care organisations delegated by local authorities, to arrange and carry out carers' assessments.

The evidence that underpinned the recommendations was of variable quality but it found that:

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

The evidence was most limited on collaborative working and on carers' assessments as a therapeutic intervention, so for these recommendations the committee supplemented the evidence with their own experience and expertise.

The committee thought it was important that carers feel that they have co-produced the assessment and that it reflects what is most important to them. They also agreed it was important that practitioners carrying out carers' assessments should have access to specialist advice, for example about particular aspects of care and treatment of the person they care for, because this might influence the support needs of the carer.

There was no evidence on whether using the lead professional approach or the whole family approach can make collaborative working easier and more effective. The committee agreed to make a research recommendation on the whole family approach to carers' assessments (see research recommendation 1).

How the recommendations might affect practice

The impact of the recommendations is likely to vary depending on how much local services already collaborate with each other and train their staff to take the initiative with assessments. Additional training or reviewing of service coordination may be needed in some areas, but because such assessments are statutory requirements, they should not introduce additional financial implications.

Full details of the evidence and the committee's discussion are in evidence review C: assessment of carers as defined by the Care Act 2014.

Return to recommendations

Preparing for and carrying out a carer's assessment

Recommendations 1.3.6 to 1.3.14

Why the committee made the recommendations

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

Qualitative evidence reported that some carers found the assessment process difficult to follow. Some carers also struggled to understand what being 'entitled to an assessment' actually meant. The committee agreed that practitioners need to give carers a clear explanation of what a carer's assessment involves and provide information in advance so that carers are better prepared and have time to reflect on their needs as carers. The committee also used the themes reported in the evidence to suggest ways of making assessments more positive for carers by making them more accessible and person-centred.

Expert testimony suggested the context in which caring takes place may be complicated, for example someone may be caring for more than 1 person or may be sharing their care responsibilities with other people, and so the committee agreed assessors should take account of this.

According to the evidence, carers' assessments are sometimes carried out in conjunction with those of the person they care for, which in some cases can mean the carer's own needs are not separately assessed. This was also supported by expert testimony. The committee agreed on the importance of making sure the carer's needs are considered independently, while providing an option to link with the cared-for person's assessments.

The Care Act 2014 states that carers' assessments must include an assessment of the ability and willingness of the carer to provide care, so assessors must not make assumptions about how willing or able a carer is to perform any given caring tasks.

If an assessment is done in hospital, it needs to be forward-looking and connected to the completion of a statutory assessment by community staff. This helps to ensure meaningful support for carers during transfer from hospital, because the evidence showed that assessments by different services can be fragmented.

The evidence suggested that the provision of replacement care enables carers to return to or remain in work. Therefore, the committee agreed that replacement care should always be discussed during assessments.

How the recommendations might affect practice

Carers' assessments are already statutory, so the implementation of these recommendations may only involve minor changes to existing practice. Some costs may be associated with retraining, or with implementing more flexible and individualised assessments, but the committee agreed these were implicit to what is an adequate assessment as required by the Care Act 2014. The committee considered that sharing information with carers in advance of the assessment so that they are prepared would not have significant complications. It could be facilitated by the creation of a frequently asked questions resource, for example.

Full details of the evidence and the committee's discussion are in evidence review C: assessment of carers as defined by the Care Act 2014 and evidence review D: work, education and training.

Return to recommendations

Work, education and training

Recommendations 1.3.15 to 1.3.17

Why the committee made the recommendations

Although there was no high-quality evidence, the committee was able to make recommendations in areas where the lower-quality evidence aligned with their own experience. Some qualitative evidence showed that carers valued being offered services, practical support and financial support to stay in work, education and training. Evidence also suggested there may not be enough opportunities presented during carers' assessments to encourage their use and uptake. This chimed with the committee's concern that practitioners carrying out assessments often overlook carers' wishes about work, education and training.

The committee agreed that it was important for assessing practitioners to have good local knowledge about these types of opportunities for carers, as well as the community support options available (such as replacement care) to help carers take up these opportunities if they wish.

How the recommendations might affect practice

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

Full details of the evidence and the committee's discussion are in evidence review D: work, education and training.

Return to recommendations

After a carer's assessment

Recommendations 1.3.18 to 1.3.20

Why the committee made the recommendations

There was some evidence that after an assessment, carers don't always feel that they have received helpful information or advice. Although this evidence was low in quality, having mostly come from survey studies with uncontrolled and potentially biased participant samples, it was supported by the combined experience of the committee. They agreed that practitioners should always make sure an assessment leads to clear outcomes and practical benefits for the carer. This means ensuring good communication with other practitioners and organisations and carrying out any agreed actions.

The committee agreed that if a carer's support plan is prepared as a result of an assessment, it should be monitored and reviewed regularly to ensure it achieves outcomes that are important to the carer.

How the recommendations might affect practice

The cost of implementing the actions identified as part of assessment will vary from case to case and will be informed by local eligibility requirements for funded support and on local arrangements for sharing information about carers' support requirements as well as monitoring and review. They should not have large cost implications and do not represent a significant change in practice.

Full details of the evidence and the committee's discussion are in evidence review C: assessment of carers as defined by the Care Act 2014 and evidence review D: work, education and training.

Return to recommendations

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

Recommendations 1.4.1 to 1.4.4

Why the committee made the recommendations

The Care Act 2014 mandates providing information for carers on work, education and training, and the committee used a combination of evidence and expert consensus to build on that legal requirement. There was some evidence that a lack of information and advice, combined with the fragmented nature of local support services, often acted as barriers to carers remaining in, returning to or entering work, education and training. The committee agreed it was important to make widely available person-centred advice and information specifically for carers. This was supported by evidence that carers welcomed advice and information from practitioners who understood the particular challenges they face in combining work and caring, including associated benefits and welfare advice. One way that the committee proposed services may do this is by designating a 'carer champion' to offer expert advice when needed and to assist in training other practitioners working in the service about carers' needs and rights under the Care Act 2014.

There was some limited evidence showing the disadvantages experienced by young adult carers striving to balance work or education with caring. The committee also noted the difficulties often experienced by older carers wishing to retain or return to employment after the end of their caring roles. They agreed that carers may lack confidence about finding work, especially if they have spent years caring at the expense of education or training. They agreed by consensus that it was relevant for all carers to be encouraged to recognise their value to employers using the skills they have built up during caring.

There was a lack of evidence about the effectiveness of particular tools or approaches for supporting carers to return to work, education or training. Supported by expert testimony, the committee agreed that there was potential in further exploring whether the use of personal budgets, either for the person being cared for or the carer in their own right, might have positive outcomes for the carer. So the committee agreed to make a research recommendation about the effectiveness of personal health and social care budgets in supporting carers to return to work, education or training (see research recommendation 2).

How the recommendations might affect practice

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

Full details of the evidence and the committee's discussion are in evidence review D: work, education and training. Other supporting evidence and discussion can be found in evidence review A: identifying carers as defined by the Care Act 2014.

Return to recommendations

Flexibilities to support employment

Recommendations 1.4.5 to 1.4.9

Why the committee made the recommendations

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

It is a requirement of the Equality Act 2010 for employers to actively promote a positive culture towards people with caring responsibilities. The committee agreed that this could include promoting opportunities for flexible working practices and use of employee assistance programmes that can provide advice and support for working carers, as well as ensuring that staff with caring responsibilities have equal access to career development opportunities.

Using expert witness testimony, the committee incorporated some specific examples of adjustments in the workplace that would benefit carers.

How the recommendations might affect practice

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

Providing flexibility for working carers may incur additional costs for employers (for example, if it's not possible to reorganise work among other staff) and for policymakers and commissioners (for example, costs of enforcing legislation). However, the committee also recognised that flexible working could assist with staff retention, bringing potentially large cost savings.

Full details of the evidence and the committee's discussion are in evidence review D: work, education and training.

Return to recommendations

Replacement care

Recommendations 1.4.10 to 1.4.13

Why the committee made the recommendations

Some limited evidence showed that carers valued being able to use replacement care locally so they could work or take part in education or training, and the committee's own experience supported this. Furthermore, economic evidence suggested that the gains from increased labour market participation could outweigh the costs of replacement care. Those gains would come in the form of generating increased taxation, reducing social welfare payments and increasing economic output.

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

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

How the recommendations might affect practice

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

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

Full details of the evidence and the committee's discussion are in evidence review D: work, education and training.

Return to recommendations

Community information, advice and support

Recommendation 1.5.1

Why the committee made the recommendation

The committee used the evidence along with their own experience to complement the legal requirements of the Care Act 2014 about providing information on community services to carers. They noted that the exact provision may vary by region and not all services will be available to everybody, so carers should be made aware of what is available to them and the ways in which they can access different types of support.

The committee suggested the kinds of information that carers would find useful, based on the evidence. They also wanted to emphasise that information giving should be ongoing to meet the changing circumstances of carers. This echoes recommendations elsewhere that carers' information and support needs should be revisited frequently (see the section on sharing information with carers about providing tailored information for carers).

How the recommendation might affect practice

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

Full details of the evidence and the committee's discussion are in evidence review F: providing practical support for adult carers.

Return to recommendations

Carers' breaks

Recommendations 1.5.2 and 1.5.3

Why the committee made the recommendations

There was a lack of evidence on effectiveness or cost effectiveness to support a recommendation about the circumstances in which carers' breaks should or shouldn't be offered. Instead, the committee based their recommendations on qualitative evidence showing that many carers struggle to maintain their own wellbeing and often overlook their own needs because of their caring responsibilities. This makes it important for practitioners to remind them regularly of the value of taking a break, including a break from their usual routines associated with caring.

The evidence showed that carers' breaks were often limited in nature, availability, quality and flexibility. This can cause stress to the carer that undermines the benefits when they are offered. The committee drafted recommendations to improve how breaks are provided when they are offered or accessed by carers.

No evidence was found about carers' passports as a means of improving support for carers, so the committee made a research recommendation to establish their effectiveness and to understand people's views and experiences of them (see research recommendation 4).

How the recommendations might affect practice

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

Full details of the evidence and the committee's discussion are in evidence review F: providing practical support for adult carers.

Return to recommendations

Peer support and support for former carers

Recommendations 1.5.4 and 1.5.5

Why the committee made the recommendations

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

Low quality evidence from 1 study suggested some perceived benefits of support for former carers (for example, reducing social isolation). Given the limitations of this evidence, the committee could only recommend considering the possibility of extending support services to people after their caring role had ended (in place of a stronger recommendation).

The committee agreed that signposting and social prescribing could potentially promote better access to peer support for carers, but there was no evidence so they could not recommend them. Evidence is emerging about the effectiveness of social prescribing more generally, so the committee made a research recommendation about its effectiveness and acceptability specifically for carers (see research recommendation 5).

How the recommendations might affect practice

Peer support for carers is available but may be configured differently in different places. There may be an increased demand for and uptake of peer support locally, which may affect coordination and training costs for voluntary services.

The committee did not think that continuing to offer support to former carers would have resource implications because for most carers this support would only be needed for a short time after their caring role ended.

Full details of the evidence and the committee's discussion are in evidence review F: providing practical support for adult carers.

Return to recommendations

Advocacy

Recommendations 1.5.6 and 1.5.7

Why the committee made the recommendations

There was no evidence in this area, but there is a legal responsibility on local authorities to provide access to independent advocacy, in line with the Care Act 2014 and the Mental Capacity Act 2005. The committee agreed by consensus that it was important to inform carers about their right to support from advocacy services and the circumstances in which they would apply. To build on this and ensure that advocates (or other representatives) can give meaningful support to carers, the committee agreed that practitioners should recognise the voice and role of advocates. In the committee's view this does not always happen in practice.

The committee also noted the important role of advocacy as set out in the Mental Capacity Act 2005.

How the recommendations might affect practice

These recommendations underline existing legal requirements and should not impact on practice.

Full details of the evidence and the committee's discussion are in evidence review F: providing practical support for adult carers.

Return to recommendations

Training to provide care and support

Recommendations 1.6.1 to 1.6.9

Why the committee made the recommendations

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

The committee used the evidence to pinpoint the common features of effective, cost-effective and acceptable carer training programmes. Tailoring programmes means their exact content would depend on the training needs of different carers but, based on the evidence, the committee recommended some core components to include. Those elements related to psychological and emotional wellbeing are included in the psychological and emotional support section of this guideline.

By consensus, the committee also agreed to add some additional components in recommendation 1.6.6 that they felt were valuable, based on their knowledge and experience, but which did not have specific support from the evidence.

Qualitative evidence suggested that some carers have insufficient information about medication management and the use and maintenance of equipment to administer medication. Therefore, the committee recommended that training programmes could include managing medicines. For guidance on managing medicines in the community, see NICE's guideline on managing medicines for adults receiving social care in the community.

The committee agreed by consensus that training could be delivered in a number of ways, in groups or one-to-one, and that it was important to acknowledge the range of skills and specific expertise needed by trainers. The committee also agreed that trainers should seek input directly from people who have been carers when designing and delivering carer training so that training programmes are based on real and recent lived experiences of caring.

From the evidence it was clear that many carers value the chance during training to meet other carers with similar experiences or circumstances, as well as the opportunity to have a break from caring. Moderate quality evidence suggested that training programmes reduced carers' sense of isolation, helped them interact with each other, discuss and resolve issues they are facing, and provide informal emotional support. Based on this evidence and their own expertise, the committee agreed that training programmes should provide a balance between learning and social and emotional support, and opportunities to explore different ways of continuing to offer support and advice to each other (peer support).

Evidence showed positive feedback from minority groups (in this case lesbian, gay, bisexual and transgender carers) that training groups which are inclusive or specific to them were valued and allowed them to meet others from that community. Therefore, the committee agreed to make a recommendation to ensure that training programmes are designed with a particular focus on being inclusive and supporting diverse groups.

There was no evidence on the impact of training for carers on caring-related accidents or incidents (involving either the carer or the person they care for), including failure to take prescribed medicine and falls. The committee therefore made a research recommendation to identify what training, support or other interventions aimed at carers help to reduce caring-related accidents or incidents (see research recommendation 3). The committee noted that it would be helpful if any new research were able to identify the association between increased accidents and specific factors such as the carer's age and their physical and mental health.

How the recommendations might affect practice

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

Providing multicomponent training programmes may involve initial additional costs. First, there may be an increase in the number of requests for training. Training may also be needed for practitioners to deliver the training. However, the components in recommendation 1.6.5 were based on the elements of the START (Strategies for Relatives) training programme. The economic evidence suggested that START was cost effective for carers of people with dementia and the committee agreed that it was reasonable to extrapolate this to all carers. Therefore, any additional costs of providing the programmes would be worth the benefits in carers' wellbeing and quality of life.

Full details of the evidence and the committee's discussion are in evidence review E: providing training for carers to provide practical support.

Return to recommendations

Use of equipment and adaptations, and moving and handling

Recommendations 1.6.10 to 1.6.11

Why the committee made the recommendations

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

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

How the recommendations might affect practice

The recommendations reinforce legislation and should improve consistency of best practice. The way services support carers with moving and handling is variable, and changes to practice will depend on the availability of services in each area. Providing advice and guidance for carers in using equipment and adaptations and in moving and handling could involve additional costs. There may be an increase in the number of carers seeking this advice or guidance, and training may be needed for the practitioners who are delivering it.

Full details of the evidence and the committee's discussion are in evidence review E: providing training for carers to provide practical support.

Return to recommendations

Psychosocial and psychoeducational support for carers

Recommendations 1.7.1 to 1.7.5

Why the committee made the recommendations

The evidence suggested that psychosocial and psychoeducational support was important to carers, and helped improve their knowledge, skills and confidence about caring as well as improving emotional support, mental wellbeing and stress management. Overall, the quality of the quantitative evidence was low so the committee agreed that psychosocial and psychoeducational support should only be considered as an option for carers rather than be offered routinely. They used the qualitative evidence and their own expertise to agree the important elements that should be included as part of this support. Some of the components included in recommendation 1.6.5 (training and skills for carers) are derived from the same evidence and also contribute to mental wellbeing and stress management. They are considered as complementary to the components here.

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

There was some qualitative evidence suggesting that carers see the timing of the support being offered as important. They believed psychological support would be most helpful at the earlier stages of becoming a carer, or soon after any times when the caring situation had changed or escalated. The committee agreed it was important to check regularly whether carers' needs and circumstances have changed and they need psychological support.

The committee also considered the timing of support in terms of carers' other commitments and responsibilities and drafted a recommendation to be mindful of their schedule and weekly circumstances.

The committee agreed by consensus that it was also important for practitioners to think about the way in which such support was provided. This might determine whether carers choose (or are able) to take up this intervention. They made a recommendation about other factors to consider, including location and accessibility, health and support needs of the carer, cultural factors and the availability of replacement care while they are away.

How the recommendations might affect practice

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

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

Full details of the evidence and the committee's discussion are in evidence review G: providing psychological and emotional support to adult carers.

Return to recommendations

Psychotherapy and counselling

Recommendation 1.7.6

Why the committee made the recommendation

The evidence on the effectiveness of psychotherapy and counselling was conflicting and was limited to cognitive behavioural therapy for carers of people living with dementia. There was not enough evidence to recommend these interventions for carers generally but the committee agreed on the importance of providing psychotherapy and counselling interventions for carers with mental health problems, in line with existing NICE guidance on mental health and behavioural conditions.

How the recommendation might affect practice

Because the provision of psychotherapy and counselling interventions to people with mental health problems is in line with existing NICE guidelines, the recommendation should not have a marked impact on practice except to highlight the importance of providing this support to adult carers.

Full details of the evidence and the committee's discussion are in evidence review G: providing psychological and emotional support to adult carers.

Return to recommendations

Support during changes to the caring role

Recommendations 1.8.1 to 1.8.4

Why the committee made the recommendations

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

The evidence was specific to transitions to a care home, but the committee agreed to highlight other changes carers might find difficult that mean they need support, for example, when a cared-for person experiences major changes in their health, becomes terminally ill or moves out of their home. The committee also recognised that significant emotional and practical support would be needed if the person being cared for dies unexpectedly. By consensus, the committee also highlighted times when support might be needed when the carer's own life changes.

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

How the recommendations might affect practice

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

Full details of the evidence and the committee's discussion are in evidence review I: supporting carers during changes to the caring rolev.

Return to recommendations

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

Recommendations 1.9.1 to 1.9.15

Why the committee made the recommendations

The quality of the evidence varied, but the evidence helped the committee to identify the information needs that carers have when they are caring for someone near the end of life. This included the need to be kept informed about the person's developing condition, and to be given information to meet their own practical and emotional needs.

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

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

A small amount of evidence found that carers of people who may lack capacity believe advanced care planning is important but can find the process uncomfortable. The committee referred to existing NICE guidance on this topic and also agreed to emphasise the importance of involving any current or potential future carers during advance care planning.

Evidence suggested that carers often had worries about care at the end of life, especially medication, including pain relief and its potential side effects. To help address these, the committee referred to NICE's guidelines about medication optimisation and the care of dying adults.

The committee drew on the evidence to suggest important considerations for practitioners supporting carers who are caring for someone at home at the end of life, as well as how to improve carers' experiences in hospitals, hospices or care units. There was strong qualitative evidence that carers value good quality care and support when they're providing end of life care at home, so the committee suggested examples of the support that would benefit them. For people dying in hospital, the committee recognised that some hospitals might struggle to always provide private rooms, so added some alternative considerations to give carers and the person dying as much dignity, privacy and personal space as possible.

The committee used some limited evidence together with their own expert knowledge to recommend support, information, advice and signposting in preparation for and after the person dies. Practitioners especially need to consider the specific issues for mutual carers when one of them dies.

How the recommendations might affect practice

The recommendations on information provision and communication will help to improve consistency of best practice and should not have significant implications for training or cost. The way that care at home is provided, and the amount of resources allocated to make it accessible, varies from region to region. Recommendation 1.9.12 was intended to improve the consistency of good support for people who are caring from someone at home so that they know about and can use local services.

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

Full details of the evidence and the committee's discussion are in evidence review H: support needs of adult carers who are caring for people at the end of life.

Return to recommendations

Finding more information and committee details

You can see everything NICE says on this topic in the NICE Pathway on supporting adult carers.

To find NICE guidance on related topics, including guidance in development, see our web page on carers.

For full details of the evidence and the guideline committee's discussions, see the evidence reviews. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting NICE guidelines into practice, see resources to help you put guidance into practice.

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