

# Consultation Response

## NICE: Carers – Provision of support for Carers

Ref: 1219

Date: September 2019

All rights reserved. Third parties may only reproduce this paper or parts of it for academic, educational or research purposes or where the prior consent of Age UK has been obtained for influencing or developing policy and practice.

Name: Daisy Cooney  
Email: [daisy.cooney@ageuk.org.uk](mailto:daisy.cooney@ageuk.org.uk)

Age UK  
Tavis House  
1-6 Tavistock Square  
London WC1H 9NA  
T 0800 169 80 80 F 020 3033 1000  
E [policy@ageuk.org.uk](mailto:policy@ageuk.org.uk)  
[www.ageuk.org.uk](http://www.ageuk.org.uk)

Age UK is a charitable company limited by guarantee and registered in England (registered charity number 1128267 and registered company number 6825798). The registered address is Tavis House 1-6 Tavistock Square, London WC1H 9NA.

Age UK is the country's largest charity dedicated to helping everyone make the most of later life. The Age UK network comprises of around 150 local Age UKs reaching most of England. Each year we provide Information and Advice to around 5 million people through web based and written materials and individual enquiries by telephone, letters, emails and face to face sessions. We work closely with Age Cymru, Age NI and Age Scotland. Local Age UKs are active in supporting and advising older people and their families in the care market.

## **About this consultation**

The National Institute for Health and Care Excellence (NICE) is currently consulting on a draft guideline covering the provision of support for adult carers. This guideline is due to be published in January 2020 and as part of the development process, stakeholders have been invited to comment on the document. Age UK welcomes this guideline as a positive step towards improving carer's practical and emotional support so they can continue to make a substantial contribution to the care and support of a loved one.

## **Key points and recommendations**

Age UK's detailed comments can be seen in the NICE proforma below. Key points from our response include:

- Recognising that many carers are older people themselves and that this brings its own health and care challenges.
- Highlighting that many carers face challenging financial situations due to their caring responsibilities.
- Stressing the importance of supporting the health and wellbeing of carers, who may also have long-term health needs.
- Highlighting the impact that caring at a distance can have on carers and recognising their continued contribution to the care of a loved one.
- Promoting the empowerment of carers both generally and as contributors and facilitators of shared decision-making with health and care professionals.

## Age UK's comments

Comment number	Document [guideline, evidence review A, B, C etc., methods or other (please specify which)]	Page number Or ' <u>general</u> ' for comments on whole document	Line number Or ' <u>general</u> ' for comments on whole document	<h3 style="text-align: center;">Comments</h3> <p style="text-align: center;">Insert each comment in a new row. Do not paste other tables into this table, because your comments could get lost – type directly into this table.</p>
1	Guideline	General	General	<p>Age UK welcomes the opportunity to comment on the draft NICE guideline on the provision of support for adult carers.</p> <p>There are currently 7.6 million carers in the United Kingdom over the age of 16 and a quarter of those who provide family care are aged 65 or over (Social Market Foundation 2017). Carers make a substantial contribution to the care of their loved ones and society as a whole; the Office for National Statistics (2016) estimate that unpaid carers provided support worth £59.5 billion in 2016 and Carers UK (2015) estimate that the total economic value of contribution made by carers in this country is £132 billion.</p> <p>Carers must not be expected to sacrifice their health and quality of life, yet they are under increasing pressure due to the lack of support available through social services. The latest data shows that within the last year 360,310 carers were either supported or assessed by their local authority (NHS Digital 2018). This represents a decrease of 7 per cent from the 386,600 carers supported in 2015/16 (NHS Digital 2018). More than one in seven carers report that they or those they support received fewer care or support services during the previous</p>

				<p>year (Carers UK 2018). Since 2014/15, there has been a 24 per cent fall in expenditure on supporting carers from £192 million (NHS Digital 2014-15) to £145m (NHS Digital 2018).</p> <p>Improving practical and emotional support for carers is essential if we are to safeguard the health and wellbeing of individual carers, the people they support and ensuring families and friends can continue to make a sustainable contribution towards the care and support of a loved one.</p>
2	Guideline	General	General	<p>As we highlighted in Age UK's 2017 response to the scope and initial draft guidelines, we continue to recommend that the guideline should explicitly recognise that many carers are older people themselves, facing their own mix of health and care issues and emphasise the importance of supporting carers to maintain good health and wellbeing.</p> <p>Just under 2 million older people are carers in the UK (Social Market Foundation 2017) and an ageing population combined with reduced access to public services has meant that more and more older people are finding themselves providing care for friends and family. Between 2010/11 and 2015/16, there was a 16.6 per cent increase in the number of older people who provided care to family and friends (Age UK 2017).</p> <p>Nearly two thirds of older carers have a health condition or disability of their own and they are often caring at quite high levels of intensity, particularly those over the age of 80 who are likely to be caring for a co-resident partner. Despite this, many carers are often</p>

				<p>unable to find a time to rest or look after their own health and care needs. Older carers are more likely to provide longer hours of care than other age groups, with half of carers aged 85 and over providing 50 or more hours per week (Age UK and Carers UK 2015). Carers UK (2017) found that 40% of carers say they haven't had a day off for more than year, despite the detrimental impact on later life, in terms of physical and mental health. In fact, nearly half of carers aged 85 and over providing 20 hours a week or more say they feel anxious or depressed (Age UK and Carers UK 2015), 69% of carers say caring has had an adverse effect on their mental health (Carers Trust), and nearly a third of carers experience feelings of loneliness (Age UK 2017).</p> <p>Maintenance of good health and wellbeing is vital both for the carer themselves and the person they care for and supporting older carers to engage with their own health needs is an important step in supporting their overall wellbeing and preventing it from deteriorating. Age UK have published <a href="#"><i>Advice for Carers: practical and emotional help when you are looking after someone</i></a>, which provides some steps to achieve this, encouraging people to be proactive in managing their own health while also recognising the crucial role GPs can play. It is important to ensure the guideline covers recommendations to support carers to maintain good health and includes measures for promoting resources like the <i>practical guide</i> which can help carers, particularly when they are starting their new role.</p>
--	--	--	--	---

3	Guideline	General	General	<p>Alongside specific offers for health and wellbeing, many carers face challenging financial situations due to their caring responsibilities. In a recent Carers UK report (Carers UK 2019), they show that just under half of all carers they surveyed cannot afford their bills without struggling financially. Moreover, it is estimated that hundreds of thousands of carers are missing out each year on benefits they are entitled to. When it was last counted, it was estimated that 360,000 carers are missing out on over a billion pounds of Carer's Allowance (Carers UK 2015). The impact of having to worry about finances can be extremely detrimental to a carer's wellbeing and therefore we recommend making sure the document reflects this and strongly states the necessity for adequate financial information and the same time as discussions about being a carer.</p>
4	Guideline	4	10	<p>We recommend the guideline provides advice on caring for someone with dementia. Looking after someone with dementia can bring specific challenges to a carer for which they may need tailored advice and support. Age UK provides some examples of what information may be useful for a carer of someone with dementia here: <a href="https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/caring-dementia/">https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/caring-dementia/</a></p>
5	Guideline	5	12	<p>We would suggest adding in more detail to the guideline to recognise the importance of empowering and involving carers, including through specific recommendations to promote better communication between health and care professionals, carers and the person they care for.</p>

				<p>Age UK consistently hears about cases where carers are being excluded by health professionals from conversations about a person's care needs, even in the context of carers being central to meeting those needs. On the other hand, we also hear of cases where older people are excluded from conversations, with carers or family members being prioritised.</p> <p>Promoting formal processes for genuine shared decision-making and training and supporting staff to carry this out would make an important difference to all parties being valued and involved in care, and we feel this is something that should be explicitly addressed in this guideline. We would therefore recommend amending point 1.16 so that the first bullet point reads: <i>'Provide information and advice for carers (for example about planning and coordinating care) in a way that empowers carers and values their contribution, following formal processes for shared decision-making' while respecting confidentiality</i>.</p>
6	Guideline	7	14	<p>The scope of the guideline should also consider more specifically those carers who care at a distance or do not live with the person they care for because that person lives in a care home. Estimates suggest that around half of carers do not live with the person they care for (NHS Information Centre for Health and Social Care, 2010) and carers in this situation are often overlooked and may not be included in the person's Carer's Assessment or have access to support services.</p> <p>Carers at a distance provide fewer hours of care than co-resident carers and are</p>

				<p>less likely to provide personal care. However, they are more likely to be combining care with work, childcare and other responsibilities (Carers UK, 2015), and therefore more likely to experience carer stress than co-resident carers. Similarly, carers of individuals living in care homes largely continue in a caring role, contrary to the assumption that once someone has moved into a care home, their family or friend's role as a 'carer' has come to an end. For example, 57 per cent provide support with managing finances and 35 per cent continue to provide personal care.</p> <p>For those carers who care at a distance or for a loved one in a care home, caring commitments can be particularly unpredictable. In addition, carers in this situation are more likely than co-resident carers to report reduced time available for parenting and other caring roles, leisure or holidays, as well as adverse impact on finances and increased isolation due to reduced opportunity to stay socially connected. It is therefore crucial that the scope and guideline acknowledge these groups, take their needs into consideration, and do not rely on assumptions about co-resident carers, particularly when it comes to identifying who is playing a caring role.</p> <p>As such, we would recommend adding a sentence to this section '<i>consideration should be given to those caring at a distance or supporting a loved one who has moved into residential care, given the pressure that continuing caring responsibilities can put on their lives</i>'.</p>
7	Guideline	8	21	Caring can have a significant impact on health and we know that carers are not



				<p>only likely to be living with a long term condition or disability themselves, but are likely to report being in poorer health due to their caring responsibilities. In the most recent Carers UK report (2019), carers who care for 50 hours or more reported poorer health, with 25% reporting bad or very bad physical health and carers who have been caring for 15 years or more also reported poorer health, with 28% describing their physical health as bad or very bad.</p> <p>We recommend the guideline states the importance of reminding a carer of their rights to a needs assessment by reading: <i>'Offer carers the opportunity to have conversations about their own need as carers separately from the person they are supporting and remind them of their right to a carers needs assessment and how they can access this'</i>.</p>
8	Guideline	13	19	<p>Recent research by Carers UK (2019) found that the number of carers who were also in paid work is around one is seven - 4.87 million - far higher than previously thought. Given so many carers are also juggling employment, we recommend the guideline states explicitly that most people have the statutory right to request flexible working arrangements to help them fulfil their caring responsibility and the right to time off in an emergency. Age UK provides detailed information on this topic here - <a href="https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/im-juggling-work-and-caring/">https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/im-juggling-work-and-caring/</a></p>
9	Guideline	21	19	<p>We fully support the guideline's intention to make clear the importance of continuity of professional care staff to support carers when caring for someone</p>

				<p>at the end of life, but emphasis should also be placed on access to professional care staff, particularly in the community.</p> <p>Good end of life care for people being cared for in their own home or in a residential care setting requires the input from a wide range of professional care staff in the community, yet the workforce pressures in community based health are clearly visible with the number of district nurses declining sharply (CQC 2018) and the GP workforce unable to keep pace with rising patient demand (NHS Digital 2018). NHS Providers (2018) highlighted that nearly two thirds of trusts providing community services were worried or very worried about maintaining adequate staffing.</p> <p>As a carer of someone nearing the end of their life, the greatest impact can often come from being given a quick response to questions or concerns about changing needs of the person being cared for – particularly if the person deteriorates quickly or is in an unmanageable amount of pain. By being provided with quick advice, a carer has the ability to support the person themselves or arrange support within the community, rather than relying on emergency care. In a recent Carers UK report (2019) 13% of carers felt access to a district nurse would have stopped their loved one having an unplanned emergency admission.</p>
10	Guideline	22	7	<p>As is suggested in the guideline already it is really important that any responsibilities attributed to a carer within an individual's advance care plan for the end of their life is discussed with a carer. There is potential for this</p>

			<p>guideline to be more specific about the need for health and care professionals to ensure a carer feels equipped with the right knowledge and skills to adequately support their loved one at the end of their life. Ensuring this can aide a much better end of life experience for the carer and the individual and reduce the likelihood of a carer feeling overwhelmed or panicked and an unnecessary emergency admission for the individual who is dying. In a recent Carers UK report (2019), half of carers said they felt an emergency hospital admission could have been prevented if they'd had more care and support.</p>
--	--	--	--