

## Carers - Provision of support for adult carers

Consultation on draft NICE Guideline (NG10046)

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The National Institute for Health and Care Excellence (NICE) is currently in the scoping phase for a new guideline covering the provision of support for adult carers. This guideline is due to be published in July 2019 and as part of the development process, stakeholders have been invited to comment on the document that outlines who and what it will cover (available online [here](#)). 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.
- Reiterating that older carers can face a variety of negative effects on their own life due to caring for another person if they are not properly supported.
- Highlighting the impact that caring at a distance can have on carers and recognising their continued contribution to the care of a loved one.
- Stressing the importance of supporting the health and wellbeing of carers, who may also have long-term health needs.
- 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 No.	Page number or <u>'general'</u> for comments on the whole document	Line number or <u>'general'</u> for comments on the whole document	Comments
1			Age UK welcomes this new NICE guideline on the provision of support for adult carers and the opportunity to comment on it. There are an estimated 2.75 million older people in England who need some form of help and support, the vast majority of whom rely, at least in part, on informal help from family and friends (NHS Information Centre for Health and Social Care, <i>Survey of Carers in Households 2009/10, 2010</i> ). Carers make a substantial contribution to the care of their loved ones and society as a whole, but they are under increasing pressure due to a lack of support from social care services. 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.

2	4	100-101	<p>We would like the scope and the guideline to explicitly recognise that many carers are older people themselves, facing their own mix of health and care issues. Analysis by Age UK estimates that there are now over 2 million carers aged over 65, 417,000 of whom are over the age of 80. This means around 1 in 5 people (18.2 per cent) within the older population provide care for a family member or a friend (based on University of Essex, Institute for Social and Economic Research and NatCen Social Research, <i>Understanding Society: Waves 1-5, 2009-2014</i>). Being an older carer can bring additional challenges. 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. Caring can have a particularly detrimental impact on later life, in terms of physical and mental health as well as income and leisure time. For example, caring can adversely affect income, pension accumulation and the development of social networks, although it can also be a positive experience. We would therefore recommend that a sentence be added in this section to say <i>'The guideline will acknowledge and address the particular issues faced by older carers'</i>.</p>
3	4	104-109	<p>The scope 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 the carers do not live with the person they care for (NHS Information Centre for Health and Social Care, 2010). Of those, 37 per cent usually live within walking distance, 44 per cent live within a 30 minute journey and the remainder further away, many of whom include neighbours and friends (Carers UK, <i>State of Caring 2015, 2015</i>). Carers at a distance provide fewer hours of care than co-resident carers and are 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. 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. As such, we would recommend adding a sentence following line 104 to say <i>'Specific consideration will also 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>

4	5	125-139	<p>We feel the guideline should highlight the importance of supporting carers to maintain good health and wellbeing. This is vital both for them and the person they care for and it is particularly crucial for older carers because the very fact of caring and the length of time someone is providing care can have a severe impact on their health. As outlined in comment 2, many older carers live with long term conditions and disability themselves. Older carers are also more likely to live with long-term back pain as well as anxiety and depression (Age UK/Carers UK, <i>Caring into later life: the growing pressures on older carers</i>, 2015). 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, Carers UK, the Carers Trust, NHS England and Public Health England recently published <i>A practical guide to healthy caring</i>, 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. We therefore recommend adding a bullet point saying: <i>'Providing information, support and interventions to help carers to maintain good health and wellbeing, including through health promotion programmes and materials'</i>.</p>
5	5	127-128; 137	<p>The scope and guideline should 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. 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. 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 2 on line 127 so that it reads: <i>'Providing 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'</i></p>