Carers: provision of support for adult carers

Consultation on draft scope
Stakeholder comments table

25/04/17 to 24/05/17

ID	Type	Organisation name	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
1	SH	Admiral Nurses	General	General	Currently there is inequality in services due to numbers of Admiral Nurses. It is not acceptable that to receive this service you must live in a specific area. All carers of dementia across the UK should have the opportunity to access this service if required.	Thank you for your comment. Equality of access is of course in principle fully supported. However, whilst there may be substantial regional differences in the number of Admiral Nurses available to people with dementia, these are funding and implementation issues that are outside the scope of the guideline.
2	SH	Admiral Nurses	General	general	The draft scope does not outline roles and responsibilities; page 3/2 identifies who the draft scope is for and identifies a range of providers but, for example, it goes on to discuss assessment and providing support and advice to help adult carers to enter or to remain in work; training carers to provide practical support; providing social and community support interventions etc. but not who it is proposed should do what. These aspirations have already been claimed although depending on the local authority area support for carers is ambiguous; some local authority's work well with charities that provide support groups, training etc, and the presence of some charity organisations in some areas is greater than in others. There is however not always joined up awareness between health, social care and the voluntary sector and people easily get lost in the system, or remain on the margins receiving little of no support.	Thank you for your comment. The scoping document is intended to set out the intended audience and subject of the guideline, as well as the questions that will be reviewed and subjected to a health economic analysis by the technical team. The evidence gleaned from the reviews will be presented to a guideline committee composed of a wide range of individuals (including lay members, and health and social care professionals) all of whom have an expertise in adult carers and social care. The guideline committee will then make recommendations based on the available evidence, which will be open to consultation and comment on by registered stakeholders such as your organisation. As such, identifying the specific individuals, groups, or other social and healthcare professionals who are to implement the particular recommendations of the guideline committee would be premature.
3	SH	Admiral Nurses	General	general	The draft scope doesn't discuss sustainability; whilst the Care act "strengthened the rights and recognition of carers..." Admiral nurses have very few clients who have, following a carers assessment, achieved a satisfactory level of support. In the main they get directed to voluntary groups	Thank you for your comment. The text has been amended to make clear that reviews of carers will be explicitly examined in this review question.

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					or given vouchers for respite care of between 2 to 4 hours per week; follow up assessments/reviews often have to be requested and initiated by the carer rather than be planned and arranged by social services. Sustainability of approach needs to be considered in the draft scope along with the role of statutory agencies.	
4	SH	Admiral Nurses	General	general	The social services framework remains heavily weighted towards physical incapacity which affects the equality of services available to people with dementia and other mental health issues. If a person is physically able to complete a task then little consideration is given to the impact of their mental health on their ability. This has an obvious knock on effect to carers as they continue to provide the care needed and without recognition.	Thank you for your comment. One of the main topics of this guideline is to determine what the most effective and cost-effective forms of support are for adult carers. Indeed, the review questions specifically cover support for a wide variety of domains including (though not limited to) practical support, psychological and emotional support, and support for end of life care. Although the guideline will not focus on specific conditions, the reviews will look at different sub-groups (for example physical vs mental health issues) where appropriate. More details will be provided in the protocols.
5	SH	Admiral Nurses	General	general	Carers often feel overwhelmed by the number of professionals involved and are unsure who to turn to. This can lead to them not seeking help or lengthy searches for the right person to provide the support. Some of the factors contributing to this are: • The use of jargon and abbreviations • Team names and job titles which change on a regular basis and have no meaning for the patients i.e. Community Independence Service and Integrated Community Lead • Staff not able to spend time explaining to patients their roles • Joint working which is not facilitated with shared IT systems and clinical processes • Poor communication These factors limited the accessibility of services to people who are not able to articulate their needs in a confident manner or those who are already feeling overwhelmed.	Thank you for your comment. It is recognised that carers can find it difficult to navigate services and come to an understanding of what is available and who provides them. Indeed, one of the main overarching goals of this guideline is to establish what the views and experience of adult carers are on the various aspects - from identification and assessment to support and transition - of the current pathway available to them, with a view to establishing whether and how it should be reconfigured. As such, service providers will be expected to make any changes necessary to implement the recommendations of the guideline committee.
6	SH	Age UK	General	General	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	Thank you for your comment. The main aim of this NICE guideline is to establish

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					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, *Survey of Carers in Households 2009/10*, 2010). 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.	how the pathway for adult carers can be improved. In order to do so, the most recent evidence relevant to the issues you raise, among others, as well as what the views and experiences of carers are of the current pathway will be considered.
7	SH	Challenging Behaviour Foundation	General	General	It would be helpful to give specific consideration to carers who manage a personal budget on behalf of their relative. When a person has complex needs this can involve employing a large staff team which results in the family carer taking on tasks including recruitment, employment contracts, payroll, training, supervision, account, pensions etc. With large packages of care this is similar to running a small business. Whilst progressive options for family carers managing budgets are very welcome it would be helpful to look at the needs of carers for support with managing personal budgets including brokerage to set up the budget, employment advice, accountancy support etc. A number of families contacting the Challenging Behaviour Foundation via our information service have reported that they have been offered insufficient support to manage a personal budget causing a negative impact on their health and wellbeing. Whilst managing a personal budget is a choice, due to past service failures and a lack of local services some carers feel that managing a personal budget is the only option for their relative to receive good quality support and live near their family and friends.	Thank you for your comment. This issue will be specifically examined in the guideline under advice and intervention. Note that more detail will be provided in the protocols.
8	SH	Challenging Behaviour Foundation	General	General	It would be helpful for the guideline to include carers who do not provide regular day-to-day care although still provide significant support to their relative e.g. supporting their relative to take part in activities, arranging & attending medical appoints, being an appointee, managing the lease agreement on a Motability car etc. etc. It would be helpful to recognise this group of carers and the significant role they play and ensure the recommendations are inclusive of their needs as well as the needs of relatives who provide regular day-to-day care. As part of this it would be helpful to recognise that some care services are	Thank you for your comment. It is acknowledged that there is wide variation in the demands of providing care, for example in the frequency that carers are asked to provide care. More generally, it is acknowledged that there is substantial variation in the amount, and nature, of care that carers provide and that the intensity of the caring role can be very different depending on the severity of the condition

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					very poor and in such instances family carers play a significant role in advocating for their relative and to include in the scope the support carers need in order to effectively advocate for their relative when challenging poor care such as information about make a complaint, the role of the ombudsman, legal advice, safeguarding processes etc. There is widespread recognition of the lack of adequate support for people with learning disabilities and behaviour that challenges which is being addressed by a programme of reform called Transforming Care led by NHS England and the LGA. *Transforming Care for People with learning disabilities – next steps* states: "The Government and leading organisations across the health and care system are committed to transforming care for people with learning disabilities and/or autism who have a mental illness or whose behaviour challenges services. We have made progress, but much more needs to be done." (page 4).	of the person being cared for, where they live etc. As such, all different varieties of carers and caring roles will be considered in the guideline.
9	SH	Challenging Behaviour Foundation	General	General	It would be helpful to acknowledge the lifelong caring role of family carers who have a relative with a learning disability who may be caring for their relative for many decades and the additional challenges this poses. In many cases the person with a learning disability will outlive their parents and it is therefore essential for carers to have information about planning for the future when they are no longer around to care for their relative	Thank you for your comment. The guideline will include any evidence identified concerning adult carers of adults with learning disabilities that is relevant to the review questions. The issue of the needs of carers when the person being cared for is at the end of life and after this period will also be specifically examined in the guideline. Note that more detail will be provided in the protocols.
10	SH	Department of Health	General	General	It would be helpful for the guideline to recognise that there is substantial variation in the amount and nature of care provided by carers, and that incidence of potential negative impacts (e.g. giving up paid employment/other activities, isolation, depression and reduced quality of life) is associated with increasing intensity of caring role (noting that intensity of caring role is not simply a function of total number of hours spent caring). With this in mind, it would be helpful for the guideline to include a particular focus on interventions that are effective in supporting carers in the most intense caring roles.	Thank you for your comment. It is acknowledged that there is substantial variation in the amount, and nature, of care that carers provide and that the intensity of the caring role can be very different depending on the severity of the condition of the person being cared for. As such, all different varieties of carers and caring roles will be considered in the guideline.
11	SH	Esoteric Practitioners Association (EPA)	General	General	**Introduction** This Guideline scope on Carers: provision of support for adult carers offers an immense opportunity to set the standard for what support can	Thank you for your comment. This guideline is specifically about adult carers of adults and young people aged 16 or

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					be offered to carers. It is important to note that in considering this consultation, the answer is unlikely to be addressed by the NICE guidelines alone as the issues raised in this consultation are something much broader in scope representing a more fundamental change in our societal thinking. This consultation begins to address some of these issues. The degree of importance of this consultation hits home when we consider that without carers we would have a crisis of care – the pressure it would put onto Health and Social Care would lead to a breakdown in the system. Given the statistics on rising illness and disease, that we are living longer but in poorer health, and that our communities are often socially isolated, the trajectory is that we will need to rely on carers more than ever before. Hence the support for adult carers is paramount in the coming years and beyond. **Carers and their health and wellbeing.** We know that lifestyle plays a role in our health and well-being - according to WHO 60% of related factors to individual health and quality of life are correlated to lifestyle. The evidence for the importance of healthy lifestyles is now overwhelming (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4703222/). New research conducted in Iran shows that lifestyle changes in diet and levels of physical activity improve the health of entire communities. http://www.who.int/mediacentre/multimedia/podcasts/2009/lifestyle-interventions-20090109/en/ Whether people are carers or not given the rise in lifestyle related conditions, one could say that we all need to take responsibility for our own health and wellbeing, and, carers are very much part of the population where lifestyle has become an important issue, as carers can become sick through their own lack of care to themselves whilst caring, and due to their own lifestyle. The evidence regarding carers health and wellbeing shows that many carers will always put the needs of the cared for person first regardless of the impact on their own health and wellbeing and this approach does not work as it rapidly leads to stress, exhaustion, depression and other related health conditions. Carers UK states:'3 in 5 carers have faced depression because of the caring role'. (https://www.carersuk.org/help-and-advice/health/looking-after-your-health/stress-and-depression/hidden-issue-depression) (https://www.carersuk.org/help-and-advice/health/looking-after-your-	over who need continuing care, their views, experiences, needs, and what are the most effective/cost-effective interventions to support them throughout the course of their lives as carers (and beyond). It is of course recognised that carers are best positioned to provide care when they themselves are in 'good' physical and mental health and available interventions to maintain, improve and support them to attain or sustain them will be examined. However, as the guideline is still in its early stages, it would be premature to recommend a public health awareness and education initiative before the guideline itself has been completed. Note that more detail will be provided in the protocols.

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					health/stress-and-depression) So, a carer might be perceived to be delivering great support to a cared for person, but it is not sustainable if they are doing it from a place where they lack care and support to themselves, or where they are feeling resentment or are disregard for their own health and wellbeing, as this will surely lead to health (mental or physical) problems at some stage or another. And hence, foundational to this consultation response we propose a nation-wide public health awareness raising and education initiative that enables carers to realise: 1. When and where they are carers and 2. That caring is best done when we have first taken care of ourselves.	
12	SH	Esoteric Practitioners Association (EPA)	General	General	**Societal Breakdown and Isolation – a factor in society today** It is well known that societal breakdown of communities begins where people are isolated. We have lost a sense of supporting one another. It is also well documented that social isolation has a detrimental effect on an individual's health and well-being. Many carers don't identify themselves as carers and simply get on with the job of looking after their family member. This way of thinking starts the cycle of isolation since they then do not even think about what support they might need or be entitled to. In addition, unless carers know where to look for this information or go seeking it, it is not easy to find and public awareness is scant. Community support can vary depending on where you live. Increasingly we have lost the capacity to connect to our neighbours in a meaningful way. Even though there are many services out there to support carers, looking within our communities to how we can support each other is a valuable resource that could be utilised more. This will require a shift in the mindset that has become prevalent in today's busy task orientated society. What compounds the problem is the significant breakdown and huge disconnect in the family unit. Although there are families that share the responsibility, there are countless others that do not come together to support in the care of a family member. This often leaves the carer in an isolated situation and feeling burdened. In addition, some health care professionals can be solely focused on the cared for person and so do not always provide information to the carer about what support they might need. As the first contact with a health	Thank you for your comment. As you note, the role of carers in our society is a complex and multi-faceted issue. The specific role of how carers should be initially identified and how they should be subsequently supported (and who might do this) is the main topic of this guideline.

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					care profession will most likely be a GP, their role is crucial in starting to assess the needs of both the carer and cared for person, and providing or signposting information.	
13	SH	Esoteric Practitioners Association (EPA)	General	General	**What is needed now?** The EPA supports the view that a long-term perspective on health is fundamental to achieving, improved health and well-being; the potential for cost savings is a natural consequence of this. To focus solely on short-term objectives would be extremely short sighted. **We propose:** ¥ **An integrated health care system** that works in partnership with patients and communities, businesses, not just health and social care practitioners. The Southcentral Foundation Healthcare system of Alaska is modelled in this way. It rejected the established healthcare model and established it's own: https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/intentional-whole-health-system-redesign-Kings-Fund-November-2015.pdf ¥ **An education and awareness programme,** possibly designed and led by Public Health England to raise public awareness of the responsibility people have for their own health. The UK population on the whole has abandoned its most precious resource in their lives, themselves. When all attention is given to homes, cars and material possessions and care of body is neglected and abused, there are serious consequences for individuals, families and the state. In the Southcentral Foundation Healthcare System, patients, known as 'customers,' are empowered and given the message to 'actively share responsibility for their and their family health and wellness.' https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/intentional-whole-health-system-redesign-Kings-Fund-November-2015.pdf ¥ **Optimising Collective Corporate/Social Responsibility –** we propose forming partnerships with voluntary organisations, charities, business as well as Public sector organisations. The future does not lie in an existence based on silos, but whole communities working together to support everyone. For example, businesses, communities and care agencies could offer health and safety and other courses for registered carers as part of their commitment to	Thank you for your comment and for your helpful references. It is of course recognised that groups function more efficiently and effectively when each of their elements - whether at the level of users, professionals, or organisations etc. - cooperate. Exactly how the current pathway available to adult carers should be reconfigured to improve services will be determined by the recommendations of the guideline committee and services will be expected to implement them accordingly.

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					social responsibility.	
14	SH	Esoteric Practitioners Association (EPA)	General	General	¥ **Care for the Carer starts with self-care –** as stated above**,** we cannot rely solely on the health system to fix us when we get sick we have a responsibility for our health, and for self care and self management and there are initiatives that could support this e.g. http://www.selfcareforum.org/ as well as public health and whole system initiatives on self-care for carers, and for us all in families, workplaces and communities. ¥ **All NICE guidance include an emphasis on self-care and responsibility -** Health is the most central concern for societies globally, and yet not treated with the seriousness it deserves. We can all cite chronic ill-health statistics, what is deplorable is a lack of will to do anything about it. Self-care should not be ignored or sidelined but become central to every NICE guidance written. This is one way we begin to raise awareness – to begin to highlight the destructive consequences of life-style choices that kill and disable people in their millions each year. It's time to end the belief that there is nothing we can do to change things. Carers could become self-care champions if provided with awareness and education to support. Health and social care staff could also become self-care champions with education and awareness in their workplaces. EPA practitioners and members in the UK and internationally have direct experience of self-care and are testimony to its effectiveness in supporting people to turn their lives around, beyond all recognition. Hundreds, as a consequence of bringing self-care into their daily lives have become self responsible, regained true health, actively contribute as employees, volunteers, and community members. http://www.unimedliving.com/healing/sacred-esoteric-healing/client-testimonials/from-exhaustion-and-feeling-false-to-feeling-vital-and-truly-looking-after-myself.html **We propose that NICE becomes enquiring and curious about self-care** as understood and practised by EPA members and practitioners. In our experience self-care is the single most important determinant of improved and sustained health and well-being and the	Thank you for your comment and for the references. It is of course acknowledged that all people should be concerned to look after their own physical and mental wellbeing. The guideline committee will consider the extent to which carers' physical and mental wellbeing is affected by the demands of caring and have included self-care as one of the areas the GC may consider in relation to the provision of information and support.

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					only intervention that would result in a fall in spiraling ill-health statistics. **Responsibility to care for ourselves -** if more people were supported to care for themselves at an earlier stage, levels of chronic ill-health would fall, as would related costs. There are already communities living independent and healthy lives through practicing effective self-care and responsibility. Why wait until there is a crisis to introduce self-care, when it can be introduced much earlier and become a normal part of life? http://www.unimedliving.com/self-care/what-is-self-care/self-care-is-not-selfish.html http://www.universalmedicine.net/before--after.html http://www.unimedliving.com/self-care/what-is-self-care/self-care-myths.html For further evidence of the benefits of self-care see: Keep, J. A. (2013) Developing self-care at work. PhD, University of the West of England. http://eprints.uwe.ac.uk/21799/1/Phd%20Study%20Jane%20Keep%2012102013%20Final.pdf	
15	SH	Esoteric Practitioners Association (EPA)	General	General	**Training for practitioners** There is no mention in the scope about training for health and social care practitioners/professionals but the EPA feels this is an important aspect. Commitment to addressing and bridging the 'siloed' gap between health and social care services is crucial. All GP's and health professionals should receive training in relation to identifying carers and signposting to appropriate services, such as local authorities or local carers groups. Every NHS service could have a designated carers champion who identifies services and ensures other professionals in the practice are kept up to date and that everyone has the appropriate training. It is also key to ensure practitioners who work with carers as well as adult carers understand some key points, such as: 'necessary care' and managing expectations (ie that carers understand potential services and support that may be available without them feeling abandoned or creating unrealistic expectations) through supervision and education programmes.	Thank you for your comment. The recommendations of the guideline committee will determine whether the current pathway available to adult carers should be reconfigured (and if so, how). As such, service providers will be expected to make any changes necessary to implement the recommendations. Please note that it is out of the scope of NICE guideline to make recommendations about training for healthcare professionals, as it is expected that all health and social care professionals who are likely to be in a position to identify carers have the appropriate training to enable them to do so.

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16	SH	Esoteric Practitioners Association (EPA)	General	General	**Further clarification needed** Please see comments below for the scoping document: Line 130 The second part of point 3 is unclear, in particular the sentence 'planning for the caring role'. It would be very helpful if this could be clarified so it is clear whether this means: 1. developing a carer care-plan following a carers assessment 2. a carer planning in advance for a caring role as a relative or friend becomes unwell or a disabled child moves toward the transition to adult services or 3. does it mean contingency planning? 3.1 line 206 does 'planning' mean 'care planning'? 3.2 is unclear, 'What assessments are helpful for developing and reviewing a carer's plan?' A bit more context would be useful to clarify whether this means the type of Local Authority assessment or who undertakes the assessment, or whether it means including assessments from other sources such as health professionals etc.	Thank you for your comment. The phrase 'planning for the caring role' and related expressions is intended to cover a wide range of situations and will be defined more precisely in the various protocols for the review questions. The use of the word 'assessment' in the document refers to assessment as defined by the Care Act 2014. This will be made clear in the protocols and related guideline documents.
17	SH	Hospice UK	General	General (193-248)	A whole area of guidance is omitted here between 3.51 and 3.53 related to the *recording* of carers contextual and demographic information and *assessment of support needs* • should a new record be created or should information be kept in the patients record ? • how is this information safely shared? This has come out strongly as an issue in Professor Gunn Grande's research to date. Organisations (GPs, hospitals, hospices) also need to demonstrate *capacity* to *assess* carers needs, to get the importance of carers needs and support embedded in culture, with time for training, and resources to collect data and audit against standards of best practice.	Thank you for your comment. The issue of record keeping will be specifically examined in the guideline.
18	SH	Local Government Association	General	General	There is guidance for councils, produced by or in partnership with the LGA, in implement the carers element of the Care Act 2014. Links to resources are: Resources for local areas: assessment and eligibility, carers and the whole-family approach: http://www.local.gov.uk/sites/default/files/documents/assessment-and-eligibilit-900.pdf The Care Act, a guide to efficient and effective interventions for implementing	Thank you for your comment and for your helpful links.

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					the Care Act 2014 as it applies to carers: http://www.local.gov.uk/sites/default/files/documents/care-act-2014-guide-effic-a81.pdf LGA resources page on the Care Act Needs Assessment and Carer Assessments: http://www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/care-and-support-reform/implementation/first-contact/needs-assessments North West Carers Assessment Framework: http://www.local.gov.uk/sites/default/files/documents/briefing-note-nw-carer-as-976.pdf	
19	SH	Local Government Association	General	General	It has been specified that 'Parent Carers' are out of scope – they are however adult carers so arguably should be in-scope. If NICE are planning specific guidance for this group, or if there is a reason they are out of scope, this should be make clearer.	Thank you for your comment.The general scope of the guideline is to provide evidence-based guidance for adult carers of other adults or adult carers of young people aged 16 or over who need ongoing care, whether or not they are parents of the people they are caring for. The scope has been prioritised in this way because of specific issues regarding adults, specifically adults who are increasingly taking on caring duties of other older adults in the home. However, this guideline will consider the role of whole family assessments and in this context only, care for children under 16 will be included. There are no current plans for NICE to develop a guideline specifically concerning the parental care of children under 16 with health and social care needs. However this decision will be kept under review by NICE.
20	SH	Local Government Association	General	General	There appears to be an assumption that the main way to support carers is to offer respite care – there are other interventions to support carers that should be in scope.	Thank you for your comment. Please note that although explicit mention of respite care has been removed, it will be only one of the issues that will be examined when considering the types of practical support that should be given to carers. Note that more detail will be provided in the

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						protocols.
21	SH	Local Government Association	General	General	The guidance is aimed at carers themselves – as such, the language needs to reflect the experience of carers themselves, rather than, for example, the NHS. The scope highlights that many carers do not identify themselves as such – this guidance should ensure it does not contribute to their self-identification as 'not a carer' in its use of language (eg Carer Competencies). Rather, it should seek to speak to a wider audience to engage anyone delivering unpaid care.	Thank you for your comment. As you note, it is recognised in the scoping document that some people who care for another do not think of themselves as carers. As is clear, the guideline is intended for adults who care for an adult or someone aged 16 or over that needs continuing care, and the recommendations will apply to any such person regardless of whether they think of selves as carers. That said, in undertaking the writing of this guideline, particular attention will be paid to the language used so as not to inadvertently incorrectly imply that the recommendations do not apply to the subset of individuals that do not self-identify as carers.
22	SH	Open University	general	General	**General comments** The authors are to be congratulated on this comprehensive scope. The following are some suggestions about some additional points that would be worth addressing: • caring is presented as time specific and as a static experience. There needs to be a recognition that changing demographics means many people will care more than once across their life course. The effects of different periods of caring can also be cumulative • the implementation of guidelines needs to take into consideration the impact of reductions in public spending, particularly reductions in local authority budgets and NHS funding • as needs become more complex and move to care at home gathers pace, there will be more pressure on carers to care for longer and mme greater demands, Guidelines that are effective on the future need to address carers' changing circumstances • caring essentially takes place within a dyadic relationship. There is no acknowledgment of the centrality of this relationship to caring and	Thank you for your comments and suggestions. The issue of how adult carers should be supported in times of change - for both the carers themselves and those cared for - will be specifically examined. Note that more detail will be provided in the protocols. In making recommendations for whether and how each aspect of the pathway available to support adult carers should be reconfigured, the guideline committee will take into account the impact, among other things, of the budgetary constraints you refer to.

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					the way that interventions often ignore this dyadic relationship. - the guidelines seem to assume that family care is the best option. In reality this is not always the case. How can the guidelines reflect this reality? - a recent NIHR SSCR funded scoping review of the existing body of carer research could inform the development of this guidelines and also shows where existing evidence can be drawn upon	
23	SH	RCN	General	general	The document provided a comprehensive overview of the all necessary requirements to support an aging population of carers with the UK. All fundamental concerns covered. Nil to add.	Thank you for your comment. Your support is greatly appreciated.
24	SH	Royal College of General Practitioners	General	General	An excellent approach with emphasis that there is much more learning to do. The research questions are particularly important and the emphasis on joint and updated records with regular audit	Thank you for your comment. Your support is greatly appreciated. The issue of record keeping will be specifically examined in the guideline. Note that more detail will be provided in the protocols.
25	SH	Royal College of Nursing	General	General	The Royal College of Nursing welcomes the draft scope and look forward to the guidelines and subsequent quality standard that will address key areas for quality improvement for this group. Although in the main carers are older people, there are increasing numbers of people, particularly people of working age who are caring for one or more relatives and also have dependant children. There is increasing number of working age people working as full time carers whilst working or having to give up work to care. The physical, emotional and financial burden can be significant.	Thank you for your comment. Your support is greatly appreciated.
26	SH	Royal College of Nursing	General	General	Some young people may still be accessing education yet this guideline only refers to health and social care settings. Impact on education should be included.	Thank you for your comment. It is not clear whether you intend this point to apply to carers or the person cared for. The

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						guideline committee will examine what the most effective/cost-effective interventions are for enabling adult carers to enter or remain in education (or work/training). As such, the impact of caring on carer education, where the carer is below the age of 18, is outside the scope of the guideline.
27	SH	Royal College of Occupational Therapists	general	general	We felt Carer led and disease specific peer based groups, and the use of "apps" Need to consider how people find the information and how services can sign post. Having access to these groups would reduce the risk of isolation Access to this information would be dependent upon computer literacy so may need to initially ensure carers have access to learn how to be computer literate. Use of online information could assist in ensuring access for all.	Thank you for your comment. The available evidence on the effectiveness/cost-effectiveness of carer-led and disease-specific groups as well as that of digital apps - whether on- or off-line - will be reviewed by the technical team as appropriate. Computer literacy is clearly vitally important in the modern world and it is of course essential that the user of any intervention that required the use of a computer, mobile phone or other relevant technology be appropriately trained or enabled to use it. It is likely that implementation issues such as this - whilst strictly outside the scope of this NICE guideline - would be considered by both the guideline committee when making recommendations and the NICE Implementation Team.
28	SH	Royal College of Occupational Therapists	General	General	We felt that it was important to ensure that carers are able to develop "contingency plans" looking at a safety plan in case of crisis. This could be based on the "family group conference model".	Thank you for your comment. The guideline will cover contingency planning. The precise form that this will take will be determined by the recommendations made by the guideline committee.
29	SH	Royal College of Occupational Therapists	General	General	Access for carers to "carers health Checks". This would be cost effective as would pick up any early signs of illness or lifestyle concerns.	Thank you for your comment. Health checks will be explicitly examined in the guideline. Note that more detail will be provided in the protocols.
30	SH	Royal College of Occupational Therapists	General	General	Clear signposting and guidance for carers who are involved with caring for those people who do not meet the threshold for statutory services.	Thank you for your comment. It is of course vitally important that all users of health and social care services, whether

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						carers or not, are provided with adequate information regarding where they are in the relevant pathway and what services are or could be available to them. Whether or not the current signposting and guidance for carers needs updating or amending will be considered by the guideline committee after taking into consideration the available evidence.
31	SH	Royal College of Occupational Therapists	General	General	If carer is caring for more than one person that the needs of all the cared for are taken into account. For example if one parent is admitted to hospital that the needs of the other person are considered automatically on discharge.	Thank you for your comment. As noted in Section 3.1 of the scoping document, particular attention will be given to carers who are caring for more than one person.
32	SH	Royal Mencap Society (Mencap)	General	general	The development of guidelines to support carers will provide a vital tool to those providing unpaid support in often incredibly challenging situations. We welcome the development of these guidelines and the opportunity to comment on these in relation to those caring for people with learning disabilities. We welcome all areas included in the draft scope, below are some additional key points and areas that we would like to see considered:	Thank you for your comment. Your support is greatly appreciated.
33	SH	Royal Mencap Society (Mencap)	General	General	• All guidance on carers must recognise and be inclusive of the various caring roles and responsibilities that people have. Greater understanding must be afforded to those whose role is not 'hands-on' at surface level, for example family carers of those not living in the family home. • There must be recognition of the importance of getting support right for the person - and that this has a huge effect on the carer's wellbeing. It is vital that individuals get the support they need, with staff who have the right skills to support the person's needs. • It is also important that family carers can easily access social workers and other professionals and that queries and concerns are acted upon in a timely way. • Family carers should not have to explain their family member's needs again and again to different professionals. Information must be properly recorded to ensure continuity of care, regardless of turnover of staff. • There must be enough funding in the system to ensure the person continues to be able to get the support they need and there is not a constant fear of cuts.	Thank you for your comments and suggestions as to how the pathway and related services for adult carers can be improved. It is recognised that the views and experiences of adult carers, which will be sought and considered in the writing of this guideline, are vitally important to enable an understanding of the state of the extant support pathway and evidence-based recommendations as to how it can be fruitfully reconfigured. Please note that funding issues are not strictly within the scope of the guideline. Regarding prevention, it is indeed the purpose of the guideline to examine what the best ways are to minimize the negative impact of caring on carers and to ensure that they are appropriately supported whilst they are doing so.

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					• It is important that cuts are not made to the important services available to support carers to ensure that they are able to remain equipped and supported as carers. • There must be a focus on prevention. Carers must be able to access support before crisis point. • Carers guidance must ensure that the rights of all carers are championed and that people with learning disabilities and their carers are respected and valued. • The knowledge and expertise family carers have about their loved ones should be listened to and valued . This will help ensure that their loved ones gets the support they need. • Ensuring that the Care Act is working for people with a learning disability and family carers through monitoring and understanding their experiences is vital.	
34	SH	Royal Mencap Society (Mencap)	General	General cont…	• Carers should be able to access high quality carers assessments which look at all the carer's needs and outcomes they want to achieve. This is a real opportunity to make sure carers get the information and advice they need and access the support they need. It is an important opportunity to plan for the future and to avoid crisis situations. It is an opportunity to listen to and focus on the carer and their needs and also to recognise and value the work they do. • Reviewing and monitoring laws affecting carers and the people they care for is important to ensure that they are working in the way they should without forming additional issues for carers. For example, ensuring family carers are properly involved and consulted in best interests decision as they should be in line with the Mental Capacity Act. • Ensuring access to regular, high quality, suitable short breaks. Improving the availability of services including respite/ short break services and ensuring that no person is considered 'too complex' to access the breaks that they require (this will require the short break service to be sensitive and responsive to the needs of the person and planned in a person-centred way). • Ensuring carers can access timely high quality independent information and advice including: Information about the Care Act and the right to a carers assessment, Information about the Mental Capacity Act. Related to this is information about rights around the sharing of information. Too often families are told that 'data protection' and 'confidentiality' are reasons why information can not	Thank you for your comment. It is accepted that all individuals that use social and health care services, whether carers or otherwise, must be fully informed of their rights and the services available to them. Equally, whilst health and social care professionals are expected to provide adequate advice and support, they can only do so within the confines of the law as set out by the relevant acts governing confidentiality and information governance. The views and accounts of the experiences of both adult carers and the relevant health and social care professionals about how information and advice is currently provided will be specifically examined, as well as the issue of how carers, as defined by the Care Act 2014, should be assessed. Note that more detail will be provided in the protocols.

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					be shared with them - they need to be clear on the law and know their rights around this, How the rights of the person and families change at transition between child and adult services, Information about benefit entitlements, Targeted support for older carers and younger parents, Information about how to challenge about lack of services/support or cuts to a service, Information about how to challenge poor healthcare and social care, Information and advice available proactively, Information and advice must be made available at the earliest possible stage, at diagnosis, school and transitions - this will have a significant and positive impact on families and may have the effect of avoiding crisis situations with people better able to access appropriate advice, information and services. •	
35	SH	Royal Mencap Society (Mencap)	General	General cont…	• There must be available information and advice for carers of all age groups, including those who may be new to the caring role or may undertake this including those who may be new to the caring role or may undertake this in future. The needs of each group will vary. For example: o Some carers also feel isolated o People may get in touch because services and personal budgets are being cut o Parents who give up work or spend days off work to care for a disabled child can be especially worried about finances o Support for those family carers who fall into the mid-range age group (ie support for those who are not older carers or carers of children or young people), this group should not be lost o People who may take up the caring role in future should also be considered e.g. siblings. • Boosting Advocacy and peer support for family carers, including support to attend meetings where needed. • Building a firm understanding of the range of impacts that may be had on the health and wellbeing of a carer as they undertake their role and ensuring there is available information on where and how to access services that may offer the required support, and that carers are able to access this support	Thank you for your comment. It is acknowledged that there is wide variation in the needs of carers relative to variables such as age of the carer, the condition of the person being cared for, and whether the former lives with the latter. Concordant with this variation, the vital importance of adequate information and advice about issues such as personal budgeting for carers of all types is acknowledged. These and related issues will be examined in the guideline where the views and accounts of the experiences of both carers themselves and health and social care professionals will be sought in the literature review and considered by the guideline committee. Note that more detail will be provided in the protocols.
36	SH	Royal Mencap Society (Mencap)	General	General cont…	Note: There are recommendations in relation to supporting carers of people with profound and multiple learning disabilities (PMLD) in 'Raising our sights:	Thank you for your comment and for your helpful references. The types of evidence

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					Services for people with profound intellectual and multiple disabilities' Mansell (2010). It is important these inform the guidance for and about carers. Two particularly relevant ones relating to short breaks and information and advice are: ○ ***'Commissioners of health and social care services should identify mechanisms for supporting and enabling families to get advice and help in securing and running self directed services from user-led organisations or self-help groups of other families.'*** - Recommendation 2 ○ ***'Commissioners of health and social care services in every area should commission a range of short break services that provide staff with sufficient skills, expertise, equipment and facilities to meet the needs of families supporting adults with profound intellectual and multiple disabilities. No family supporting an adult with profound intellectual and multiple disabilities at home should be denied regular short breaks.'*** - Recommendation 27. • Mencap and the PMLD Network also produced a Raising our sights how-to guide, with an accompanying film, on Support for carers of people with profound and multiple learning disabilities (2012)[1]. This could also be used to inform the guidance for and about carers. It focuses on what local areas can do to implement Mansell's recommendations relating to improving support for carers.	that will be reviewed by the technical team will be determined by the guideline committee once the development phase begins and will be explicitly stated in the review protocols.
37	SH	Royal Pharmaceutical Society	General	General	As the carers flu vaccination campaign has shown, when a carer visits a pharmacy (for example to collect a prescription), pharmacy teams have a window of opportunity to offer services that could help the carer maintain their health and well-being. Community pharmacists have a huge role in reassuring carers, helping to reduce their anxiety, acting as convenient and accessible points for information/ signposting and general advice on medicines and lifestyle issues. Carers often neglect their own health and wellbeing needs and community pharmacists have the opportunity to recognise this and support the carers.	Thank you for your comment and for your useful suggestions.

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[1] www.mencap.org.uk/pmld

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					Some examples of services that community pharmacists could provide to carers include: 1. Identify carers and tag their medical records 2. Notify the carer's GP 3. Provide them with general health advice 4. Provide them with an NHS health check 5. Offer them a flu vaccination 6. Offer them a pneumococcal vaccination 7. Help them access electronic prescription service 8. Provide a home delivery service 9. Screen carers for hypertension, COPD and diabetes risk factors 10. Offer them services such as smoking cessation weight management etc. 11. Offer them an MUR or NMS for themselves. 12. Give advice on how to use, store and administer medicines safely 13. Advise them on disability aids and equipment 14. Refer carers to their local carers' service for information, advice and support.	
38	SH	Royal Pharmaceutical Society	General	General	Medicines and how they are used needs to be within the scope of this guidance for carers. There should be an expectation that carers are well informed about the medicines the person they are caring for is taking, they should have the opportunity to voice an opinion about the medicines and be supported so that they can play a part in helping the patient to take their medicines. This can be supported by pharmacists working in all care settings and may require access to specialist pharmacists, such as those specialising in mental health. There are a range of carer organisations and many other different organisations providing care and support in a variety of ways. Most of these organisations have little or no proper access to good advice about medicines. They need help and support in order to be well informed around medicines and their use and this guidance provides the opportunity to make that the norm.	Thank you for your comment. It is expected that adult carers who are responsible for the dispensing of medicines to the people they care for are provided by the relevant professionals with adequate information and advice about these medicines. It is also expected that all social and health care professionals fully involve carers in the care of the person that they care whilst respecting their rights as specified by the relevant laws covering confidentiality and information governance.

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					One issue that is encountered when involving carers in the care of their patients is the issue of confidentiality and sharing patient information with a person who is not the patient. This guidance should provide some clarity on this matter so healthcare professionals are able to share information, particularly around medicines, with carers as carers are often the ones ensuring that the patient takes their medicines.	
39	SH	SCIE (Social Care Institute for Excellence)	General	General	- It would be fairer not to address adult carers together as one. Bear in mind that the needs and interests of a 19-year old and a 79 year old will be very different	Thank you for your comment. It is acknowledged that the needs and types of support that may assist adult carers can vary widely relative to the age of the carer. Age is explicitly acknowledged as an equality consideration and will be considered by the guideline when making their recommendations.
40	SH	Sheffield City council	general	general	The below comments are from a carer.	Thank you for your comments, your input is greatly appreciated.
41	SH	Sheffield City council	General		I think this underestimates the poor quality of life of many carers: their stress/ anxiety /uncertainty about the future/ fear of the present and how things are changing financially/ anger/ despair/ guilt	Thank you for your comment. Generally, it is recognised that carers' quality of life can be profoundly affected by their experience of caring. As such, the impact of caring on the carer, carer mental health and carer quality of life - as specified in Section 3.6 of the scoping document - are amongst the main outcomes that will be sought and examined in determining whether and how the current support pathway should be reconfigured. Note that more detail will be provided in the protocols.
42	SH	The National LGB&T Partnership	General	General	In general, social care providers should ensure that information for carers and for people receiving care is inclusive for LGBT people, who often report that information isn't appropriate to them. This means that published material should use LGBT-affirmative language and imagery, and that all providers of care have received LGBT awareness training on LGBT issues so they are able to truly provide person-centred care. Sexual orientation and trans status should be monitored, in order to help build the evidence around the needs of LGBT carers and LGBT individuals who receive care.	Thank you for your comment. First, NICE is committed to eliminating discrimination, advancing equality of opportunity, and fostering good relations (as required by the Equality Act 2010) and to complying with the Human Rights Act 1998. As specified in Section 2 of the scoping document, the NICE equality impact assessment concluded that the guideline will examine inequalities related to, among other things,

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						LGBT carers. As such, the guideline will be written in a way that respects the way in which LGBT carers wish to be thought about. Second, all health and social care professionals are expected to have the appropriate training relevant to the person they are providing advice and support to, including LGBT issues. Finally, the issue of whether the sexual orientation and trans status of carers should be monitored as a matter of course will be considered by the guideline committee when making their recommendations.
43	SH	Hospice UK	General	General (127-147)	The scope focuses mainly on deliverable interventions for carers and omits some of the key steps in *structure and process* which will prevent adequate carers support being given.	Thank you for your comment. In determining the most effective and cost-effective interventions for adult carers and making their recommendations as to what best practice should be, the guideline committee will make explicit what processes should be followed. Service providers will be asked to implement any changes to current service structures in order to comply with the guideline committee's recommendations. Note that several of the questions will also examine the views and experiences of both carers themselves and the relevant health and social care professionals, which will inform the guideline committee's recommendations.
44	SH	Royal College of General Practitioners	General	3.3	Financial difficulties and hardship are common amongst carers as they have put their own employment prospects on hold to care for the family member. Information about attendance allowance (non means tested) carers allowance (means tested) help with council tax for people with dementia and setting lasting power of attorneys need to be available in accessible formats with primary and secondary care. Organisation of medication including use of dosette box system to help with multiple medications.	Thank you for your comment and for your helpful suggestions.

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					Encourage the use of the summary care records for both the person being cared for and carer so additional information is available to out of hours care staff.	
45	SH	Bury Council (comments supported by Bury CCG)	9-10	249-268	Outcomes could include a clearer goal to ensure that carers have a life outside of caring (this will promote overall wellbeing for the carer and consequently the person being cared for). As above, some carers may require support if they wish to reduce or relinquish their caring role. This relates to all of the other main outcomes.	Thank you for your comment. The issue of supporting carers when they are not caring for the person being cared for and during changes in their caring role will be examined in the guideline. Note that more detail will be provided in the protocols.
46	SH	Bury Council (comments supported by Bury CCG)	8-9	227-233	Some carers of working age have reported that they do not wish to attend the current carer groups on offer. However, they would be interested in groups that are relevant to their personal interests, such as walking or exercise groups, which would engage them in a social interaction outside of caring. For carers of working age, support would need to be outside of standard working hours.	Thank you for your comment. The issue of enabling carers to engage in social activities not related to caring will be examined in the guideline regarding providing practical support. Note that more detail will be provided in the protocols.
47	SH	Bury Council (comments supported by Bury CCG)	8-9	234-239	Some carers have reported that it is important for them to feel like they are being listened to as 'experts by experience' by health and social care professionals. Community based befriending/ keep in touch type services could enable carers to talk to someone impartial, which could help with emotional wellbeing. Low-level programmes and coping techniques to support mental health can also be useful (Helping Yourself to Wellbeing is a popular programme in Bury).	Thank you for your comment and for your helpful suggestions. The role of social and community, as well as psychological and emotional, support will be examined in the guideline. Note that more detail will be provided in the protocols.
48	SH	Bury Council (comments supported by Bury CCG)	7-8	197-201	It is crucial to have good quality and accessible information and advice in a range of locations (hardcopies and online). Better use of social media is required to reach a larger number of carers. Information and advice should include a wide variety of relevant topics.	Thank you for your comment and for your helpful suggestion. It is of course essential that the available information be of high quality, comprehensive, and easily accessible in a range of formats. It is inevitable that the use of online portals such as social media will, become increasingly important in the modern world.
49	SH	Bury Council (comments supported by Bury CCG)	7-8	197-201	Professionals should ensure that carers are included in health and social care processes (of the person being cared for), as appropriate.	Thank you for your comment. The Committee will be considering communication between carers and health and social care professionals in the context of support for the carer and will be looking at evidence about the views and experiences of carers and what is helpful

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						in that context.
50	SH	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, Newcastle Gateshead CCG, Northumbria Tyne and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East	7-8	197 - 201	Information needs to be timely, relevant, individualised and accessible in both form and language - given in manageable amounts and revisited to check understanding at a later date Carers guidance and information packs are Carers guidance are distributed by Newcastle upon Tyne Hospitals Trust (NUTH) to carers identified on the wards and at pre-op assessment stage http://www.newcastle-hospitals.org.uk/downloads/Equality%20and%20diversity/Carers_Pack_-_final.pdf On-line information should be linked to carer support services locally and nationally Carers need a choice as to how they receive the information – written, spoken, digital, one to one, group work, support groups etc Information given should be directive, supportive and enabling i.e. signposting to support services, condition specific Electronic information could be personalised - either through an app or via a central repository supporting and enabling access as and when needed	Thank you for your comment and your helpful references and suggestions. The importance of adequate information provision will be addressed in the guideline. Note that more details will be provided in protocols.
51	SH	The National LGB&T Partnership	7-8, and general	197-199, and general	The National LGB&T Partnership carried out the largest known research into the views of LGBT recipients of social care and their carers with 251 respondents as part of the LGBT Companion to the Adult Social Care Outcomes Framework (ASCOF) in 2014. This is available at: http://lgbt.foundation/policy-research/ASCOF/ Only 4% of LGBT respondents to the survey felt they were able to balance their caring responsibilities with their own quality of life. The majority of respondents (64%) said they couldn't balance their caring responsibilities with quality of life, with many describing this as difficult to achieve. This suggests that LGBT carers struggle to balance their caring roles and maintain their desired quality of life. The report subsequently recommends that local authorities should provide social care services with appropriate signposting and resources so that carers have information that is relevant to their specific needs as LGBT people. As with all services, many LGBT carers will access mainstream support and find	Thank you for your comment, and helpful suggestions and references. The NICE equality impact assessment concluded that the guideline will examine inequalities related to, among other things, LGBT carers.

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					it fulfilling and appropriate; others will prefer to access services which are explicitly inclusive of their identities, experiences and needs, and where they don't need to fear talking about sexual orientation or gender identity. One means of doing this is for local authorities to also provide clear pathways between carers and the services provided by LGBT organisations, to ensure appropriate services for them are identified early. This could also be appropriate for other communities who would benefit from more specific support, such as carers from black, Asian and minority ethnic backgrounds.	
52	SH	Public Health England	1	General	It would be useful to specifically specify how many older carers over the age of 65 there are, and highlight some of the specific implications for this group, in terms of them tending to have their own health problems… often with multiple long term conditions and comorbidities. The Carers Trust have facts and figures that could be used to support this.	Thank you for your comment. The full guideline will have a detailed introduction, which will include information about the prevalence of older carers as well those of other age groups.
53	SH	Public Health England	1	General	It would be useful to specify how many older carers over the age of 65 there are, and highlight some of the specific implications for this group. For example, older carers may have their own health problems, including multiple long term conditions and comorbidities. The Carers Trust has facts and figures that could be used to support this.	Thank you for your comment. The full guideline will have a detailed introduction, which will include information about the prevalence of older carers as well those of other age groups.
54	SH	Parkinson's UK	1	13-14	The draft scope makes no mention of the age profile of adult carers and the additional impacts that caring into older age can have. For example, forthcoming academic research examining the experience of carers of people with Parkinson's shows that the average age of a carer of Parkinson's is 70. In many cases they provide around 16 hours of unpaid care a day. We therefore recommend that the scope is extended to examine how carers needs change depending on their own age, the length of time they have spent caring for their loved one and their own frailty.	Thank you for your comment. It is acknowledged that the needs and types of support that may assist adult carers can vary widely relative to the age of the carer. Age is explicitly acknowledged as an equality consideration and will be considered by the guideline committee when making recommendations. Specific attention will be given to the topic of older carers
55	SH	Royal College of Nursing	1	12	The current remuneration to carers who give up employment is totally inadequate and places additional stress on them. This needs to be acknowledged.	Thank you for your comment. Unfortunately funding issues are not within the scope of the guideline. However, all service providers would be expected to implement any changes required to conform to best practice as determined by current NICE guidance. Note that the topic

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						of effective support for carers to enter or remain in work is explicitly covered in the scope of the guideline.
56	SH	Leeds City Council	1	13	There needs to be a concerted effort to use 'carers' rather than "unpaid carers" - All other people with input to people's care should be referred to as "paid carers", "care workers" etc	Thank you for your comment. The scope simply sets out the topics which the committee will consider when reviewing evidence. The scope has used the term 'unpaid carer' in some instances for clarity and 'carer' in others. In developing the guideline the committee will agree on appropriate and consistent terminology, taking into account the main audiences for the guideline. Definitions will be included in a glossary.
57	SH	Macmillan Cancer Support	1	13	Suggest including a clear definition of a "carer" at the beginning e.g. a carer is anyone who provides unpaid support to a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.	Thank you for your comment. A definition of the term carer, as defined by the Care Act 2014, is included on page 2 of the scope in the section about why the guideline is needed.
58	SH	Carers Trust	1	15	• Many carers do not care for someone they love. We do not recommend that "loved one" is used. There are many reasons someone is a carer; love is not necessarily one of them. For example, someone who is a former partner of a person with care needs, or a neighbour. • Caring is not often acknowledged as a privilege. Many carers may find the time they spend caring hazardous to their health and income, exhausting and demoralising. Many carers are not given the choice to care, and are doing it because of the lack of available health and social care services the person they care for receives.	Thank you for your comment. This sentence has been deleted.
59	SH	Carers Trust	1	16	Add in "carers'" so that it reads "carers' health and wellbeing"	Thank you for your comment. This sentence has been deleted.
60	SH	Carers Trust	1	19	This needs a rephrase so that it makes it clear that it is likely that the number of people with caring responsibilities will increase. At the moment this reads as though carers almost need to be "recruited".	Thank you for your comment. The text has been amended to take away this implication.
61	SH	Carers Trust	1	25	Many young carers in transition and young adult carers find their chances of entering the workplace or college and university disrupted by their caring circumstances.	Thank you for your comment. The issue of how best to support adult carers over the age of 18 to enter or remain in education/work/training will be specifically examined in the guideline. Note that more detail will be provided in the protocols. The

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						issue of how carers below the age of 18 can best be supported to enter or remain in education/work/training is outside the scope of the guideline. However, it is expected that at least some of the recommendations pertaining to adult carers will be applicable to carers below the age of 18.
62	SH	Carers Trust	1	26	This also affects carers' incomes, and potential income.	Thank you for your comment. The text has been amended to take into account your suggestion.
63	SH	Carers Trust	1	27	This may be better expressed in terms of the cost of recruitment and the loss of experienced staff.	Thank you for your comment. The text has been amended to take into account your suggestion.
64	SH	Leeds City Council]	1	27	Reduction of income for carers reduces their spending power, which impacts the national economy	Thank you for your comment. The text has been amended to take into account your suggestion.
65	SH	Local Government Association	2	45-48	Suggested rewrite: Although the Care Act 2014 gives unpaid carers specific rights to personal budgets, direct payments, information and advice, assessment and support to maintain their health and well-being only a small proportion (in one area estimated 46 as 7%) are identified as unpaid carers by social care and health bodies, and so many may be missing out on care and support.	Thank you for your comment. We have amended the text with your suggestions.
66	SH	Local Government Association	2	50-52	By 'contingency planning', do you mean carer breakdown? It would be useful to be clearer about what NICE mean by 'contingency planning' in the context of unpaid carers.	Thank you for your comment. The reference to contingency planning has been removed.
67	SH	Bury Council (comments supported by Bury CCG)	2	37-38	Many carers do not identify with the term 'carer'.	Thank you for your comment. We have slightly amended the paragraph and hope it is clearer. This is a key issue for the guideline to address.
68	SH	Local Government Association	2	32 -33	The reference to a 'service' is outdated language, and does not reflect the personalised approach to supporting carers. A more recognised phrase would be 'high quality and consistent care and support'.	Thank you for your comment. We have amended the text with your suggestions.
69	SH	Carers Trust	2	29	We suggest this is phrased as "Paid care support workers" as the use of professional with care workers implies that unpaid carers aren't professional.	Thank you for your comment. We have amended the text to "Support from paid

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					While of course they are not paid, many carers may have their own professional background, as well as having experience that could be used by health and social care staff to involve carers as partners in care.	care workers…"
70	SH	Macmillan Cancer Support	2	30	Amend to "appropriate or affordable"	Thank you for your comment. The text has been amended.
71	SH	Carers Trust	2	36	We suggest the word "dependence" is rephrased – there are many reasons why it is entirely appropriate for carers to have the support of health and social care staff, and also for the person they care for, to have support and services from health and social care staff. It is important this guideline is not used as an opportunity to reduce carers' support on the grounds that they are "dependent" on it.	Thank you for your comment. This sentence has been removed.
72	SH	Carers Trust	2	37	• Many health and social care professionals do not identify carers either. This implies that carers should be identifying themselves. Also, identifying is only part of the solution, making an assessment and offer of support is part of it too. • Using the term "hidden" carers is potentially difficult – who are they hidden from? Many carers have not been identified because professionals are not aware of what a carer is or how to support them.	Thank you for your comment. The text has been amended to remove the implication that carers should be identifying themselves. The assessment of carers will be examined in the guideline. Note that more detail will be provided in the protocols. The expression 'hidden carers' has been clarified and is intended to indicate that a person providing care either does not explicitly think of themselves as doing so or is not known to health or social care providers.
73	SH	Leeds City Council	2	39	Many "hidden carers" come from ethnic communities where the role of "carer" is not generally recognised as different from other forms of family/community support. The role is "expected", particularly of women, so there would be no reason for those persons to assume they even need support, much less that it exists.	Thank you for your comment. The text has been amended to account for this.
74	SH	Carers UK	2	40	Might be more appropriate to say that the Care Act applies to adult carers of adults here. Current wording suggests that this is an exhaustive definition of a 'carer' but it is not.	Thank you for your comment. The text has been amended as suggested.
75	SH	Local Government Association	2	40	The Care Act 2014 has *substantially* strengthened the rights and recognition of carers within the social care system.	Thank you for your comment. The text has been amended as suggested.
76	SH	Carers UK	2	43	Helpful to include this clarification here.	Thank you for your comment. The text has been amended to make clear that the scope of the Care Act 2014 excludes adults who are paid to provide care or who

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						do so voluntarily.
77	SH	Carers Trust	2	44	This guideline does not mention the implementation of the Care Act for carers, which has been found to be poor, especially given the lack of sustainable social care funding solutions that include carers.	Thank you for your comment. The scope refers to the Care Act 2014 in a number of places and the focus of the guideline is very much tailored to support the implementation of the Care Act and make recommendations in the context of this legal framework using the best available evidence about what works and is most effective and costs effective. It is hoped that the guideline recommendations will help local authorities especially to prioritise the sorts of help and support that carers most need and want.
78	SH	Leeds City Council	2	45	In order to flag individuals as carers, health workers (being most likely to be in contact with the situation) need training to recognise that someone is a carer & advise them that they can be given this status in their dealings with authorities of all kinds, which can lead to them accessing the support they need	Thank you for your comment. It is expected that all health and social care professionals who are likely to be in a position to identify carers have the appropriate training to enable them to do so.
79	SH	Carers Trust	2	52	Young adult carers need particular support, such as that identified in the Care Act statutory guidance around raising their aspirations. The Care Act and Children and Families Act work together to give young carers in transition, and young adult carers, particular rights. See p17 of http://www.local.gov.uk/sites/default/files/documents/care-act-and-whole-family-6e1.pdf	Thank you for your comment and for your reference. It is acknowledged that carers below the age of 18 years need particular support in addition to that required by adult carers. However, whilst such carers are outside the scope of this guideline it is expected that at least some of the recommendations pertaining to adult carers will be applicable to carer's below the age of 18 years.
80	SH	Hospice UK	3	58	Dementia carers guidance needs to be identified here (is mentioned on Line 165 – but needs to be here too?)	Thank you for your comment. The list on pp. 2-3 is not intended to be exhaustive. All relevant extant and upcoming NICE guidance will be referred to in the short and full versions of the guideline.
81	SH	Macmillan Cancer Support	3	64	The list of people and organisations the guidance is aimed at is broad. Some e.g. local authorities may have much higher levels of knowledge of the subject area than others e.g.families of adult carers. How will NICE ensure that the guidance is accessible to all?	Thank you for your comment. All NICE guidance is available free online from their website. NICE also provides several versions of the guideline: a full guideline

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						(detailing the entire review process from literature review to data analysis and decision making of the guideline committee) and a short guideline (composed of the recommendations of the guideline committee) - both of which are intended for health and social care professionals - and a jargon-free version for the public. Further information is available at the NICE website (www.nice.org.uk).
82	SH	Carers UK	3	65	In Carers UK's view the guideline should cover all carers and not only adult carers of other adults. If the scope was widened, a number of changes would be needed that we have not set out here.	Thank you for your comment. The general scope of the guideline is to provide evidence-based guidance for adult carers of other adults. The scope has been prioritised in this way because of specific issues for adult carers, as defined by the Care Act 2014, who are increasingly taking on caring duties of other older adults in the home. However, this guideline will consider the role of whole family assessments and in this context only will consider carers who are under 18 years of age. There are no current plans for NICE to develop a guideline specifically concerning carers under 18 years of age. However this decision will be kept under review by NICE. That said, it is expected that at least some of the recommendations for adult carers will be applicable to carers under the age of 18.
83	SH	Carers UK	3	65	The current wording does not make it clear that the guideline as currently drafted does not apply to adult carers of children	Thank you for your comment. The text has been amended to make this clear.
84	SH	Carers UK	3	71	Should specify residential care providers, domiciliary care providers, hospices and allied health professions e.g. OTs and pharmacists here too	Thank you for your comment. A reference to tertiary care has been added. A specific mention of residential care has also been made as an example of the kinds of settings that will be considered in the guideline. Please note that the list of

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						examples given is not intended to be exhaustive.
85	SH	Hospice UK	3	75	Including hospices and palliative care teams	Thank you for your comment. A reference to tertiary care has been added, which will include hospices and palliative care teams. Please note that the list of examples given is not intended to be exhaustive.
86	SH	Carers UK	3	83	Welcome mention of employers here – On average 1 in 9 people in the workplace are carers. Reference to job centres is also welcome.	Thank you for your comment. Your support is greatly appreciated.
87	SH	Hospice UK	3	84	Could include community and neighbourhood centres – which are not the same as carer support groups – there are many ways that communities informally support carers e.g. in the post office– as they go about. daily life – information and support needs to be diffuse	Thank you for your comment. It is acknowledged that communities informally support carers in a variety of ways. A wide range of interventions and ways of supporting adult carers will be examined in this guideline. Note that more detail will be provided in the protocols.
88	SH	Royal College of Occupational Therapists	3.3	general	Carer stress management advice that is easily accessible perhaps groups. This would be cost effective as may reduce need for support if carer becomes unwell. Access to assist in understanding of ones stress could lead to reduction in likelihood of safeguarding type incidents.	Thank you for your comment and for your helpful suggestions. A wide range of interventions and ways of supporting adult carers will be examined in this guideline. Note that more detail will be provided in the protocols.
89	SH	Royal College of Occupational Therapists	3.3	General	Clear access/signposting for carers of Substance Misuse Outreach services, Crisis services	Thank you for your comment and for your helpful suggestions. A wide range of interventions and ways of supporting adult carers will be examined in this guideline. Note that more detail will be provided in the protocols.
90	SH	Royal College of Occupational Therapists	3.3	134	We felt that the types of training mentioned were very important and there should be clear pathways on who delivers training or where to get the training. Cost effective for "cared for" and carer as reduces time spent on tasks, safer and would reduce risk of physical injury	Thank you for your comment and for your helpful suggestions. As you have noted, this issue will be specifically examined in the guideline. Note that more detail will be provided in the protocols.
91	SH	Royal College of Occupational Therapists	3.3.	135	We felt that there should be training around practical techniques for caring for people with dementia for example assisting someone to mobilise. This again would be cost effective as could reduce the need for statutory services.	Thank you for your comment and for your helpful suggestions. A wide range of interventions and ways of supporting adult carers will be examined in this guideline. Note that more detail will be provided in the protocols .

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92	SH	Royal College of Occupational Therapists	3.3	137	We felt Information around assistive technology that is regularly updated as the systems change frequently to be easily and readily available.	Thank you for your comment and for your helpful suggestions.
93	SH	Royal College of Occupational Therapists	3.5	240	End of Life To ensure that services are equitable for all conditions. Those with dementia may have different needs. Clarity in the document about what is meant by end of life. Staff to have knowledge of services available so that they can signpost so that the carers can get the individual support they may require. This includes on line support	Thank you for your comment. First, the expression 'end of life' is a widely-used term in health and social care, and a definition will be included in the glossary of the guideline. Whilst there may general forms of support that can be fruitfully provided to those who are providing care for people at the end of life, more specific forms of support will of course be required relative to the type of physical and/or mental condition that the person being cared for has. For condition-specific guidance, please see the relevant NICE guideline. Second, it is expected that all health and social care professionals have the appropriate training and knowledge for those that they are supporting. Finally, any evidence identified on the role of online support systems will be examined as a matter of course in conducting the reviews specified in the scoping document.
94	SH	Age UK	4	104-109	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, *Sate of Caring 2015*, 2015). 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	Thank you for your comment. The text has been amended to be clear that specific consideration will be given in the guideline to adult carers that care at a distance or who do not live with the person they are caring for.

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					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 '*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'*.	
95	SH	Department of Health	4	106-109	In order to remove any potential doubt that carers of people with developmental disorders such as autism are within the scope of the guideline, we suggest modifying the definition of 'people receiving care' as follows: "Adults with health and social care needs, including people with sensory, cognitive or physical impairments, mental health conditions, substance misuse, learning and developmental disabilities ~~disability~~, dementia and other complex, long-term conditions, and people at the end of life".	Thank you for your comment. The text has been amended to include reference to developmental disabilities.
96	SH	Parkinson's UK	4	102-104	Parkinson's UK agrees that specific consideration should be given to mutual caring, and to those who are providing care for more than one person. As noted in comment one, we also feel that further consideration should be given to older carers and those who have been providing care for several years. People in these situations are likely to have more complex needs and the need for different support than those who are younger or have been caring for a shorter period of time. A partner of a person with Parkinson's who has cared for boyfriend for nine years explains: *"My boyfriend has had Parkinson's since he was 39, he's now 48. He is a beautiful caring person who I love dearly. But our relationship is changing, I seem to be taking on a mothering type of role which neither of us like. I don't want to take on this role. I feel I am losing the close bond I have with him and starting to get impatient, snappy and resentful. It's like I am grieving for the loss of our relationship."*	Thank you for your comment and for your support. Older carers has been added to the scope in Section 3.1 as a specific group that will considered in the guideline. Note that age is also a specific equality consideration. The issue of the types of support for older carers and for those who have been carers for several years will thus be specifically examined in this guideline. More detail will be provided in the protocols.
97	SH	Age UK	4	100-101	We would like the scope and the guideline to explicitly recognise that many	Thank you for your comment. Older carers

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					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, *Understanding Society: Waves 1-5,* 2009-2014*)*. 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 *'The guideline will acknowledge and address the particular issues faced by older carers'.*	has been added to the scope in Section 3.1 as a specific group that will considered in the guideline. Note that age is also a specific equality consideration and that more detail will be provided in the protocols.
98	SH	Bury Council (comments supported by Bury CCG)	4	89-90	The Equality Impact Assessment does not clearly explain why all carers are not included. We believe a guideline would also be useful for young carers and adult carers who care for children with disabilities.	Thank you for your comment. Whilst this issue is outside the scope of the guideline, it is expected that at least some of the recommendations will be applicable to carers below the age of 18 years and to those caring for children under 16. The Equality Impact Assessment aspect of the scope has been updated to include more information about this.
99	SH	National Bereavement Alliance	4	100-101	Here it would be helpful to include former carers – specifically those whose cared-for person has recently died. They could be described as 'bereaved former carers'	Thank you for your comment. The guideline will cover support for adult carers during times of change, and will specifically address support for carers of people at the end of life and after they die.
100	SH	Sheffield City council	4	Section 3.1	1This section also needs to refer to those who don't do everyday practical caring but who nevertheless are fully involved in most other aspects of their relatives life eg have power of attorney over money, are benefits appointees , go to medical appointments, are fully involved in planning the best outcomes for their family member alongside support staff. All of this leads to a high degree of stress and anxiety, even if not physically exhausting in the way hands on caring must be.	Thank you for your comment. It is acknowledged that there is substantial variation in the amount, and nature, of care that carers provide and that the intensity of the caring role can be very different depending on the type and severity of the condition of the person being cared for, where they live etc. As such, all different

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						varieties of carers and caring roles will be considered in the guideline.
101	SH	Hospice UK	4	93	Should include remote carers (living far away) and non-kin carers ie friends and neighbours? Could also include carers of people already in e.g. nursing homes – they may still be providing care and need support	Thank you for your comment. The text has been amended to be clear that specific consideration will be given in the guideline to adult carers that care at a distance or who do not live with the person they are caring for. As for non-kin carers, noted that no restriction on the relationship of the carer to the person cared for has been specified.
102	SH	Carers Trust	4	100	We do not understand how this will relate to transition - parent carers, young carers, and young adult carers. The Care Act, and Children and Families Act, work together to give young carers and parent carers in transition, and young adult carers, particular rights.	Thank you for your comment. Issues regarding changes in carers' roles will be covered in the guideline. Whilst issues pertaining to carers below the age of 18 years are outside the scope of the guideline, it is expected that at least some of the recommendations for adult carers will apply to carers below the age of 18.
103	SH	Hospice UK	4	100	Specifically to include non-kin carers – see recent publication in PalliativeMedicine http://journals.sagepub.com/doi/abs/10.1177/0269216316666785	Thank you for your comment. No restriction on the relationship of the carer to the person cared for has been specified.
104	SH	Macmillan Cancer Support	4	108	How does NICE define "complex, long-term conditions"? Does this include cancer, and if so please could cancer be mentioned specifically as it can get overlooked in discussions around carers and caring.	Thank you for your comment. Evidence relating to support for carers of adults with cancer will be examined in the guideline. Note that more detail will be provided in the protocols. Please also note that the text has been slightly amended.
105	SH	Royal College of Occupational Therapists	4	108	To include Autism/Asperger's as a separate condition as we feel that this diagnosis may not fit into learning disability or mental health conditions but the impact of the condition can be very great.	Thank you for your comment. Evidence relating to support for carers of adults with autism or Asperger's syndrome will be examined in the guideline. Please note that the text has been slightly amended.
106	SH	Carers Trust	4	110	We wonder if this means long-term care? This could be easily misunderstood as being around continuing health care?	Thank you for your comment. The term 'continuing' has been replaced with the term 'ongoing'.
107	SH	Leeds City Council	4	110	'continuing care' could be confused with continuing healthcare – suggest change 'continuing' to 'ongoing'	Thank you for your comment. The term 'continuing' has been replaced with the term 'ongoing' as suggested.

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108	SH	SCIE (Social Care Institute for Excellence)	4	98 to 117	**Groups** - Suggest adding specific groups such as economically active and economically inactive (labels used in census). - Look more at how diversity relates to any particular needs/challenges etc - Consider adding 'facilitative' groups, for instance employers, third sector orgs such as Age UK, Carers UK and Employers for carers	Thank you for your comment. The scoping group considered whether to amend the text as suggested but decided that examining the category of economic activity (as it pertains to carers or people being cared for) is not a priority. The intended target audience of the guideline (see Section 2 of the scoping document) includes third sector organisations such as charities.
109	SH	Age UK	5	125-139	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, *Caring into later life: the growing pressures on older carers*, 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 *A practical guide to healthy caring*, 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 *practical guide* which can help carers, particularly when they are starting their new role. We therefore recommend adding a bullet point saying: *'Providing information, support and interventions to help carers to maintain good health and wellbeing, including through health promotion programmes and materials'.*	Thank you for your comment and for your helpful references. It is acknowledged that the health and wellbeing of carers, especially that of older carers, can be substantially affected by and when caring for another. Note that the role of carer health checks will be examined in this guideline and that more detail will be provided in the protocols.
110	SH	Local Government Association	5	136-139	There is a very local element to offering support and advice –the third sector plays a key part as do support networks, etc.	Thank you for your comment. Issues regarding the role the third sector can play will be examined in the guideline. Note that more detail will be provided in the protocols.
111	SH	Bury Council (comments supported by Bury	5	129-131	Some carers have told us that they would like to see more support around future planning (in the event that they are no longer able to continue with their caring role).	Thank you for your comment. Issues regarding planning for the future will be specifically examined in the guideline. Note

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		CCG)				that more detail will be provided in the protocols.
112	SH	Local Government Association	5	120-122	Just to note that most people do not think of their own home as a 'care setting', and there is unlikely to be unpaid care provided in 'non-home' settings.	Thank you for your comment. The text has been amended to take this into account.
113	SH	Age UK	5	127-128; 137	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: *'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'*	Thank you for your comment. The committee acknowledged that the decision making process regarding care can be frustrating for carers, and this will be one of the issues addressed in the guideline. The committee agreed there was no need to modify this key area in the scope, however your useful input will be taken into account when developing the research protocols.
114	SH	Think Local Act Personal	5	132 - 133	Think Local Act Personal, in partnership with ADASS North-West and Yorkshire and Humberside regions, has produced a report 'Supporting Working Carers' and a document aimed at employers 'Top Tips for Supporting working carers'. Both documents are due to be launched w/c 12 June 2017 and will be available on the TLAP website. The documents were produced following desk based research and a series of interactive workshops for key stakeholders (carers organisations, employers, national bodies, Local Authority commissioners etc.). The documents outline the benefits to employers of ensuring that working carers are supported and the tips outline the steps employers can take to ensure a supportive environment at work.	Thank you for your comment and for your helpful references.
115	SH	Sheffield City council	5	Section 3.3	The comments above are relevant to this section on identifying carers	Thank you for your comment. It is acknowledged that there is substantial variation in the amount, and nature, of care that carers provide and that the intensity of the caring role can be very different depending on the type and severity of the

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

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						condition of the person being cared for, where they live etc. As such, all different varieties of carers and caring roles will be considered in the guideline.
116	SH	SCIE (Social Care Institute for Excellence)	5	128 - 122	- Suggest adding 'workplaces'.	Thank you for your comment. The setting section of the scope focuses on settings where carers are providing unpaid care and support to family members. It would be extremely rare and not common practice for this care and support to be taking place in the carers place of work so we cannot include 'workplace' as one of the settings. However the committee will be looking at support and advice that can help carers enter, remain or return to work.
117	SH	Leeds City Council]	5	112	Need to make it clear that receiving Carers Allowance is not the same as being paid for proving care – suggest using "paid carers", "care workers" etc	Thank you for your comment. We believe that the text is clear and does not need to be changed. All the definitions will be provided in the guideline glossary.
118	SH	Carers Trust	5	114	The Care Act and Children and Families Act work together to give young carers in transition, and young adult carers, particular rights. See p17 of http://www.local.gov.uk/sites/default/files/documents/care-act-and-whole-family-6e1.pdf	Thank you for your comment and for the information.
119	SH	Carers UK	5	116	Carers UK feels particularly strongly that parents of disabled children should be covered by this guideline. Many of the same kinds of support available from local carers' services will be provided to adults caring for children and adults. Carers of disabled children are often in lifelong caring roles and though the nature of the caring may change and there will be important transition points, much of the practical and emotional support needed is consistent throughout the caring journey.	Thank you for your comment. The general scope of the guideline is to provide evidence-based guidance for adult carers of other adults or adult carers of young people aged 16 or over who need ongoing care, whether or not they are parents of the people they are caring for. The scope has been prioritised in this way because of specific issues regarding adults, specifically adults who are increasingly taking on caring duties of other older adults in the home. However, this guideline will consider the role of whole family assessments and in this context only care for children under 16 will be included. The are no current plans for NICE to develop a

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						guideline specifically concerning the parental care of children under 16 with health and social care needs but this decision will be kept under review by NICE. However, it is anticipated that at least some of the recommendations in this guideline will also be relevant to carers of disabled children.
120	SH	Carers UK	5	120	At some point in the guideline, it would be helpful to highlight that it applies to carers who support someone in residential care.	Thank you for your comment. Reference to residential care has been inserted in Section 2.
121	SH	Hospice UK	5	122	To include neighbourhood and community settings – as per Line 84 point	Thank you for your comment. We have amended to include neighbourhood and community settings
122	SH	SCIE (Social Care Institute for Excellence)	5	123 to147	- Around identification of hidden carers and assessment of need. Suggest looking at where 'hidden' need occurs and why; and also have guidance that assume some carers will remain hidden, look at profiling this via evaluation and making informed assumptions around need. Reality is that not only will some carers remain hidden, they have a right to, but we know enough to provide general environments that reflect and meet known need, such as the workplace. - More assessment of reasons for economic inactivity and barriers to return to employment - More broadly, guidance on how to create community-related carer friendly environments – including workplaces – we should not just focus on individual need	Thank you for your comment and for your helpful suggestions.
123	SH	Bury Council (comments supported by Bury CCG)	5	124	Some carers may require support if they wish to reduce or relinquish their caring role.	Thank you for your comment and for your helpful suggestion. The committee agreed with your suggestion, and it will be taken into account when drafting research protocols.
124	SH	Carers UK	5	124	This section should include something about signposting to welfare advice	Thank you for your comment. This guideline will look at the information needs for carers, and the importance to signpost to welfare advice will be included in research the protocols.
125	SH	Admiral Nurses	5	125	Refers to hidden carers which we understand is defined as carers who do not realise that they are providing care. Admiral Nurse experience is such that	Thank you for your comment. It is acknowledged that carers of people with

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					people often will not accept that they are caring for someone who is physically able to attend to their needs yet psychologically impaired. The social care system is reluctant to acknowledge this as caring as well which compounds the problem. The most stressful caring situations are those when the cared for person needs 24 hour supervision but is still reasonably independent with their ADLS as limited formal support is available.	mental health conditions but who are otherwise physically capable of looking after they can face substantial barriers to receiving support. One of the main aims of this guideline is to review the views and experiences of carers and health and social care professionals in orders to identify whether and how services should be reconfigured to provide a more effective and equitable service for all.
126	SH	Carers Trust	5	125	See comment under page 2 line 37	Thank you for your comment. The text on p. 2 has been amended to remove the implication that carers should be identifying themselves. The assessment of carers will be examined in the guideline. The expression 'hidden carers' has been clarified and is intended to indicate that a person providing care either does not explicitly think of themselves as doing so or is not known to health or social care providers. The text in Section 3.3. is only intended to be a brief description of the main areas that will be covered. See also Section 3.5 for the review questions that will be addressed. Note that more detail will be provided in the protocols.
127	SH	Royal College of Nursing	5	125	We feel that the best way to identify carers is through health and social care professionals who are commonly involved in the assessment review, treatment and care of people being cared for by relatives.	Thank you for your comment and for your helpful suggestion.
128	SH	Royal Mencap Society (Mencap)	5	125	We welcome the recognition of hidden carers within this specification and the need to effectively identify carers in order to provide them with effective support, and information. The term ‘carer’ is often not clear-cut, Mencap supports a number of families for whom the caring role involves supporting a family member who lives outside of the family home. The intensity in such cases remains high with families meeting various needs including: personal healthcare needs, financial needs, emotional needs, physical needs and various other demands, though they are not often classed as carers when doing so.	Thank you for your comment. This guideline will survey the current evidence base relevant to any adult who provides unpaid care for one or more adults in all health and social care settings (including people's homes). As such, the recommendations of the guideline committee will prima facie apply to all carers regardless of whether they live with the person that they care for or not.

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					Other people, who would be considered carers under current definitions, fail to see themselves as such, instead considering themselves to be 'just a family member or 'just someone who cares'. Confusion over what constitutes a carer, and the different definitions used by different organisations may be depriving many unpaid carers of opportunities and resources available to them. Caring involves a wide range of responsibilities and roles, a number of families have spoken on the need to be constantly 'on the ball' to ensure effective care for their loved-ones despite their living outside of the family home. Many speak of the relentless responsibilities and the wide range of demands that they must meet in often very complex situations. We are also aware of family carers who must meet aspects of the caring role simply because no one else is able to do so, this includes aspects of hands-on and emotional care. One parent explains that she feels that her sons paid carers do not provide adequate support to allow her to lessen her caring role: **"I feel that I am always 'clearing up after' the paid carers. When my son comes home I need to support him to wash properly and make sure he has suitable clothes."** **"I'll be a carer for the rest of her life, even if she's told she's 'not a carer any more' when my daughter is not living with me"-** Mother of a young adult with Learning Disabilities **"The appointments and sleepless nights continue despite my children living in residential services"-** Mother to two children with learning disabilities	
129	SH	Royal Mencap Society (Mencap)	5	125 cont..	Family carers tell us that identifying people as carers may be done better with firmer and clearer definitions and support that is available to people with all forms of caring responsibility. Definitions of carers should be improved, with recognition of those who care for someone who lives outside of the family home.	Thank you for your comment and for your helpful suggestions. The scope of the guideline includes carer assessments and various forms of support and advice (e.g. practical, psychological and community support) and the relevant literature

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					Many family carers want recognition of their role simply to improve understanding among services that they remain fully involved and aware of the persons life in order to ensure that their voice remains heard, although all of these carers maintain a need for further support that is not met by the current system. A lack of understanding of the different caring roles that people undertake leads to significant differences in the information, respect and rights afforded to carers, this issue should be rectified to improve access for carers to vital information, support and advice.	(including that on the views and experiences of carers) will be examined. The issue of remote carers (i.e. those who do not live with the person being cared for) has been added to the scope in Section 3.1.
130	SH	Leeds City Council	5	127	Add information and advice about financial issues including claiming welfare benefits, income maximisation, managing money, Power of Attorney	Thank you for your comment. Section 3.3 is intended to provide brief descriptions of the areas that will be covered in the guideline and as such are not intended to provide an exhaustive list of the types of issues that will be covered. Note that the issues you refer to will be examined in the guideline under the questions about information and advice and changes to the caring role and that more detail will be provided in the protocols.
131	SH	Local Government Association	5	127	Suggest the advice for carers is beyond 'planning and coordinating care', as this puts them purely in the role of carer and not looking after themselves. It should include personal care, staying healthy and active, managing finances, etc.	Thank you for your comment. Section 3.3 is intended to provide brief descriptions of the areas that will be covered in the guideline and as such are not intended to provide an exhaustive list of the types of issues that will be covered. Note that more details will be provided in the protocols.
132	SH	Royal College of Nursing	5	127	There need to be single platforms that provide one stop shop situation / information for carers. Internet based, where possible, would be easiest, to keep information up to date.	Thank you for your comment and for your helpful suggestions.
133	SH	Royal Mencap Society (Mencap)	5	127	Information and advice is a key requirement for carers of people with learning disabilities, we welcome that this forms part of the scope. Many carers report a lack of information and advice available for them, this	Thank you for your comment and for your helpful suggestions. One of the main aims of this guideline is to canvass the views and experiences of both carers and health

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					can mean they are not aware of the availability of support and how this may be accessed. It can be the case that the advice needed is only found when people are already at crisis point. **'We had no idea that he was entitled to support from social care, from birth. It was only when we broke down in front of his consultant, from years of sleep deprivation and stress that we found out. She made a referral for respite care, but this wasn't enough. J needed support that we couldn't give, and in the end we had to take the council to tribunal to get him into a specialist boarding school.'** - Parents **'Looking back, our lives would have been transformed if we had known of someone we could easily turn to, who could explain the system and guide us through it. Just someone on the end of a phone, or to visit us through the hard times.'** - Parents of young person with learning disabilities Many family carers have had to fight to get the support their loved one needs and can report a lack of trust in the system. Many want to be able to access independent advice and information. *'Generally, families did not look first to statutory agencies for help or advice nor did they think that families in future would be best served by doing so. They identified user-led organisations like centres for independent living or self-help groups of other families with experience of using self-directed services as likely to be the most useful sources of support.'* – Mansell (2010), Raising our sights: Services for people with profound intellectual and multiple disabilities Many carers highlight the importance of carers networks and groups and peer support. They say this can be an important way to learn about rights, such as benefit entitlements, and how to challenge, as well as getting emotional support and practical advice from other carers with lived experience. However, concerns were raised about these networks being underfunded.	and social care professionals in order to identify whether and how the current pathway should be reconfigured to provide efficient and effective support to carers. It is expected, however, that all health and social care services provide adequate information for carers and non-carers alike about where they are in the care pathway, what opportunities there are, and how they can be accessed.
134	SH	Royal Mencap	5	127	The Information and advice section should include the following key areas	Thank you for your comment. Section 3.3

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		Society (Mencap)		cont…	that are pertinent to the lives of carers of people with learning disabilities: It is vital that carers are aware of the advocacy services available to them, and to the person that they care for. Carers should be able to access good quality, effective information to help them to effectively support the person that they care for. For example, information about rights, housing and support, financial services and benefits and support to help them understand changing needs. **2.1 How to reach carers** It is vital that there is understanding of the differences in caring roles, and the impact of each role on how and where a person may access advice and support. For example, some carers of people with learning disabilities may better access information and advice through established networks such as family forums, whilst others may be unable to give the time to have presence at face to face events and may require online information that can be accessed at any time. Likewise, there must be understanding of the need for carers to be able to access information in different formats, some may not have the time to sit and read information and may prefer it in a filmed format, whilst others may prefer printed or online leaflets and written information that can be easily accessed and read at any time.	is intended to provide brief descriptions of the areas that will be covered in the guideline and as such are not intended to provide an exhaustive list of the types of issues that will be covered. Please note that carers of people with learning disabilities are one of the groups that will be examined in the guideline. Furthermore, issues regarding information and advice about personal budgeting and housing will also be examined. Note that more detail will be provided in the protocols.
135	SH	Kirklees Council	5	128	Add to examples: recognising own needs, importance of looking after own health, achieving a healthy work-life-caring balance.	Thank you for your comment. The text has been amended as suggested. Specifically, according to your and other stakeholders' comments, we added the following examples: for example, about personal budgeting, housing, planning & coordinating care, looking after one's own health and self-care. The committee will also consider your useful suggestions when designing review protocols.

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136	SH	Leeds City Council	5	129	Add new point: "initiatives to promote public awareness of the carer role and promote carer-friendly communities".	Thank you for your comment. Public information campaigns are outside the scope of the guideline.
137	SH	Royal Mencap Society (Mencap)	5	129	The Care Act strengthens the rights of carers, however a recent study states: 'The new research from national disabled people's charity Revitalise found that over half (55%) of England's local authorities had spent less overall on services for disabled people and carers since the Care Act came into being than in the year before… and half[of local authrotities] had carried out an average of 22% fewer Carers Assessments during the same period' - Revitalise press release, 2016 It is vital that carers who could benefit from a carer's assessment are able to access them. They are pertinent to ensuring that carers get the support that they require. It is vital that carers know about their rights under the Care Act and understand how a carer's assessment could help them. As well as assessing whether the carer is eligible for support it is an important opportunity for the carer to talk about their needs and for there to be a focus on them. They provide an opportunity to prevent crisis situations and enable proactive planning ahead for a time when the carer is no longer around. It is vital carers are able to access carers assessments and that these are high quality and lead to the carer getting the support they need.	Thank you for your comment. Whilst it is acknowledged that there has been variation in spending by local authorities on services for people with disabilities and their carers, funding and implementations issues are not within the scope of the guideline. All adults that care for another adult in need are entitled to a carer assessment under the Care Act 2014 and local authorities are expected to provide such an assessment without prejudice and discrimination. The precise form that carer assessments should take (which constitute 'best practice') will be examined in this guideline. Note that more detail will be provided in the protocols.
138	SH	Leeds City Council	5	132	After "Support and advice", add "including help to access reasonable adjustments such as flexible working patterns and digital / remote solutions to reduce the need to be away from work".	Thank you for your comment. All relevant interventions, online or otherwise, intended to support carers in entering or remaining in work will be examined in the guideline. Note that more detail will be provided in the protocols.
139	SH	Royal Mencap Society (Mencap)	5	132	Carers who need to take time off work to attend meetings or return home to provide support can be unable to maintain the level of employment required to fully support their family member as a direct result of their role. 'Families may also experience discrimination in the provision of health and social care services. Services may be denied because the person is deemed 'too disabled' to be coped with by staff – even though families are expected to cope. For example, families report not being able to access short breaks, work or day activities because of the degree of their family member's	Thank you for your comment, and helpful suggestions and references.

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					disability.' (Jim Mansell, Raising out sights) It is vital that consideration is given to the needs of carers in this regard, including coversations about the best ways to support them into/ back into work education or training and the infrastructures that they will require around themselves and the person they care for to do this successfully.	
140	SH	SCIE (Social Care Institute for Excellence)	5	132	- suggest adding 'return to'	Thank you for your comment. The text has been amended as suggested.
141	SH	Carers Trust	5	134	This may be better phrased around "Equipping and providing carers - where they agree to do so - " where this has been identified as an area of care which carers are willing to take part in – carers need to not only agree to care, as well as agree which aspects of caring they are prepared to do and not do. It is not simply the case that carers need to be trained to move and handle, this could be a paid care support worker role, and this could imply that this is a way of not having a package of support which would support a carer and a disabled person or older person.	Thank you for your comment. This was only an example and not intended to be exhaustive of the kinds of practical support that will be considered. Note that choice is implicit as no carer would be compelled to receive training.
142	SH	Royal College of Nursing	5	134	There need to be better affordable social care and 'sitting services' that allow carers to attend work and/or study.	Thank you for your comment and for your helpful suggestion. This guideline will look at interventions to help carers to enter, remain and go back to work or study.
143	SH	Royal Mencap Society (Mencap)	5	134	It is vital that there is an understanding the different sorts of needs that people will be supporting when considering the provision of training for carers. For example, it would not be sufficient to give the same training to all carers of people with learning disabilities since their needs in terms of physical and emotional support will vary dramatically. Carers would require training on an individual assessed basis, and must be able to access such training around their care-giving schedules. For some, this may meant that why will be unable to access traditional training methods and may require the use of technology or additional support to attend training. **5.1. resilience training** Carers are required to be resilient in the face of immense challenges. Resilience training, begun at the earliest possible stage can support carers to 1. Understand the behaviour and communication needs of the person	Thank you for your comment and your helpful suggestions. Whilst some general forms of support may be appropriate to all carers regardless of the particular condition that person cared for has, it is acknowledged that some carers will need specific training relative to this condition. Health and social care providers are expected to provide carers with sufficient information so that they are informed of where they are in the care pathway and what the various opportunities available to them are.

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					they care for 2. Look after themselves and be better equipped to look after the person being cared for 3. Access local support, and know where to do so in future 4. Access peer support, and know where to do so in future (particularly where the training programme involves carers training other carers alongside other professionals)	
144	SH	SCIE (Social Care Institute for Excellence)	5	134	- IT training and support (could be a life line)	Thank you for your comment. The committee will consider this point in drafting research protocols.
145	SH	Leeds City Council	5	136	Point 6 should include digital technologies and solutions to facilitate the caring role; personal budgets and direct payments; housing issues; unsuitable housing	Thank you for your comment. Practical support for carers using digital technology will be examined in the guideline. Please note that the text has been amended to include specific reference to digital technology. Issues regarding support for personal budgeting and housing will be examined in the question on advice and information. Note that more detail will be provided in the protocols.
146	SH	Parkinson's UK	5	136	Parkinson's UK is disappointed that the draft scope does not include the prevention of health problems and associated conditions among carers within the 'key areas that will be covered'. This is a significant focus of the Care And Support Statutory Guidance which accompanies the Care Act 2014. For example, Section 2.3 notes that: '*The local authority's responsibilities for prevention apply to all adults, including […] carers, including those who may be about to take on a caring role or who do not currently have any needs for support, and those with needs for support which may not be being met by the local authority or other organisation'* Preventing carers of people with Parkinson's from developing the need for support is of crucial importance, given the complexity of the condition. It is also important to prevent the development of health problems, as these can lead to mental health problems too. The wife of a person with Parkinson's explains: "*I had to help so much with meal times that by the time he had finished eating my own meal was cold.*	Thank you for your comment. The importance of prevention of health problems has been discussed when developing the scope of this guideline. It is an underlying aim for the guideline to consider interventions that help carers maintain good health and wellbeing. This is reflected in the carer related outcomes set out in section 3.6. These will be used to guide the protocols for all the research question The selected outcomes reflect this. Please note that the role of carer health checks will also be examined in the guideline, and that more detail will be provided in the protocols.

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					And often, by the time I could eat, I didn't want the food. In the end my lack of appetite led to bad health. I started to feel very ill and I developed diabetes. I don't think I would have developed that condition if I hadn't been a carer. *"The problem is that because I didn't feel I was looked after enough by the health service (they didn't see me as needing support), they ended up with two patients instead of one."* We therefore recommend that the scope is updated to include support and advice to help prevent carers developing the need for support.	
147	SH	Royal College of Nursing	5	136	The type and quality, appropriateness and frequency of respite care must be addressed in some detail. Home based respite care is often better for the cared for person but is rarely offered.	Thank you for your comment and for your helpful suggestions. All relevant interventions will be examined in the guideline. Note that more detail will be provided in the protocols.
148	SH	Royal College of Nursing	5	136	We feel that placement in care homes is likely to be the most cost effective respite but there should be an exploration of whether a live in carer could be considered as some people do not do well in care homes.	Thank you for your comment and for your helpful suggestions. The issue of respite care will be specifically examined in this guideline. Note that more detail will be provided in the protocols.
149	SH	Royal Mencap Society (Mencap)	5	136	**6.1 support and interventions for carers, including aids and adaptations; supporting communication with health and social care professionals; providing respite care and breaks from caring responsibilities.** It is important to recognise the need for all carers to access support and interventions that are appropriate for their individual needs and experience. Carers should be asked what would be most helpful to them in order to ascertain appropriate support. Carers require access to appropriate advocacy to support them with communication with health and social care professionals and to support their emotional needs. Advocacy services are often difficult to come by, and difficult for carers to access- it may also be difficult for carers to access advocates with a good understanding of their individual needs and experience enough to support them through complex systems. **6.1.1 Short breaks** Seventy percent of families responding to a Mencap survey said they had reached or nearly reached breaking point because of the lack of short-break	Thank you for your comment. It is recognised that all health and social care providers have experienced substantial difficulties in adjusting to well-publicised funding cuts in recent years. Unfortunately, whilst all such providers are expected to provide support in line with best practice and as recommended by NICE guidance, implementation and funding issues are outside the scope of the guideline.

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					services whilst those caring for people outside of the home environment quote diminishing services as a significant stressor. (Mencap report on cuts to short breaks services, 2013) Over a quarter of councils have closed or reduced capacity of short breaks services in the last three years, and over half have cut spending on short breaks. Last year 84% of adults with a learning disability who were known to social services did not get any short breaks whatsoever. 4 out of 10 family carers of people with a learning disability have had their short breaks services cut in the last three years and the same number say their services have got worse. 8 out 10 family carers have reached, or are close to reaching, breaking point due to a lack of short breaks. A mother explains her difficulties in accessing short breaks for her learning disabled daughter: **"Respite/short breaks would make the biggest difference to me and my husband. The two of us have had four days' break together over 40 years. While my daughter was allocated funding for respite after I went to the LGO, she could not take this up, as there was no suitable provision in the area. Short breaks are really important for our daughter as well."**	
150	SH	SCIE (Social Care Institute for Excellence)	5	136	- suggest adding 'assistive technology'	Thank you for your comment. The text has been amended to make explicit mention of assistive technology.
151	SH	Parkinson's UK	5	138	We strongly agree that respite care is an important issue for carers. However, it is crucial that respite care is both accessible and of high quality. Forthcoming research into carers' experiences of looking after people with Parkinson's shows that poor quality respite that does not support the cared for person effectively can increase demands on the carer even further when the person they care for is returned home. We are not aware of other NICE guidance on respite care, we therefore recommend that this guideline specifies what good quality, accessible respite	Thank you for your comment. The guideline will be looking at respite care and will aim to make recommendations about the effectiveness and cost effectiveness of different types of respite care

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					care looks like.	
152	SH	Esoteric Practitioners Association (EPA)	5	193	**Identifying Carers as defined by the Care Act** It is currently challenging to easily identify carers. Research by Carers UK in 2016 concludes that: The majority of carers take years to recognise their caring role: https://www.carersuk.org/for-professionals/policy/policy-library/missing-out-the-identification-challenge Not recognising a caring role is a significant barrier to accessing support and this is compounded by the fact that health care practitioners are trained to focus on the cared for person as their primary responsibility, not the carer. For example: A woman with Type 1 diabetes and vascular dementia being cared for by two sons, has over five years been regularly visited at home by various health practitioners who have never talked to them about their role as carers. A failure to identify carers and their needs can impact on quality of care given to cared for and also care giver. For example the woman in question is becoming incontinent and needs additional support by a female but the sons are still saying it's OK 'We can cope'. Guidance on identifying and assessing carers already exists for GPs and health care practitioners. The following document gives examples of questions to assess their role as carer's and their health needs: https://www.england.nhs.uk/wp-content/uploads/2016/05/identifying-assessing-carer-hlth-wellbeing.pdf The question is what prevents GPs from routinely implementing this guidance? Lack of resources and overwhelm could be part of the issue particularly in urban settings, and this requires further attention and support. There are also examples of health authorities responding to the needs of carers: For example Cambridgeshire Health Authority is supportive of carers as seen in the following document: Supporting Carers an Action Guide for Practitioners contains practical examples and systems of how best to support carers. http://www.carerssupportcentre.com/assets/documents/gp-supporting-carers	Thank you for your comments and for your helpful references. We agree that there are major issues around the identification of carers and regarding people undertaking a caring role who do not identify themselves as carers and therefore do not seek appropriate help and support. These are key issues for the guideline.

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153	SH	Esoteric Practitioners Association (EPA)	5	197	**Information and advice – signposters/facilitators** This is best co-ordinated by designated people in each organization including health providers but also the voluntary and public sector as well as businesses. Health and social care practitioners could work in partnership with the network of carers support centres that exist and this model could be expanded throughout the country. North and South Lincolnshire Carers Support Centres are already implementing all the interventions from the guideline scope document: http://www.carerssupportcentre.com/north-lincolnshire/training-workshops/	Thank you for your comment and for your helpful reference and suggestions.
154	SH	Esoteric Practitioners Association (EPA)	5	214 and 234	**Self-care training for carers** Training in true self-care is a fundamental support for carers. Carers typically put the cared for before themselves and this has consequences in the long term. Self-care training supports each person to value, love, and nurture themselves and conveys the benefit of not neglecting self. It offers practical tools to enable the care giver to consider their own needs in every situation whether it be relating and communicating with the cared for person or health practitioners. This also includes their relationship with food, rest, sleep and personal organizational skills. We ask this question: ' Can we truly care for another, if we do not care for ourselves?' Proven benefits self care is improved well-being of both parties. We can also utilise the training resources that are already available: For example in the voluntary and not for profit sector, Self-care programmes are and could be offered cost free by voluntary organisations, health and well-being clinics, for example Carers UK, Carers Trust.	Thank you for your comment. The importance of looking after ones own health and wellbeing and the role of self-care will be considered. The scope has been amended to include reference to self-care
155	SH	Esoteric Practitioners Association (EPA)	5	214 and 234	**Carers as experts** We propose that caregivers are supported and trained to become subject experts through focused interventions from healthcare practitioners: Dementia is syndrome of illnesses family and carers often find difficult to understand and manage, partly because of its characteristics and also due to lack of information about the disease. A report by Carers Trust ' A Road Less Rocky' found that carers of people with dementia are not getting the support and advice they often desperately need. With information and knowledge carer's can be transformed from being ill-informed, confused and distressed to becoming empowered dementia	Thank you for your comment and for your helpful references. The issue of training will be specifically examined in this guideline. Note that more detail will be provided in the protocols.

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					care experts. What is needed is quality education by experienced practitioners, clinicians and neuroscientists. Courses offered face to face or on-line enable greater understanding of the nature and trajectory of the disease. Understanding, equips carers to be more resourceful, confident, and respond with more understanding to the person and changes in moods and behaviour. This considerably reduces levels of stress. An EPA member who is a carer, recommends these two excellent, accessible free on-line courses by the University of Tasmania: Understanding Dementia MOOC and Preventing Dementia MOOC. Although study requires an investment in time which not all carers will have and competency in use of IT. https://carers.org/sites/files/carerstrust/dementia_report_road_less_rocky_final_low.pdf http://www.utas.edu.au/wicking/preventing-dementia http://www.utas.edu.au/wicking/understanding-dementia **Other examples of why this is important:** Significantly improved outcomes for stroke patients and carers whilst reducing costs: http://www.bmj.com/content/328/7448/1099 New Maudsley Method to support caregivers of people with anorexia Workshops for family members are now an integral part of the clinical services offered by the South London and Maudsley NHS Foundation Trust: http://www.kcl.ac.uk/ioppn/about/difference/16-Training-for-carers-of-people-with-anorexia.aspx The ECHO (Expert Carers Helping Others) study with young people who are unwell: http://www.kcl.ac.uk/ioppn/about/difference/16-Training-for-carers-of-people-with-anorexia.aspx Based on the examples above, we recommend that in every clinical area, partnerships are established between clinicians, practitioners and patients. In this model clinicians share their knowledge with carer and cared for and vice-versa. Care agencies and voluntary organisations could invite carers, free of charge, to subject specialist workshops on Parkinson's Disease,	

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					dementia, diabetes, eating disorders, depression etc	
156	SH	Esoteric Practitioners Association (EPA)	5	214 and 234	**Other training for carers** Carers Support Centre offers free training in first aid, back care for carers, moving and transferring, legal matters and understanding dementia: http://www.carerssupportcentre.com/north-lincolnshire/training-workshops/	Thank you for your comment and for your helpful reference.
157	SH	Carers Trust	6	145-147	• We think that discharge from hospital is an example that should be added, due to the difficulties many carers experience with functioning health and social care packaged being put in place which support both the carer and the person with care needs. • We think that it could be made more explicit around including bereavement - caring might end because someone has got better, for example, someone is in remission from cancer – bereaved carers have particular needs. • We are pleased to see fluctuating needs being mentioned – many carers need to care extensively over a period of time during a mental health crisis, for example, and then this caring may reduce.	Thank you for your comment, your support is greatly appreciated. 'Discharge' from hospital has been added as suggested. The issue of support for bereavement will be examined in the guideline. Note that more detail will be provided in the protocols.
158	SH	Local Government Association	6	145-147	A key area of stress relates to older people caring for their adult children with learning disabilities, and what will happen to them when the carer passes away – and how to manage that (both emotionally and practically). There are also mutual carers, where both parties need and give care. Also, if/once the person being cared for passes away, that is often when the health of the carer deteriorates – often as a result of underlying issues they were not addressing whilst they were caring.	Thank you for your comment. Mutual carers as a specific group are explicitly included in Section 3.1. Issues regarding contingencies for if and when the carer or the person being cared for dies will be examined in the guideline. Note that more detail will be provided in the protocols.
159	SH	Royal Mencap Society (Mencap)	6	140/ 142	**6.2 Providing social and community support interventions for carers, including support through local carers' groups and networks** Carers groups and networks can be hugely valuable both for those able to access face-to-face carers support, and those requiring virtual support because they are unable to do so. **6.3 Support for carers physical and mental health, including Providing**	Thank you for your comment. The guideline committee will consider a wide range of evidence concerning the various types of support that are currently available with a view to establishing how the current carer pathway can be improved.

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					psychological and emotional support and interventions for carers. Carers should be able to access appropriate physical and mental health support to meet their needs. Such support may need to be flexible and adaptable around the carers situation, with understanding given to the complexity of their role. Many carers may fail to access such support due to a lack of time outside of their caring role and may deem it less important than the needs of the person that they care for.	
160	SH	Royal College of Nursing	6	140	Time and day of support must be flexible enough to be convenient and also include, if necessary someone to stay with the cared for person.	Thank you for your comment. The views and accounts of the experience of carers regarding the types and forms of support that are currently available and what they would like to see implemented will be examined in this guideline.
161	SH	Royal College of Nursing	6	140	Our members have indicated that in clinical practice, most carers tell them that they do not have the capacity to attend carers' groups due to the demand of their caring duties. There could be an exploration of using a chat room type of support for people who would prefer using this medium to access support.	Thank you for your comment. The views and accounts of the experience of carers regarding the types and forms of support that are currently available and what they would like to see implemented will be examined in this guideline.
162	SH	Carers Trust	6	141	We recommend that "carers' local support services" is added in. This is extensive, and goes beyond "carers' groups". As an example of this kind of provision, Carers Trust work in partnership with a network of 150 local carers' organisations (presence in over 80% of local authority areas; 6,800+ staff); 95 support young carers; 50+ provide regulated care. The services offered by each Network Partner varies, and includes: • Emotional and practical support for carers, including providing care in the home to enable carers to take a break, Carers emergency services, offering help in a crisis. • Outreach work in GP surgeries, hospital wards and schools to reach carers who haven't come forward for support. • Information and advice on issues such as benefits, grants and other help available. • Giving carers a voice so that they are listened to by local decision makers. • Helping carers to share experiences though group support and social activities. • Access to education, training and employment.	Thank you for your comment. Issues regarding how these services can best be utilised to support adult carers will be examined in the guideline. Note that more detail will be provided in the protocols.

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					• Supporting young carers through preventative, whole family work and clubs, activities and mentoring in schools.	
163	SH	Hospice UK	6	141	As per Line 84 point	Thank you for your comment. The guideline will cover all relevant health and social care settings where support is provided, including community and neighbourhood centres.
164	SH	Royal College of Nursing	6	144	There is definitely a great need for reactive professionals who can support the carers as they care for a loved one at the end of their life. There is also a need to provide bereavement support.	Thank you for your comment. These issues will be examined in the guideline.
165	SH	Royal Mencap Society (Mencap)	6	144	People who care for people with a learning disability at the end of life, require significant additional support to do so: • Support to learn to care and understand changing needs of individual • Support to decide what role they want to take on at the end of someone's life/come to terms with person's wishes. • Named contact to offer support for patient at end of life/for carers. Support to co-ordinate all of the health and social care professionals. • Advocacy services for both the person, and their carer(s) • Named contact to offer support for carers • Fast track to assessment for increased respite/support provision • Fast track to equipment reviews including for aids and wheelchairs, where needs have increased and carers may be under increased strain. • Bereavement services/counselling before and after a person has passed away • Support tools and resources to help the person they care for understand what is happening to them/make funeral plans/say goodbye. • Benefits and housing advice – both before and after. • Clear information – one stop shops – for accessing services and support	Thank you for your comment and for your helpful suggestions. The support needs of adults who are caring for people at the end of life will be specifically addressed in this guideline. Note that more details will be available in the relevant protocols.
166	SH	Carers Trust	6	145	Transition relates to a specific concept under the Care Act and Children and Families Act, and while we agree that some of the circumstances you describe here are ones where carers might require extra support, we think using another phrase – a period of change, for example – may be more helpful.	Thank you for your comment. The term 'transition' has been replaced by 'changes to the caring role'

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167	SH	Leeds City Council	6	145	Be more specific about helping carers choose a suitable residential care/nursing home	Thank you for your comment. The need for support due to changes in the caring role is acknowledged and will be examined in the guideline.
168	SH	Royal Mencap Society (Mencap)	6	146	Those caring for someone with a learning disability may experience changes in need from one day to the next in line with the system and how issues are addressed for example, there are significant changes in rights at transition from children to adult services, and adults may experience being moved quickly from service to service (including inpatient services). It is important that family carers are able to access appropriate advice and information at all times and particularly at transitional milestones to ensure families remain equipped at each stage. For example, there are drastic changes in rights between the ages of 16-18+ for children and young people, and adults may be moved very quickly from service to service (including inpatient services). It is vital that information and advice is available at all times and particularly at transitional milestones to ensure families remain equipped at each stage. People who have formally or informally cared for a person who has been moved out of area, or into a formalised service should receive specific support to ensure that they are able to maintain relationships with the person. Many carers in this situation find that their caring role transfers to over the phone support, particularly when the person is moved some distance away, this can be an immense change and very difficult for families who feel that they are unable to leave their phones in case the person calls. Others in this situation have been known to cause themselves significant financial stress as a result of regularly making journeys to ensure that they remain in the persons life. Similarly, for those whose caring role changes suddenly, it is often difficult to 'rejoin' usual societal roles with ease, issues ranging from lacking understanding of different systems, lacking 'contacts' to support them to find things to do, to having gaps in a CV that may affect their ability to find work. Appropriate support must be given to carers around such issues.	Thank you for your comment. It is acknowledged that the caring role can vary substantially over time. This guideline is intended to improve the current carer pathway and to identify whether and if so how it can be reconfigured to best serve carers.
169	SH	Leeds City Council	6	147	Add to examples in brackets 'carers who have been bereaved' Also add that fluctuations can be due to extreme changes in relationship presented by certain factors, either acute (eg brain damage from trauma/disease) or gradual (Alzheimer's/dementia) which are equivalent to	Thank you for your comment. The issues of bereavement and 'quasi-bereavement' (as experienced by carers of people with e.g. dementia) will be examined in the guideline. Note that more detail will be

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					loss from bereavement (but can be harder to deal with as the person "lost" is still physically present).	provided in the protocols.
170	SH	National Bereavement Alliance	6	147	We welcome the reference to supporting carers through transitions, including 'after caring has finished'. In many cases, the reason that caring has finished is because the cared-for person has died. We think it would be helpful to be explicit about this (possibly by expanding the prior bullet point 9 to read 'Providing support for carers who are caring for people at end of life, including after the person has died' or '…at end of life, including bereavement support after the death).	Thank you for your comment. Please note that 'transitions' has been replaced by 'changes to the caring role'. Issues specific to when the person being cared for has died, including bereavement support, will be examined in the guideline.
171	SH	Kirklees Council	6	148	Additional key areas to include: 11 Communicating with carers 12 Working with carers as expert partners	Thank you for your comment. The scoping group considered your suggested amendments but agreed that they are already implicitly covered by the extant review questions and that therefore additional specific questions are not needed.
172	SH	Leeds City Council	6	148	Add new point "Bereavement support for carers, acknowledging that bereavement that ends a caring role may be complex". Add new point: "Providing information and advice about disability related hate crime and discrimination against carers and the person they care for". Add new point: "Awareness raising of carers issues in health and social care planning and service delivery, also within the commercial sector".	Thank you for your comment. The scoping group considered your suggestions but declined to add specific mention of the issues you raise. However support for carers of people who are at the end of life will be examined in the guideline.
173	SH	Parkinson's UK	6	148	We agree that the 'key areas to be covered' are appropriate. However, in line with our above comments, we recommend that the guideline explores support for older and long-term carers.	Thank you for your comment. The issue of the types of support for older and long-term carers will be specifically examined in this guideline. Note that more detail will be provided in the protocols.
174	SH	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, NewcastleGateshead CCG, Northumbria Tyne and Wear NHS	7	192-196	Triangle of Care, developed by Northumberland Tyne and Wear Mental Health Trust (NTW) and the Carers Trust is a useful framework for identifying carers - though not used in acute or primary care settings https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health Routine enquiry by professionals e.g. GP, Nurse, Housing, Social Worker, Pharmacy – 'do you support someone else/another adult' or on patient admission to hospital – 'do you have someone who supports you'	Thank you for your comment and for the helpful information. The available frameworks for identifying carers will be examined in this guideline. Note that more detail will be available in the relevant protocol.

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		Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East			'Getting to know you' process developed by NTW https://www.ntw.nhs.uk/pic/leaflets/Getting%20to%20know%20you.pdf National campaigns through a variety of mediums to raise the profile of carers – Carers Week, Carers Rights Day Rephrasing the question 'Are you a carer' – the term carer can have negative connotations with many thinking the term refers to paid care workers Recording and logging when carers are identified – a central repository Whole family approach – not working in silos Early identification and prevention is more cost effective than dealing with entrenched caring roles of picking up a case at crisis point	
175	SH	Sheffield City council	7	Q1	Re 1. GPs need greater training in supporting carers and in helping identify them to social services, councils ,other relevant health officials rather than just saying things like " of course you're stressed you have a disabled relative"	Thank you for your comment. It is out of the scope of NICE guidelines to make recommendations about training healthcare professionals, as is expected that all health and social care professionals who are likely to be in a position to identify carers have the appropriate training to enable them to do so.
176	SH	Bury Council (comments supported by Bury CCG)	7	193-196	Awareness raising about carers and the support available is important, not only within health and social care, but also out and about in the community, for example in shops and cafes. This helps to ensure that carers are identified and signposted to appropriate support at an early stage. Engaging employers and education providers also helps with the identification of carers (and signposting) within schools, colleges and the workplace. This could link into enrolment and induction paperwork.	Thank you for your comment and for your useful suggestions. The committee will consider this point in drafting research protocols.
177	SH	Bury Council (comments supported by Bury CCG)	7	193-196	Awareness raising and encouraging GPs (and other health professionals) to identify and signpost carers to appropriate support is also important. This not only links into early intervention and prevention, but also social prescribing.	Thank you for your comment. It is expected of all health and social care professionals that are in a position to identify people providing care as carers that they are competent to do so and make them aware of where in the care pathway they are and the opportunities (both clinical

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						and non-clinical) that are available to them.
178	SH	Local Government Association	7	190-191	You have not mentioned a local authority/council view here, only the NHS – although as you have mentioned, councils have the responsibility for assessment and provision of support, amongst other interventions, under the Care Act. As such, surely it is more appropriate to look at the economic case for councils and social care than the NHS?	Thank you for your comment. The social perspective would include local government where relevant, so economic work for the guideline can include a local authority view.
179	SH	Sheffield City council	7	Q1.1 194	NHS England's Commitment to Carers document states it takes a carer, on average, 2 years to identify themselves as being in a caring role. 70% of carers are moving through the health service and for carers health services are often the starting point (when they become a carer). It is therefore important that health professionals work to identify carers at pre-diagnosis, diagnosis and discharge of the cared-for person. Questions that help identify carers that are embedded in existing processes e.g. discharge paperwork can help people recognise they're starting a caring role. Linking carers to relevant support is also important e.g. local carers centres. Information that defines what a carer is can also help people to identify with the term carer. We know from consultation that people don't think of themselves as a carer. Those who are in a caring role may need further help to prevent, reduce or delay their needs for further health or social care support. It is therefore important that those who are moving into a caring role understand they are a carer and can then seek support designed for carers. If you're not aware of the term then it is more problematic seeking relevant support, in particular if that support is badged for carers. Linking up health and social care funded provision can make the 'journey' easier for the carer as well as making things more cost effective. Using a carers centres resources for example, to provide targeted information on the wards/waiting rooms etc can be beneficial. In Sheffield we're also exploring co-location so Sheffield Carer Centre staff work from an information centre at the Northern General hospital. This one-stop-shop approach makes it easier for the carer to access carer services and also serves as a reminder to health professionals that carers are an important priority.	Thank you for your comment. The importance of identifying carers has been highlighted as one of the main issues in the scope. The committee will consider your suggestions in drafting research protocols.
180	SH	Sheffield City council	7	Q2.1	out information by chance. We need a central source of information which is easily and readily available as well as accessible to all abilities.	Thank you for your comment and for your helpful suggestion. Online interventions will be covered, as appropriate, in all relevant questions of the guideline.
181	SH	Hospice UK	7	185	To include the significant economic impact of caring on family household	Thank you for your comment. The

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					budget	committee will consider this point in drafting research protocols.
182	SH	Carers Trust	7	193	See comment under page 2 line 37	Thank you for your comment. The introduction has been amended to include reference to health and social care professionals.
183	SH	Wiltshire Council (public health)	7	193	Essential to identify both older carers and a whole family approach (those individuals who support the carer, such as offspring)	Thank you for your comment. Issues regarding the assessment of older carers will be examined in the guideline, as will the whole family approach. Note that more detail will be provided in the protocols.
184	SH	Admiral Nurses	7	195	Empowering carers to come forward, media campaign, carers ID cards/emergency card scheme. Education of primary and secondary health care sectors. Identification at diagnosis or point of care. Carers register available to services once identified.	Thank you for your comment and your useful suggestions. Public information campaigns are outside the scope of the guideline. It is expected of all health and social care providers that all recommendations made by the guideline committee are followed and that any changes required to meet the recommendations be implemented as a matter of course. The use of ID cards, and emergency card schemes will be considered by the committee when drafting research protocols.
185	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	7	195	In West Sussex we have 18,000 registered carers about 21% of our carer population (2011 Census, 84,000 carers). The identification and signposting of carers is a strategic priority and two key aspects are important. - A robust communications strategy relating to health and social care professionals but also the general population. - The inclusion of carer clauses and KPIs in as many service specifications as appropriate. We strive to make carers 'everyone's businesses.	Thank you for your comment and for the information. The available identification interventions, tools or approaches will be examined in the guideline. Note that more detail will be provided in the relevant protocol.
186	SH	Wiltshire Council (public health)	7	195	Important to use the integrated approach	Thank you for your comment. Integrated approaches to assessment will be examined in the guideline. More detail will be provided in the relevant protocol.
187	SH	Hospice UK	7	196	Identifying carers in different settings eg at home, or in hospital or hospice. Identifying carers in the workplace is also key – see comment on line 211 Different techniques will be needed to identify, record and share information in	Thank you for your comment. The importance of identifying carers has been highlighted as one of the main issues in

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					different settings	the scope. The committee will consider this point in drafting research protocols.
188	SH	The National LGB&T Partnership	7	197	In general terms, it is recognised that lesbian, gay, bisexual and trans (LGBT) people are more likely to rely on formal care services due to a lack of support networks from family and friends. However, research has suggested that LGBT people who do rely on a carer may do so more heavily, therefore increasing the burden on the carer. Marie Curie's report 'The Reality of End of Life Care for LGBT People' (2016) found that LGBT people often delay access to palliative and end of life care, meaning those who receive unpaid support from a carer were likely to be relying on them more greatly. This trend is likely due to a combination of factors, including: - Anxiety around disclosing sexual orientation or gender identity to health & social care professionals, and fear of subsequent discrimination/prejudice on doing so; - Alternatively, a fear of going back 'in the closet' once in formal care; - Lack of LGBT representation in care homes, hospices and hospitals, which subsequently often do not present as 'safe spaces' for LGBT people; - Trans people may feel that their gender presentation may not be respected in a care environment, particularly if they lose mental capacity; - One research study found that trans respondents would rather end their life than go into residential care (Withall, L. Dementia, Transgender and Intersex People: Do service providers really know what their needs are? Alzheimer's Australia, 2014) Research has shown that LGBT individuals and carers often experience discrimination and marginalization that impacts on their ability to access services and receive the most appropriate support (ASCOF Companion, 2014). This shows it's incredibly important that carers of LGBT people, including partners, friends and family members, as well as LGBT people with long-term conditions, are able to access the support they need in order to maintain a quality of life and make informed choice about care and support. This could include specific, tailored information or support for the carers of	Thank you for your comment. The right of all carers regardless of gender or sexual orientation, among other things, to access any form of support available from health and social care providers is enshrined in the Equality Act 2010; the Health and Social Care Act 2012 also requires such providers to rectify any existing inequalities in their services. As such, all health and social care providers would be expected to be sensitive to, and appropriately trained to address, LGBT-specific issues.

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					LGBT people, who may often also be LGBT themselves.	
189	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	7	197	Advice and information is crucial. WSCC provide on-line information via 'Connect to Support' but more specifically a specialist carer support charity is commissioned to provide a carer information and advice telephone support service. At peak times five or six lines can be operating at the same time.	Thank you for your comment and for helpful information.
190	SH	Wiltshire Council (public health)	7	197	This needs to be simply set out for quick reference…carers do not want to have to read reams of paper	Thank you for your comment and helpful suggestion.
191	SH	Hospice UK	7	198	To include resources (online and real time) to support practical hands-on care, and local carers support services	Thank you for your comment. The role of online and real-time resources to provide practical support will be examined in the guideline.
192	SH	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, Newcastle Gateshead CCG, Northumbria Tyne and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East	8	209 - 2013	Educating employers about carers in the workplace and their value whilst encouraging, supporting and enabling employers to have carer friendly policies, procedures and systems in place e.g. flexible working, reasonable paid leave DWP and other employment support agencies identify bespoke support, flexibility, interventions and add incentives to enable carers to stay in work or enter the workplace Universities and FE establishments identify carers champions within their organisations and schemes to support young carers/young adult carers to access education and university e.g. North East Raising Aspirations Programme (NERAP) www.nerap.ac.uk Flexible and reactive replacement care Parity of care for people across all conditions e.g. drugs and alcohol, mental ill health, learning disability Skills building for carers both in and out of education, employment and training with accreditation where possible	Thank you for your comment and your useful suggestions. This guideline will examine the support carers need to enter, remain in or return to work, education and training. The committee will consider these programmes when drafting research protocols.

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193	SH	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, Newcastle Gateshead CCG, Northumbria Tyne and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East	8	202 - 208	Carers should be given clarity as to the purpose and potential outcomes of a statutory carers assessment in order to prepare them for the process and manage expectations In some settings e.g. acute services, carers want to concentrate on the person they are caring for, it's not always appropriate for a carers assessment to be completed at that time and this should be offered as a follow up All practitioners coming into contact with carers should be aware of the statutory duties of the Local Authority under the Care Act and Children and Families Act to offer a carers assessment on appearance of need Combined assessments of the carer and cared for can mean that the carers needs are subsumed by those of the cared for. It should be made clear that the carer has a right/choice to have a standalone assessment Reassessments/reviews should happen automatically and at any time when a carer requests this to happen Consideration given to a shared template for whole family assessment e.g... points of view (Community Team, Learning Disabilities), Getting to Know You, Carers Support Outcome Profile (PROPS) http://www.adfam.org.uk/docs/csop_questionnaire.pdf Funding Carers Centres to triage carers pre-assessment with all health professionals signposting to centres rather than trying to understand what is available/needed	Thank you for your comment and your helpful suggestions. Assessments and subsequent reviews of carers under the Care Act 2014 will be examined in this guideline.
194	SH	Bury Council (comments supported by Bury CCG)	8	202-208	A holistic approach and whole family approach can ensure the best use of resources and avoid duplication. Personalised and outcomes focussed assessments which clearly identify need are most effective. Integrated health and social care working is also critical. In addition, some areas have reported successes with self assessments.	Thank you for your comment and your helpful suggestions. Assessments and subsequent reviews of carers under the Care Act 2014 will be examined in this guideline.
195	SH	Bury Council (comments supported by Bury CCG)	8	220-226	Regular support at home (or out and about in the community) enables carers to have a break with peace of mind that the person being cared for is safe. This not only prevents social isolation for both, but it also prevents carer breakdown from occurring as the carer is able to have a break. Some carers	Thank you for your comment and your helpful suggestions. This guideline will look at different forms of support, including enabling carers to remain at work. Note

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					could even remain in work through this regular support. This could prevent the person being cared for from entering residential care (short or long term). Early intervention for people with low level needs could prevent or delay their care needs from developing.	that more detail will be provided in the protocols.
196	SH	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, Newcastle Gateshead CCG, Northumbria Tyne and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East	8	220 - 226	Consideration should be given to all carers irrespective of financial circumstances having free access to products that would support them in their caring role e.g. incontinence pads and gloves Direct payments are cost effective and flexible to meet need Building based respite/short breaks have a place Short term 24 hour cover at home – whilst not very cost effective could work in some situations e.g. hospitalisation of carer, emergency elsewhere Preventative, flexible and ongoing practical support is essential to avoid crisis Individual budgets support personal choice Carer's wellbeing fund in Newcastle supports carer's health and wellbeing. Includes carer breaks, education and training, driving lessons and items for the home such as white goods http://www.newcastlecarers.org.uk/our-services/carers-wellbeing-fund Providing replacement care where necessary to enable carer wellbeing/activity/break Clear pathway to the support they need e.g. to psychological support	Thank you for your comment and for your helpful suggestions. Issues regarding practical, community and social support for carers, including respite care and breaks, and interventions to promote and improve wellbeing, are covered in the scope and will be examined in the guideline
197	SH	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, Newcastle Gateshead CCG, Northumbria Tyne	8	227 - 233	Carer champions in community based settings e.g. places of worship, community groups, libraries to support the identification and signposting of carers Integrated community support including carers café's and drop ins – can be condition specific or general Carers Centres Good quality holistic support from trained and experienced staff	Thank you for your comment and for your helpful suggestions. Community support is included in the scope of the guideline.

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		and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East			Community Reinforcement and Family Therapy (CRAFT) training and maintenance – peer support and facilitated to support retention of skills http://www.positivepracticepartnership.org.uk/	
198	SH	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, Newcastle Gateshead CCG, Northumbria Tyne and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East	8	214 - 219	Must take into consideration what is fair in terms of training and skilling carers to provide practical support – need to ensure it is not exploitative and that carers have a choice as to whether they want to take the task(s) on board e.g. catheter care Practical and individualised training to suit the caring role e.g. managing behaviours, managing the condition delivered in a variety of ways and settings e.g. one to one, groups, online Training to manage risk/reduce harm should not be so prescriptive that it becomes restrictive Choice of training providers to be made available from the health, social care and voluntary sector Training should be accredited to support any future entry into the workplace Training should be easy to access, free of charge and delivered locally by skilled professionals/peer supporters Recovery colleges, currently for people with mental ill health and their carers should be developed for physical health conditions/needs http://www.informationnow.org.uk/organisation/recoco-the-recovery-college-collective/	Thank you for your comment and for your helpful suggestions. Training for practical support will be examined in the guideline. It is acknowledged that all adult carers should be able to access any support provided by health and social care providers regardless of their financial circumstances. It should be noted that no carer would be compelled to receive such support.
199	SH	Bury Council (comments supported by Bury CCG)	8	214-219	Regular free training delivered by trained professionals at a time and location convenient to carers (one to one training if necessary). Carers should be asked what they need and courses should be tailored as appropriate (face to face and online). This could support the delivery of good quality care and	Thank you for your comment and for your helpful suggestions. The views and accounts of the experiences of carers on training needs will be examined in the

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					prevent unnecessary hospital admissions for the personal being cared for. This could also support carers to remain well.	guideline.
200	SH	Bury Council (comments supported by Bury CCG)	8	209-213	Highlighting and promoting job roles which can fit around caring responsibilities can encourage carers to enter employment.	Thank you for your comment and for your helpful suggestion. Support for carers entering and remaining in work will be examined in the guideline.
201	SH	Bury Council (comments supported by Bury CCG)	8	209-213	Support employers to adopt flexible working policies, promoting the associated benefits to retain unpaid carers (for example, recognising the skills of unpaid carers).	Thank you for your comment and for your helpful suggestion. Support for carers entering and remaining in work will be examined in the guideline. Note that more detail will be provided in the protocols.
202	SH	Bury Council (comments supported by Bury CCG)	8	209-213	Utilise tools and materials to simplify, negotiate and record employee and employer discussions/agreements. Promote the carer passport initiative (collating information about the individual and caring role, which helps to avoid the carer continually repeating themselves).	Thank you for your comment and your useful suggestions. Support for entering and remaining in work will be examined in the guideline.
203	SH	Bury Council (comments supported by Bury CCG)	8	209-213	Promotion of the support available to carers (both in work and in the community), with a particular focus on empowering carers to take ownership of their own health and wellbeing. For example, workplace wellbeing support, or the 'When You Can Programme' which encourages exercise. Assistive technology can also support peace of mind for carers.	Thank you for your comment and your helpful suggestions. This aim of this guideline is to improve carers' wellbeing, as reflected in the outcomes.
204	SH	Bury Council (comments supported by Bury CCG)	8	209-213	Health and social care appointments out of standard office hours would be helpful to working carers.	Thank you for your comment. This guideline will address the views of carers with regards to their practical support needs. Various forms of practical support for carers will be examined in the guideline .
205	SH	Think Local Act Personal	8	209 - 211	As above	Thank you for your comment.
206	SH	Carers Trust	8	207-208	We think this means carers support plan? It would be helpful if this could be clarified.	Thank you for your comment. The text has been amended to make clear that the review question is specifically about carer support plans.
207	SH	Sheffield City council	8	Q3.1/3.2	Re 3.1/ 3.2 Carer assessments are very difficult to access. There is too little funding and staffing. We need an open approach to what are the carers ' needs and meet them and not be restricted by money concerns	Thank you for your comment. The topic of carer assessments is included in the scope and will be examined in the guideline.

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208	SH	Sheffield City council	8	Q2.1	During our consultation for Sheffield's latest carer strategy, carers told us that information and advice was an issue. People moving into a caring role want information to be specific to their situation and timely i.e. given to them at an appropriate time. Carers want to be provided with information about the long term condition/disability/illness of the person they care for and to understand how best to support them. Carers told us that the amount of information can be overwhelming, particularly whilst trying to adapt to a new caring role. Carers can be very emotionally effected e.g. a loved one has a stroke. Trying to process volumes of information whilst trying to adjust to a caring role can be very difficult for some. Particularly if it is generic information which carers have to search through to find the bits that are most relevant to them. Carers told us that navigating the health and social care systems can be difficult. Carers want to be provided with clear information that help them understand these systems/processes so they know what will happen to them and the person they care for in the future e.g. treatment pathways/Continuing Health Care Funding/social care services. Carers have also reported that there can be a lack of information. The quality/frequency/amount of information given varies depending on which hospital/ward/GP surgery the cared-for person is visiting. There isn't a systematic approach across health services. This is something guidance could help to address.	Thank you for your comment. This guideline will address the views of carers with regards to their information needs. More detail will be provided in the relevant protocol.
209	SH	Sheffield City council	8	Q3.1	I think this question is very much dependant on local circumstances/approaches. There are various models including local authorities delivering carers assessments, local authorities outsourcing this function and a blended approach e.g. local authority staff seconded to carers centres. With the emergence of the Care Act there is more of a focus on preventative services/approaches. Preventing, reducing or delaying needs for health/social care services is a more cost effective approach than supporting the carer/cared-for person during a time of emergency/crisis/breakdown. Again this is linked to identifying carers and getting information/support to them sooner. Carers have told us that emergency planning is important to them. When we did our consultation over a third of carers said they would call emergency services if for some reason they were unable to continue caring e.g. stuck in traffic so couldn't get home at the normal time. It is obviously more cost effective to avoid this by helping a carer plan for emergencies so for example rather than calling emergency services they call a relative/friend who can help them. Sheffield's emergency plan scheme is called In Safe Hands. Many local	Thank you for your comment and for your helpful suggestions. The topic of carer assessments, is included in the scope and will be examined in the guideline.

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					authorities have schemes in place and they vary in how they work.	
210	SH	Sheffield City council	8	Q67.1	Peer support groups that are condition specific or geographically based are often regarded as valuable to carers. Being able to talk to others who can understand the situation is cathartic for some carers. Online groups and volunteer lead peer support schemes can be cost effective.	Thank you for your comment and for your helpful considerations. The views and accounts of the experiences of carers on social support will be examined in the guideline. Note that more detail will be provided in the protocols.
211	SH	Sheffield City council	8	Q5.1	Re5.1 This may be helpful to some carers but a parent's role may not easily translate to that of a carer. My son, for example, refuses to live with us. He has his own home and loves to see us there but will not let us physically care for him in any way. The last time I tried to be his carer even in his own home he gave me concussion. His autism means he has things in boxes and we are parents not support staff! It would be more useful for parents to learn how to work with carers to best support the person being cared for.	Thank you for your comment and for sharing your personal experience. Providing guidance for family carers about effective ways to interact with health and social care workers to best support the person being cared is a core aspect of this area of the scope. The text has been amended to take into account your suggestion; specifically a sub-question has been to this area of the scope (Q 5.2)
212	SH	Sheffield City council	8	Q6.1	Re 6.1 MONEY NEEDED	Thank you for your comment. NICE guidelines aim to set our recommendations which have been developed based on their effectiveness and cost-effectiveness to enable commissioners to get best value for money from the funds available to them.
213	SH	Sheffield City council	8	Q7.1	Re 7.1. This is fine , but carers - need to be aware of potential opportunities - need reliable care so they are able to leave their relative - need a range of activities as not everyone just wants a chat - needs a sensible amount of time to pursue any activity; an hour occasionally is no use!	Thank you for your comment. The views and accounts of the experiences of carers' needs will be examined in the guideline. Note that more detail will be provided in the protocols.
214	SH	Sheffield City council	8	Q4.2	ADASS in conjunction with TLAP are currently producing a report on what can help carers gain and sustain employment.	Thank you for your comment and for your useful suggestion. The issue of support for carers to enter or remain in work is included in the scope and will be examined in the guideline.
215	SH	Sheffield City council	8	Q6.2	Carers have told us that they need practical support. During consultation help completing forms e.g. for benefits came up repeatedly. Training was also something that came up regularly. Things like moving and handling/Mental	Thank you for your comment and your useful suggestions. The issues raised (practical support, support to remain in

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					Health First Aid/condition specific training e.g. Dementia Friends was wanted. Carers greatly value the ability to have respite that is personalised and flexible.	work, training, and respite care) will be specifically addressed in this guideline. Please note more details will be provided in the protocols.
216	SH	Sheffield City council	8	4.2	Re 4.2 A revolution in attitude is needed here. We need more opportunities for job sharing, part time work, carers leave of a reasonable length, employers understanding.	Thank you for your comment. The issue of support and advice to help carers to enter, remain in or return to work will be specifically addressed in this guideline. Please note more details will be provided in the protocols.
217	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	8	199	Once identified, carers are generally complimentary of the advice, and information available. Often though they would have preferred to have known about it sooner. This links to 195 – making carers everyone's responsibility – engagement and good information for carers every step along the way of any care pathway.	Thank you for your comment. The issues of providing information and advice to carers will be specifically address in this guideline, with a great emphasis on the views of carers. It is expected these issues will arise from the studies. Note that more details will be provided in the protocols.
218	SH	Kirklees Council	8	201	Add: 2.2 What are the most valuable / impactful topics of information and advice to carers	Thank you for your comment. A specific question focussing on the impact of interventions targeted on information and advice delivery to carers has not been included in the scope. However the guideline will look at the views and experiences of carers regarding how information should be delivered.
219	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	8	205	Following Public Consultation, West Sussex decided to delegate, via contract, the carer assessment function to a local specialist carer organisation. This approach has seen assessment numbers treble since before care Act 2014 implementation. The quality and consistency of assessments is audited and standards have been high.	Thank you for your comment. The committee will consider the examples you pointed out and your suggestions when designing review protocols about this question.
220	SH	Hospice UK	8	206	To include examples such as CSNAT (Carers Support Needs Assessment Tool) a validated tool with high quality international evidence of effectiveness. Assessment needs to be comprehensive and person-centred. How is the result of the assessment then communicated to those who need to know?	Thank you for your comment. The issue of which tool, if any in particular, should be used to assess carer needs is covered in the scope of the guideline.

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221	SH	Parkinson's UK	8	207	As mentioned in point four, we recommend that the 'key issues and draft questions' section is expanded to include a question about which interventions are most effective at preventing carers from needing support in the first instance.	Thank you for your comment. The committee agreed that prevention is an overarching theme that should be covered throughout this guideline. The selected outcomes reflect this.
222	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	8	207	We have two types of statutory assessment a full one and a lighter touch Carer Wellbeing Review. This enables an appropriate, proportionate response that reflects the carer's needs and where they are in their caring 'journey'.	Thank you for your comment. The issue of which tool, if any in particular, should be used to assess carer needs is covered in the scope of the guideline.
223	SH	National Bereavement Alliance	8	209	Returning to work after the cared-for person has died is often a significant challenge for former carers. It would be helpful to expand this bullet point to read '…adult carers and former carers…' Similarly, many of the other points in this section could usefully be expanded to include an explicit reference to bereaved former carers.	Thank you for your comment. We will be considering the needs of carers who are caring for people at the end of life, and after the person dies.
224	SH	Hospice UK	8	211	Scope should include methods to identify carers by employers plus flexible approaches to carers leave – for which there is growing evidence of effectiveness and relevance.	Thank you for your comment. First, the issue of identification of carers will be specifically addressed in the scope of this guideline. Second, this guideline will also address the issue of providing support and advice to carers to be able to enter, remain in and return to work. Please note more detail will be provided in the protocols.
225	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	8	211	A third sector provider is commissioned to provide either one to one or group support to carers wishing to return to work or training. Carers can sometimes feel deskilled and need support to see possibilities and transferable skills. Subject to capacity advice is also available to those carers struggling to combine work and caring.	Thank you for your comment. The issue of support and advice for carers to enter and remain in work is included n the scope of the guideline.
226	SH	Wiltshire Council (public health)	8	211	Employers need to be included in the integrated approach	Thank you for your comment, the committee strongly agrees with your suggestions. Note that more detail will be

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						provided in the review protocols.
227	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	8	216	West Sussex has led the way in commissioning a dedicated Carer Health Team. A nurse led clinical team accepts referrals from professionals who believe that caring is adversely affecting a person's physical or emotional wellbeing. This team was commissioned in recognition of the fact that many carers were themselves elderly, often with their own health issues and sometimes neglecting their own health by missing appointments etc. due to their caring responsivities. The team will review the carers health/meds, advise on handling and care techniques, help the carer to better understand 'the system' refer onto the voluntary sector for ongoing support. A full evaluation has been completed and extra investment made into the service in light of the cost avoidance benefits.	Thank you for your comment. The issue of older carers and that of carer assessments are included in the scope of the guideline.
228	SH	Wiltshire Council (public health)	8	216	There are very few interventions	Thank you for your comment. Please note that the list of examples given is not intended to be exhaustive and that more detail will be added to the protocols.
229	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	8	221	Carer respite needs to be planned both and emergency. Offer choice e.g. at home, away from home, and sometimes innovative solutions need to be tried. Recently we trialled a weekend for younger people with early on-set dementia and their carers in a great setting. Evaluation available. Many carers can, and are happy to, pay for the right respite and this has enabled commissioners (working with the market) to significantly grow the number of respite hours delivered across the county over recent years.	Thank you for your comment. The issue of how respite care should be delivered will be specifically examined. Note that more detail will be provided in the review protocols.
230	SH	Dimensions UK	8	222	We note that Dimensions UK prefers to use the term 'short breaks' as opposed to 'respite'. The draft scope rightly highlights the need for these services to meet the needs of both the carer and the person receiving care. We believe that 'respite' as a term implies burden to the carer from the person they care for, which is a negative representation of the relationship. This portrayal can not only leave people feeling as though they burden their loved ones because of their need for care, but can also leave carers feeling guilty or reluctant to use such services as they don't wish to imply that their loved one is a burden. The term 'short breaks' better reflects the mutual benefit of the support	Thank you for your comment. The terminology was discussed by the committee, and it was agreed to use 'respite care' as it is standard and widely-used.

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					provided.	
231	SH	Parkinson's UK	8	222	As mentioned in point three, we strongly support the inclusion of respite care in this guideline. However, we feel it is important that this care is always of high quality whenever it is accessed. To this end, we recommend the addition of 'timely and high quality' on line 222. The entire sentence should therefore read: '*What is the most effective and cost effective form of delivering **timely, high quality** respite care to provide flexible carer breaks and respond to the individual needs of adult carers and the people they are caring for?*'	Thank you for your comment and your positive feedback. The committee agreed with your suggestions, however it was decided there was no need to modify the wording of the research question. Note that more detail, including the importance of being timely and of high-quality, will be provided in the review protocols.
232	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	8	224	Stakeholders, including professionals and carers, are generally positive of the county wide Carer Information, Advice, Assessment and Support Service. The Carer Health team also scores very highly with regard to satisfaction rates and outcomes.	Thank you for your comment. The committee will consider your useful input when designing review protocols.
233	SH	Admiral Nurses	8	227	If the cared for person is unable to be left alone what provision will be made for carers to access group support?	Thank you for your comment. The committee will consider different aspects of support, including access to group support when agreeing recommendations.
234	SH	Carers Trust	8	228	See comment under page 6 line 141	Thank you for your comment. These services will be examined in the guideline. Note that more detail will be provided in the protocols.
235	SH	Wiltshire Council (public health)	8	228	There should be a list of local networks rather than the family trying to find what is available….this varies from one place to another	Thank you for your comment. This guideline will specifically look at the views of carers regarding social support, however it is out of the scope of NICE guidelines to provide a detailed list of available local resources.
236	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	8	229	60 carer support group run across West Sussex each month. Some are 'open' in that any carer can join, others are specific e.g. for carers of substance misuse or mental health. A carer ring-back service is also invaluable for those carers feeling quite desperate and needing someone to talk to. This is staffed by trained people though not necessarily fully qualified counsellors. Some carers struggle to find the time to attend outside support. Our Facebook	Thank you for your comment. Various forms of practical support for carers, including the use of digital and assistive technologies, are covered in the scope of,the guideline.

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					and Twitter pages for carers can be useful for some. Assistive technology also has a place in supporting carers and the timely matching of need to a technical solution is something we do.	
237	SH	Carers Trust	8	214 and 217	See comment under page 5 line 134	Thank you for your comment. This is only an example and not intended to be exhaustive. Note that the element of choice is implicit as no carer would be compelled to receive training.
238	SH	Sheffield City council	9	Q10	Re 10 : Again, always a battle	Thank you for your comment.
239	SH	Local Government Association	9	252-261	Establishing a level of burden using an inventory or measurement tool is very impersonal and risks simplifying what is a very personal experience. Equally, the description of 'carer competency' is unlikely to resonate with Carers, and could actually offend them – it appears that they are being judged on their ability to care, rather than a focus on what their needs are to keep on caring. As stated earlier in the document, many people do not identify themselves as 'carers' but simply family members or friends who are helping a loved one. Reducing their efforts to a set of competencies is unlikely to engage the audience this is wanting to target.	Thank you for your comment. Use of the term 'burden' and reference to specific measures have been removed and the text has been amended. The use of the term 'competency' has also been replaced by 'skills'.
240	SH	Bury Council (comments supported by Bury CCG)	9	243-248	Again, a good understanding of the health and social care system is required. A good quality and robust support plan should be prepared with the person being cared for and their carer, in advance, as appropriate. This must be flexible to allow for changes.	Thank you for your comment. Planning is currently covered in the scope of the guideline (please see the following sections of the scope "3.3 Activities, services or aspects of care"; "3.5 Key issues and draft questions").
241	SH	Carers Trust	9	243-248	See comment under page 6 line 145	Thank you for your comment. The text has been amended as suggested.
242	SH	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, Newcastle Gateshead CCG,	9	243 - 248	Effective joint working between adult and children social care services Specialist young adult carer's workers can support transition as can peer support Young carers need to be included in the pupil premium that schools can access The physical environment in which young carers are supported is really important – not always appropriate for them to access adult carers	Thank you for your comment. The issues of supporting adult carers to enter or remain at work or education and support for bereaved carers, are included in the scope of the guideline. Note that the scope of the guideline covers adult carers (i.e. over 18 years-old) of people aged 16 or over who have ongoing healthcare and social care needs. However, it is expected

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		Northumbria Tyne and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East			service/building Supporting carers to move beyond the caring role either through death or recovery and encouraging throughout the caring role Awareness raising and capacity building to train up schools, universities etc to be able to identify and support young adult carers in transition opportunities to enable young carers to think about accessing or reengaging with education and employment training when caring role decreases There needs to be focus on individual support and choice through the transition period Mixed media approach needed to give young carers/young adult carers in transition information Vocational needs of young carers should be recognised at all points in their transitions journey – close working with employment organisations to appreciate issues and try to overcome them Carers need preparation and support when losing the cared for person and their caring role either through death or movement into care NERAP – support, raising aspirations and skills building to get young carers and young adult carers into universities http://www.nerap.ac.uk/) Care coordination to support transition (as in Q8) – understanding the system and how to navigate it – supporting young people through an effective care coordinator	that at least some of the recommendations pertaining to adult carers will be applicable to carers below the age of 18.
243	SH	The National LGB&T Partnership	9	240-244	The points when caring requirements change, or when the individual being cared for has died, are particularly significant for carers of LGBT people.	Thank you for your comment and for your very useful suggestion. The right of all

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees.

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					Respondents to Marie Curie's internal survey of hospice staff found a common theme appeared around complex family relationships and how that impacted on the carer, particularly if there was a difference in who the individual had disclosed their sexual orientation and/or gender identity to, or where familial relationships had broken down. The family may not accept the role played by the carer if they were in a same-sex relationship with the individual, as demonstrated by one respondent to the Marie Curie survey who stated 'Another was not allowed by the deceased's family to take up his role'. Specific support or signposting is clearly needed for carers around such transitional points in the caring role which can be particularly difficult when concerning LGBT identities.	carers regardless of gender or sexual orientation, among other things, to access any form of support available from health and social care providers is enshrined in the Equality Act 2010; the Health and Social Care Act 2012 also requires such providers to rectify any existing inequalities in their services. This guideline will specifically discuss and address any potential difficulties LGBT carers may face.
244	SH	Bury Council (comments supported by Bury CCG)	9	240-242	Carers and families need to have a good understanding of the health and social care system, particularly when the illness/end of life pathway happens quickly. Perhaps a designated liaison service would support this. Bereavement services should also be offered as standard which could link into the community based befriending.	Thank you for your comment and helpful suggestions. Providing support for carers who are caring for people at the end of life is already part of this guideline (please see "3.3 Activities, services or aspects of care" and "3.5 Key issues and draft questions"). The committee will consider your useful input when designing review protocols for this question of the scope
245	SH	Hospice UK	9	240-242	**Support needs of carers at the end of life, and after the person dies** Need some reference to the fact that 'needs' will be informational, social (including work-related), practical, psychological and spiritual. Consider the role of local end of life support services such as hospices and palliative care teams? There is a body of evidence of a range of valuable assessment and support interventions provided by these teams. (Gunn Grande, Gail Ewing, Samar Aoun, Kelli Stajduhar, Peter Hudson research) *'After the person dies'* - this needs defining - the scope won't include bereavement support - does it mean support needed in the immediate hours or days after a death?	Thank you for your helpful comment and suggestions. The issue of support of carers at the end of life and after the person dies, including bereavement support, is covered in the scope of the guideline.
246	SH	Multi-Agency Response from	9	240 - 242	How to care and support the individual at end of life – feeding, hydration, personal care, moving and handling, medication	Thank you for your comment and helpful suggestions. For general issues regarding

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		Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, Newcastle Gateshead CCG, Northumbria Tyne and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East			Good information about powers of attorney, advanced decisions, choices regarding end of life care etc and access to finances to support this Practical support with regards to housing, finances, procedures Preparation for end of caring role and loss of a loved one 'void' – aftermath Bereavement support options – depending on the grief response, including support to deal with feelings of relief/guilt Support to deal with family dynamics – rights and roles Continuing benefits payments e.g. attendance allowance Advice, guidance and support on procedures if death is not expected e.g. drug related death or complicated death Support around funerals and funeral costs, fees have to be paid up front and this can be impossible to manage causing further stress at a very difficult time	end of life including how to provide care and support to people at end of life see the following NICE guidance: • Care of dying adults in the last days of life (2015) NICE guideline NG31; End of life care for adults (2017) NICE quality standard 13). Specific issues regarding support for carers who are caring for people at the end of life are included in the scope of the guideline.
247	SH	Sheffield City council	9	Q7.2	Being aware of what services/support is available locally can be very useful to carers. If you don't know what is there to help then you can't access the full range of local provision. Carers often reported that they weren't aware that there was help out there and wished they'd have realised sooner. This will vary from carer to carer and locally depending on what services are there. It is important to take a person-centred strengths based approach. Linking carers into services/goods that will prevent, reduce or delay their need for health/social care support. For some carers it's peer support groups, for others it's being able to access appropriate information, some want practical services e.g. telecare and others more emotional support e.g. counselling. Many of these services are available locally to the carer as well as wellbeing focused provision e.g. social prescribing. All of these services can be helpful to carers.	Thank you for your comment and for your helpful suggestions. This guideline will specifically look at the views of carers regarding social support, however it is out of the scope of NICE guidelines to provide a detailed list of available local resources.
248	SH	Sheffield City council	9	Q8.2	Re8.2 Most emotional support is not sufficient or helpful. Too little consideration is given to the fact carers have to battle every step of the way to get any help. We need cooperation not a fight. We need better trained/ knowledgeable/ consistent social workers. The whole psychology of having someone with a disability is made worse by the approach of many social workers/ medical staff / council staff	Thank you for your comment. It is out of the scope of NICE guidelines to make recommendations about training health and social care practitioners (e.g. social workers), as it is expected that social workers, who are likely to be in a position

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						to support adult carers, will have the appropriate training to enable them to do so.
249	SH	The National LGB&T Partnership	9	231	For LGBT carers, it's possible that a lack of services specifically for people who are both LGBT and carers is an issue to appropriate support, advice and information. Research into the experiences of young LGBT carers in Scotland aged 16-25 by Carers Trust Scotland 'Young People Caring OUT There' (2016) suggests issues faced are complex and specific to their situation. One young person suggested it 'doubles the chances of your discrimination' as being a young carer and being LGBT are stigmatized in their own distinct ways. It's likely there are similar parallels in adult LGBT carers too, such as a need for health & social care professionals to be aware of issues faced by LGBT carers, and to provide direct support or refer where appropriate, and to be aware that they are more likely to face poor physical and mental health. LGBT people feel underrepresented in support services. so consider the need to provide specific services or information for LGBT carers, such as support group (example at Gateshead Carers http://www.gatesheadcarers.com/services/lgbt-carer-support/)	Thank you for your comment, and helpful suggestions and references. As specified in Section 2 of the scoping document, the NICE equality impact assessment concluded that the guideline will examine inequalities related to, among other things, LGBT carers. As such, the guideline will be written in a way that respects the way in which LGBT carers wish to be thought about.
250	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	9	231	Social and community support is promoted via our 'Carer friendly communities' work-stream. We work with employers but also businesses to be 'carer aware' in order to provide more places and spaces for carers to feel valued and celebrated. In June for National Carers week, a number of events are planned across the county to bring carers together.	Thank you for your comment. The issue of social support will be specifically addressed in the guideline.
251	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	9	235	Counselling and the aforementioned 'ring back' service are both important psychological interventions. We also have a contract with Cruse to provide bereavement support. Peer support is often of psychological benefit e.g. carer groups.	Thank you for your comment. The issue of psychological support will be specifically addressed in the guideline.
252	SH	Wiltshire Council (public health)	9	235	Often support from friends/ family is more welcome and therefore this should be taken into account	Thank you for your comment. The issue of social support will be specifically

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						addressed in the guideline.
253	SH	Hospice UK	9	236	To include 'maintaining their resilience'.	Thank you for your comment. The text has been amended as suggested - the term 'maintaining resilience' has been included in the draft scope.
254	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	9	237	Feedback from carers and other stakeholders is positive with regard to the above. As ever the challenge is to match each carer with the right support at the right time.	Thank you for your comment. Various forms of support for carers - including peer support, psychological interventions, and support for the carer both at end of life of the person being cared for and after this time - are covered in the scope of the guideline.
255	SH	National Bereavement Alliance	9	240	Alternatively, point 9 here could be expanded to encompass all relevant areas for those caring for people at the end of life, including into their bereavement. This would include • Support and advice to enter or remain in work, education and training • Practical support (eg information about registering the death, organising the funeral) • Social and community support • Psychological and emotional support As the update of the 2004 NICE guidance on *Supportive and Palliative Care for Adults with Cancer* will not now include an update of the chapter on bereavement support, we believe it is crucial that this set of guidance for carers addresses this issue. It would be a missed opportunity to	Thank you for your comment. These services will be examined in the guideline and made explicit in the protocol of the review question. The issue of social support will be specifically addressed in the guideline.
256	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	9	241	Carers need to be recognised, listened to and involved as in most care situations but perhaps even more so at 'end of life'. Staff need to understand what is available to carers, during and post end of life care, so they can signpost accordingly. We commission two hospice schemes whereby ex-carers act as befrienders, following a period of training. This is working well and is well received,	Thank you for your comment. The available evidence on the views and accounts of the experiences of carers will be examined with respect to carer assessments, and various forms of support, including practical, social, community and psychological support.
257	SH	Hospice UK	9	242	Why is NICE not including a question such as *What are the views and experiences of adult carers, health and social care practitioners about the forms of support at the end of life that are useful?* This would come within	Thank you for your comment. The question as phrased is intended to implicitly cover the views and experiences of carers about

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					Section 3.5.9 This question is asked in Section 3.5.6, 3.5.7 and 3.5.8 and is especially relevant for carers providing end of life support.	end of life.
258	SH	Kirklees Council	9	242	Add: 9.2 What interventions are effective and cost effective for improving support for carers who are caring for people at the end of life	Thank you for your comment. A specific question focussing on the impact of interventions targeted on carers who are caring for people at the end of life has not been included in the scope, because this carers will be a sub-group in other questions included in the scope, and addressed there.
259	SH	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	9	245	Transition is crucial, in terms or prevention. We target: Carers in hospitals – caring may increase as a result of an hospital admission or indeed begin. Carers who are beginning to fall ill and may not be able to care much longer – carers' health team. Young adult carers (18-25) We have a dedicated service as their needs are generally different to older carers. Ex-carers looking to get back into society, training work.	Thank you for your helpful comment and suggestions. The committee agreed transition is crucial for carers in terms of prevention, and this issue will be specifically addressed in the guideline.
260	SH	Dimensions UK	9	247	Many parents of adults with learning disabilities and autism may find that the level of care they provide for their loved one fluctuates. For example, may they have their child return to live with them in times of crisis, when residential support elsewhere has broken down. Services should be sensitive to the rapidity with which a carer's situation might change, so that they can respond effectively to changes in need.	Thank you for your comment and helpful suggestions. The issues of transition and change of needs during the course of being a carer are covered in the scope of the guideline.
261	SH	Dimensions UK	9	248	We emphasise that even when caring has come to an end in terms of the cared for person living with the carer, there is often significant, continuing practical and emotional investment for the carer. The design of services should meet the needs of those who may no longer be caring for their loved one in their own home, but none the less regularly provide care for someone in other settings, such as residential services. For parents of children with learning disabilities, such a situation may be the case for many years and both practical and emotional support should be available.	Thank you for your comment. The committee agreed with your considerations that is important supporting carers during transitions in terms of their needs and in particular is central, continuing support for adult carers when caring has come to an end by delivering effective and centred services. Please note that, carers of children are out of the scope of this guideline.

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262	SH	Kirklees Council	9	248	Add: 11 Communicating with carers 11.1 What are the most effective and cost effective ways to communicate with carers about their caring situation 12 Working with carers as expert partners 12.1 What are the most effective and cost effective ways to support carers to become expert health and care partners 12.1 What are the most effective and cost effective ways to encourage health and care professionals to recognise carers as expert health and care partners	Thank you for your comment. The scoping group considered your suggested amendments but agreed that they are already implicitly covered by the extant review questions and that therefore additional specific questions are not needed.
263	SH	Carers UK	9	249	Outcomes should include health outcomes not just quality of life. GP patient survey could be used to track this.	Thank you for your comment. The scope currently includes both quality of life and health outcomes (e.g. morbidity related to caring, carer mental health).
264	SH	Carers UK	9	249	This should also look at whether carers who wish to remain in work are able to.	Thank you for your comment. No changes have been made on the scope, as this outcome will be covered as part of the category "impact of caring on the carer". Note that more detail will be provided in the protocols.
265	SH	Carers UK	9	252	Avoidance of the term burden where possible – although these are the names of the tools, Carers UK would welcome language that talks about impact rather than burden since this is disrespectful to the person being cared for.	Thank you for your comment. The text has been amended as suggested - the term "burden" has been removed from the draft scope.
266	SH	Leeds City Council	9	255	The Caregiver Burden is not an appropriate measure – it is very old fashioned	Thank you for your comment. Explicit reference to the Caregiver Burden Inventory has been removed. The guideline committee will decide whether it should be included as a measure of the impact of caring on the carer.
267	SH	Leeds City Council	9	256	Should read "carer confidence and competency"	Thank you for your comment. The text has been amended: the term "carer confidency" has been replaced with the term "carer skills".
268	SH	National Bereavement Alliance	9	258	We would recommend including vulnerability/resilience in grief as an outcome for bereaved former carers (eg using the Adult Attitude to Grief Scale)	Thank you for your comment. Vulnerability and resilience to grief are captured by the outcome of carer mental health. Please note that the list of examples given (e.g. depression) is not intended to be

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						exhaustive, and that more details will be provided in the protocols.
269	SH	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, Newcastle Gateshead CCG, Northumbria Tyne and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East	9	234 – 236	Carer peer support workers , Wellness Recovery Action Plan (WRAP) sessions for carers, positive psychology courses in Northumberland Tyne and Wear Mental Health Trust www.ntw.nhs.uk Five ways to wellbeing sessions delivered by Talking Therapies service Clear pathways to psychological support services once need is identified e.g. crisis Awareness of and access to statutory and community based support services e.g. health, adult social care, Samaritans, confidential listening services, carer centres, counselling, alternative therapies Low level emotional support given by many professionals needs to be valued and time given to it Early identification and prevention to prevent high level psychological need occurring Cared for person needs to have the right care package in place – this reduces stress and impact on carer's mental health and wellbeing A break from the caring role and the cared for (links to Q7) – support needed to access respite for the cared for but in the case of carers supporting individuals with substance misuse problems, financial support is needed to access a break as there are no 'respite' facilities for this client group Care coordinator should be appointed once the condition is diagnosed – this would end some of the confusion as to who is dealing with what Fully understanding pathways for treatment and recovery and the journey the person with care needs will be taking Whole family approach to treatment - many organisations do not proactively promote and implement common sense confidentiality/inclusivity	Thank you for your comment. Various forms of support for carers, including practical, peer and psychological, are covered in the guideline.

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					Timely diagnosis of the cared for persons condition so carers can manage the condition/behaviours effectively without negative impact on their own health and wellbeing	
270	SH	Macmillan Cancer Support	10	265	The only reference to outcomes for the person receiving care is "6 The person receiving care staying in their preferred place of care". Could also include "quality of life/well-being of the person being cared for"	Thank you for your comment. The focus of this guideline is adult carers. We have included this outcome as we consider the person staying in the preferred place of care is directly related to the carer receiving the adequate support. For specific conditions, please refer to other NICE guidance.
271	SH	Royal College of Nursing	6 & 8	145 & 209	We agree that there is a need for possible re-training and/or a 'mentor' to help carers with re-training and/or back to employment such as help with job or education applications. This could be achieved through the third sector.	Thank you for your comment. Issues regarding support to return to employment and the potential role of the third sector are covered in the scope and will be examined in the guideline.
272	SH	Admiral Nurses	9,10		This section reads like the Admiral Nurse role description, such good practice already exists for families affected by dementia.	Thank you for your comment. The scope of the guideline covers various forms of support and the relevant evidence will be examined.
273	SH	Admiral Nurses	7, 8, 9	197, 214, 234	We feel it is important to stress the essential role Admiral Nurses provide to support/ educate/ guide/ planning care etc. This role is essential for carers of people with dementia and extremely cost effective when you consider the benefits of such a role. One area of great impact is the reduction in hospital admissions – admission to hospital negatively impacts on the person's wellbeing and increases their risk of harm. We also know that people with dementia experience distress and functional decline often resulting in change of residence on discharge. Carers are at high risk of carer breakdown if not acknowledged, appreciated and supported in their role. If carer breakdown occurs the cared for is likely to be admitted to hospital. We feel these are fundamental elements to consider. This is why we believe that the Admiral Nursing Service should be included in the NICE recommendation and guidelines.	Thank you for your helpful comment and suggestions. The issue of the varying needs of carers, how these can be identified, and the support and advice that can be provided to them to prevent such breakdown are covered in the scope and will be examined in the guideline.

Document processed	Organisation name – Stakeholder or respondent	Disclosure on tobacco funding / links	Number of comments extracted	Comments
2017-05-12 NICE consultation comments - Adult carers - PHE 180517.DOC	Public Health England	[Insert disclosure here]	1	
Adult Carers - DH comments May 2017 - DH 250517.doc	Department of Health	n/a	2	
Bury Comments Form Final - Bury CC 190517.doc	Bury Council (comments supported by Bury CCG)	None to disclose	21	
Carers Trust comments-form - Carers Trust 250517.doc	Carers Trust	[Insert disclosure here]	24	
Comments form Newcastle for submission - Newcastle County Council 190517.doc	Multi-Agency Response from Newcastle City Council Adult Social Care, Newcastle upon Tyne NHS Hospitals Trust, NewcastleGateshead CCG, Northumbria Tyne and Wear NHS Mental Health Trust, Newcastle Carers, Newcastle Young Carers, British Red Cross, PROPS North East	None	10	
comments form - final to NICE - RCGP 250517.doc	Royal College of General Practitioners	None known	2	
comments-form (3) - Challenging Behaviour Foundation 250517.doc	Challenging Behaviour Foundation	None	3	
comments-form (95) - RCN 110517.doc	RCN	[Nil to enclosed]	1	
comments-form - Kirkless CC 250517.doc	Kirklees Council	None	5	
comments-form - Macmillan 252517.doc	Macmillan Cancer Support	n.a.	5	
comments-form - Open University 250517.doc	Open University	[Insert disclosure here]	1	
comments-form - Wiltshire Council 250517.doc	Wiltshire Council (public health)	None	7	
comments-form carers final - Royal Pharmaceutical Society 250517.doc	Royal Pharmaceutical Society	None	2	
Comments-form Supporting carers RCN Final Vs - RCN 250517.doc	Royal College of Nursing	[None]	12	
comments-form WSCC, Carers Commissioning Lead 23-05-17. - WS CC 250517.doc	West Sussex County Council (lead commissioner for Carers Support Services in West Sussex and its three CCG partners)	NA	15	
comments-form.Leeds - Leeds CC 250517.doc	Leeds City Council	[Insert disclosure here]	15	
comments-form_NICE guidance Carers_LGA 250517.doc	Local Government Association	None	14	
Dementia UK comments-final (Carers scope) - Admiral	Dr Karen Harrison Dening on behalf of Admiral Nurses	[for office use only]	10	

180517.doc				
NBA response to NICE guidance on adult carers - NBA 250517.doc	National Bereavement Alliance	n/a	5	
NICE 'Provision and support for adult carers' guideline draft scope - Parkinson's UK response.doc	Parkinson’s UK	None	7	
NICE - Adult Carers - Dimensions UK 250517.doc	Dimensions UK	None	3	
NICE Adult carers comments form - EPA 24.5.17.doc	Esoteric Practitioners Association (EPA)	N/A	11	
NICE Carers guidance comments-form - Think Local Act Personal 250517.doc	Think Local Act Personal	None	2	
NICE Carers Scope FINAL Hospice UK 250517.docx	Hospice UK	None	17	
NICE carers submission - MENCAP 250517.docx	Royal Mencap Society (Mencap)	N/A	16	
NICE comments-form adult carers - sheffield City Council 250517.doc	Sheffield City council	NA	20	
NICE consultation comments - Adult carers - PHE 250517.doc	Public Health England	[Insert disclosure here]	1	
NICE GUIDELINE SCOPE Carers UK comments - Carers UK 250517.doc	Carers UK	[Insert disclosure here]	12	
Provision of Support for Adults Carers - Guideline scope -SCIE feedback 250517.doc	SCIE (Social Care Institute for Excellence)	None	7	
Ref 1517 Age UK response - NICE guideline on Carers - Provision of support for adult carers FINAL - Age UK 250517.doc	Age UK	[Insert disclosure here]	5	
support for adult carers draft scope comments-form Royal College of OT 250517.docx	Royal College of Occupational Therapists	None	12	
The National LGB&T Partnership - Carers comments form 180517.docx	The National LGB&T Partnership	N/A	5	

Registered stakeholders [Insert link]