



advice and support for older age

**Independent
Age**

Carers' strategy

30.6.2016



About Independent Age

Whatever happens as we get older, we all want to remain independent and live life on our own terms. That's why, as well as offering regular friendly contact and a strong campaigning voice, Independent Age can provide you and your family with clear, free and impartial advice on the issues that matter: care and support, money and benefits, health and mobility. A charity founded over 150 years ago, we're independent so you can be.

Website

For more information, visit our website www.independentage.org

Helpline

We give free, confidential advice over the telephone for older people, their families and carers on issues such as getting help at home, adaptations, care assessments, paying for care, staying in touch with other people and welfare benefits.

Call our team of experts on 0800 319 6789, Monday to Friday, 8am-8pm, and Saturday to Sunday, 9am-5pm, or email your query to advice@independentage.org

Registered charity number 210729

Carers Strategy Consultation – survey question responses

Text boxes ask for 500 word limit

Identifying people as carers

1. Scale of 1-10 – how important is it that carers are identified better in the future
2. Are there specific ways of identifying carers that you would find helpful or have found helpful?

Our response relates specifically to older carers. We believe this group have particular circumstances and needs in their caring role based on research we carried out in 2015.

Reaching and intervening early to meet the needs of older carers must be recognised as a priority for the health and care system, given the huge implications for their health and wellbeing (and the consequent costs to the system).

There are nearly half a million older carers who provide more than 50 hours of care a week. Our research report with the Strategic Society Centre, *The Bigger Picture*, drew on data from the HSCIC to estimate that around 200,000 had an assessment or annual review from their Local Authority, and of these fewer than 100,000 older carers received any services or support from their Local Authority. This suggests that large numbers of older carers are not identified by local social care services and are therefore missing out on potential help and support.

In order for more older carers to be provided with the support they need, we believe that GPs could play a vital role in connecting them with services. This would be a valuable way of identifying older carers because the majority of older adults have some contact with their family doctor. In addition, we believe there is a case for considering a wider duty on the NHS to identify carers and refer them to appropriate support.

Providing information and advice

1. Scale of 1-10 – how important is it that carers receive better information in the future
2. Are there specific ways of providing information and advice for carers that you would find helpful or have found helpful

Our response relates specifically to older carers. We believe this group have particular circumstances and needs in their caring role based on research we carried out in 2015.

Under the Care Act, new information and advice services should act as a resource to carers. Older people need to be empowered with the knowledge of their rights as carers, including their new rights under the Care Act. Importantly, this includes information and advice about getting a carer's assessment, the options for respite care and details about voluntary organisations who provide support for carers. Information and advice to older carers needs to make sure

they recognise the impact that caring can have on their health and to seek support with this.

In our report on Information and Advice since the Care Act (January 2016) we found significant differences in the quality of information and advice local authorities were providing on adult social care. Although information for carers was an area where local authorities tended to perform well (121 had accurate information for carers) there were still 21 local authorities providing out of date information or no information at all for carers.

Making a new service available does not guarantee that it will reach older carers, particularly given that older people are much less likely to use the internet. Local Authorities should treat older carers as a priority group for information and advice and not assume that making information available online will reach this group.

Services and other formal support for carers

1. Scale of 1-10 – how important is it that formal support for carers improves in the future
2. Are there specific types of services or formal support that you have found helpful or would find helpful

Our response relates specifically to older carers. We believe this group have particular circumstances and needs in their caring role based on research we carried out in 2015.

Older carers face particular stresses and strains as a result of their caring role, which impact on their wellbeing. Many struggle to access services. We believe that meeting the needs of older carers ought to be a core concern of the health and care system. The Care Act gives carers new rights to assessment and support. It will be important to monitor this carefully to ensure it's happening.

Older carers have concerns about the future and what will happen to their loved ones if they are no longer able to provide care as they get older or when they die. It is important that services support older carers to make appropriate **contingency care plans** to help alleviate their fears about the future.

Much greater consideration needs to be given to **'former carers'** particularly when they support a loved one to move into a formal care setting, or when they are bereaved. There are substantial gaps in provision for bereaved carers and missed opportunities to provide support. Older carers need a range of support with practical and emotional issues, in the period immediately following bereavement and in the months beyond when they rebuild their lives. This support needs to be carefully designed and timed to enable older carers to draw on their expertise and return to paid work, volunteering or other fulfilling roles.

Carers who took part in our research were keen on the idea of a **'Carer's Friend'**, a named individual to stand alongside them in their role as carers, providing practical support in navigating the system as well as emotional support. Carers argued that this role may well be suited to volunteers who had experience of being carers themselves. Concepts similar to this have been tested

in other areas, for example through Timebank's 'Carers Together' programme and these have had some positive results on emotional resilience and reduced social isolation.

Respite care is an extremely important service which allows carers of all ages to take a break from their caring duties to allow them to focus on their own health and wellbeing needs. Without it, carers face long periods of time spent caring with little to no relief which in many cases results in poor health. Our report highlighted that some carers had refused respite care due to its poor quality and others talked of how where they had accepted respite care, they still felt a sense of unease and worry that the respite care would not be adequate.

Valuing and involving carers in services for the person they care for

1. Scale of 1-10 – how important is it that services for the people carers look after value and involve carers more in the future
2. Are there specific ways etc

Our response relates specifically to older carers. We believe this group have particular circumstances and needs in their caring role based on research we carried out in 2015.

There are many ways in which the services provided to the people carers look after could be improved by involving carers. Quality of care is a significant issue for carers. The shortcomings of the care and support system impact on carers as well as on people who need those services.

Our research looked at one area in particular: when carers' loved ones move into residential care or supported/independent living. In this situation, there is a need for greater awareness among professionals of the ongoing roles that carers play in care provision. These roles need to be acknowledged and the ongoing support they continue to provide should be facilitated.

In assessing the suitability of placements for carers' loved ones, consideration must be given to the carer's role, and in assessing carers whose loved ones have moved into a care setting, consideration must be given to the impact on the carer's ability to maintain relationships, providing support to enable carers to visit and keep in touch. This is a key criteria for care and support in the Care Act.

Supporting working carers and ensuring a life outside caring

1. Scale of 1-10 – how important is it that support for working carers improves in the future
2. Are there specific forms of support that help carers maintain employment and a life of their own etc.

Our response relates specifically to older carers. We believe this group have particular circumstances and needs in their caring role based on research we carried out in 2015.

Older carers feel strongly that it is unfair that they do not receive Carers Allowance when they are receiving more than £62.10 a week State Pension. This impacts on their ability to afford the extra costs of caring as well as to maintain a life for themselves outside caring. We have called for the government to revisit how to better recognise carers' contributions through the social security system.

Older carers need tailored packages of support which enable them to keep up the activities and relationships which are important to them and which allow them to continue an independent life. Only a minority of older carers receive any support at all from their Local Authority.

Older carers need a range of support with practical and emotional issues, in the period immediately following bereavement and in the months beyond when they rebuild their lives. This support needs to be carefully designed and timed to enable older carers to draw on their expertise and return to paid work, volunteering or other fulfilling roles.

In our research, older bereaved carers said they would like access to a 'former carers' group, for mutual support, which could be developed by carers' organisations. It would be useful to see how groups like these could be developed in a way that is linked more to outcome-focussed support designed to help find new ways of using their time, talents and resources in later life.

Other experiences and support

1. Space to write about other experiences, or other support that has been or would be helpful

Next page allows upload for research reports

Supporting documents:

Building a better country for older people

Our vision, like the Government's, is to see the UK become the best country in the world in which to grow old. Older people should be able to lead the lives to which they aspire and live with dignity, choice and control. This is especially important for older carers, many of whom will have their own health and care needs whilst supporting a loved one.

The number of older carers is only set to grow, with Age UK and Carers UK estimating that there will be over 1.8 million carers aged 65 or over by 2030.¹ Research shows that the older the carer, the more hours of care they are likely to provide. More than half of carers aged 85+ provide 50 or more hours a week of care.² In many circumstances these caring roles are taken on voluntarily with people seeing themselves primarily as a husband, wife, daughter, son or a friend. However, there are serious questions about whether older carers are getting the right help and support from health and social care services.

Older people are also the biggest users of health and social care services in the UK. People aged 65 and over account for one in six of the population, but they account for more than half (54%) of all hospital bed days.³ Focusing on adult social care, over half (51%) of the adult social care budget of Councils with Social Services Responsibilities is spent on those aged 65+,⁴ with this age group accounting for 78% of supported residents in residential care and 79% of those in receipt of council funded home care.⁵

This means that the NHS and care are vital to ensuring that the UK is the best country in the world to grow old in.

Unfortunately, this vision will remain unfulfilled whilst the NHS and social care remain underfunded. Although the November 2015 Spending Review did commit some extra funding to social care via the 'social care precept', it did not commit enough to deal with the challenges facing the system.

¹ Age UK/Carers UK, *Caring into later life: 'The growing pressure on older carers'*, 2015

² *ibid*

³ Health and Social Care Information Centre. Focus on the Health and Care of Older People, June 2014.

⁴ Health and Social Care Information Centre. [Personal Social Services: Expenditure and Unit Costs, England 2013-14](#)

⁵ Health and Social Care Information Centre. [Community Care Statistics: Social Services Activity, England 2013-14](#)

The knock-on effects of this under-funding are being felt by the NHS. In particular, delayed transfers of care as a result of social care have increased dramatically.

The funding pressures on the NHS and social care

While there have been welcome measures to increase the NHS budget, in line with NHS England's 5 Year Forward View, the budget for social care has actually declined since 2010, despite ever increasing demand.⁶ The Public Accounts Committee has reported that between 2010-2011 and 2014-2015, local authority spending on social care fell by 7% in real terms.⁷

As we have seen, the NHS has consistently missed its four hour A&E target. The last time the 95% target was met was July 2015, and prior to that it had not been met since August 2014.⁸

Cuts to adult social care budgets, combined with the pressures on the NHS of an ageing population, mean that the NHS is facing further increases in demand which it is struggling to cope with. Against this backdrop, the NHS has committed to making £22bn worth of efficiency savings by 2020, a figure it does not look set to be reached by the end of this Parliament.

The impact on older carers

Unmet need

The effects of a social care system in crisis, paired with an NHS under significant strain, means that there are many older carers who do not have access to the help and support that they need. It also means that older carers are likely to be the ones left to fill in the gaps where formal care is failing to meet need.

We know that there were 400,000 fewer people receiving social care services in 2014/15 than in 2009/10, some of which is a consequence of reduced social care budgets.

Our report '[The Bigger Picture](#)' estimated that around 380,000 older carers provide more than 50 hours of care a week without any support from their local authority.⁹ When older carers are directed towards their local authority, processes to gain help are often seen to be complicated and confusing,

⁶ ADASS, ADASS Budget Survey, June 2015:

http://www.adass.org.uk/uploadedFiles/adass_content/policy_networks/resources/Key_documents/ADASS%20Budget%20Survey%202015%20Report%20FINAL.pdf

⁷ Public Accounts Select Committee, '*Personal Budgets in social care*' *Second report of Session 2016-2017*, June 2016

⁸ <https://www.england.nhs.uk/statistics/statistical-work-areas/ae-waiting-times-and-activity/statistical-work-areasae-waiting-times-and-activityae-attendances-and-emergency-admissions-2015-16-monthly-3/>

⁹ Lloyd J, Strategic Society Centre and Independent Age '*The Bigger Picture: Policy insights and recommendations*' November 2014

discouraging many people from seeking help and leaving them unaware of their legal entitlements.¹⁰

Respite care – a case study

Whilst there have been many noticeable effects of decreasing funding for adult social care, Independent Age found in our report, [‘You don’t stop the worrying. The difficulties of caring in later life’ that cuts to respite care was one way in which pressure in the system was manifesting itself. Our report highlighted that many older carers feel that respite care provision is inadequate at best, and non-existent at worst.](#)¹¹

Our report highlighted that some carers had refused respite care due to its poor quality and others who accepted respite care reported that the care they received was inadequate.¹²

Respite care is an extremely important service which allows carers of all ages to take a break from their caring duties and focus on their own health and wellbeing needs. Where respite care is inadequate or non-existent, carers face long periods of time caring with little to no relief, which in many cases results in poor health.¹³

Pressure in the NHS

In ‘You don’t stop the worrying’ we recommend that local GPs should take the lead on identifying carers and signposting them to the relevant information and advice.¹⁴ Independent Age believes that GPs should be given a sufficient support framework in order to help identify and signpost carers, especially at a time when there are huge pressures on the NHS.”

Without fundamental support for older people, including older carers, there is a real danger that the health and care issues which affect older people will remain hidden until they manifest themselves at crisis point.

¹⁰ Independent Age, ‘You don’t stop the worrying: the difficulties of caring in later life’ June 2015

¹¹ Ibid

¹² Ibid

¹³ Carers Week, ‘Building carer friendly communities’ June 2016

¹⁴ Independent Age, ‘You don’t stop the worrying: the difficulties of caring in later life’ June 2015

A fundamental review of the future of health and social care

Given the pressures and inadequacies of current health and care provision for older people and older carers as outlined above **Independent Age is supporting the call made by former Care Minister Norman Lamb MP, and former Health Secretaries Stephen Dorrell and Alan Milburn for a cross-party Commission to examine the future of the NHS and social care.**

We need to have an honest conversation about how we can provide the health and care support that older people, and older carers need. That is why we are calling for the establishment of a Commission to examine the future of the NHS and social care, and make clear recommendations for Government on how to address the challenges currently facing health and care.