How can we improve support for carers?

Government response to the 2016 carers call for evidence
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Introduction

An unpaid carer is someone who provides unpaid help to a friend or family member needing support, perhaps due to illness, older age, disability, a mental health condition or an addiction.

Informal carers provide invaluable assistance to the people they look after. This is often a rewarding experience but can be very demanding and, for many carers, detrimental to their physical and mental wellbeing.

It is likely that most of us will become a carer at some stage in our lives. We will almost certainly know someone close to us – a partner, family member, friend or neighbour – who already fills that role. According to the 2011 Census, around one in ten of the population are carers and this number will only increase as our population continues to grow, age and diversify.

In recent years, recognition and support for carers has improved. The Care Act 2014 was a historic piece of legislation which introduced important new rights for carers, putting them on the same footing as the people they care for.

Carers now have legal rights to a needs assessment and thereafter support should they be eligible. Alongside the Care Act 2014, the Children and Families Act 2014 extended the right to these assessments to all young carers, regardless of who they care for or the type of care provided. This means that when a child is identified as a young carer, the needs of everyone in the family will be considered, triggering responses and support - where appropriate - from both children’s and adult’s support services.

However, there is still more to do to ensure that recognition, engagement and support for carers are as fully embedded across health and social care systems as they can to be.

Some carers will have care and support needs themselves and they may also have extensive contact with the health and care system regarding the individuals they look after. However, the majority of carers have relatively little contact with those same services to address their own health concerns. As a consequence, many are lacking the formal support they need. It is, therefore, important that consideration of carers goes beyond health and social care systems.

Between 18 March - 31 July 2016, the Department of Health put out a call for evidence, "How can we improve support for carers?" We wanted to hear directly from carers about the most helpful, effective and important ways the health and care sector could improve support. We were pleased and grateful to receive an overwhelming response; 6,802 people and organisations took the time to give us their views, experiences and suggestions.

Overview of the call for evidence

The Department of Health and Social Care commissioned The Evidence Centre, an independent organisation, to analyse the responses and this response draws heavily on their work. The analysis identified a number of commonalities across the responses. Carers accounted for 77 percent of respondents, with the remainder coming from organisations, groups, relevant professionals, individuals in receipt of care and their families.

In addition to these written responses, the Department of Health, Carers UK and the South East England Forum on Ageing (SEEFA) facilitated events to feed into the work on the National Strategy for Carers which were not included in the analysis of written responses. This response collates the views and inputs from the various focus groups alongside the findings from the call for evidence.
Call for evidence- the process

To raise awareness and encourage engagement, the Department of Health disseminated information to organisations and stakeholder groups and asked groups to run promotional events and further publicity was generated through, social media, email and print newsletters, and also departmental attendance at conferences and other events.

The Department accepted responses by email and post, using an online questionnaire and notes from discussion events. People were encouraged to use an online questionnaire as the principal way to provide feedback. The questionnaire contained both open (unprompted) and closed questions (with pre-defined categories to select from). A paper version of the questionnaire was also issued and this could be submitted by post or email.

Questions were split into six different sections, as follows:

- Impact of caring
- Identifying carers
- Valuing carers
- Information and advice
- Supporting adult carers
- Supporting young carers

Focus groups

Five focus group events were facilitated to feed into the Department’s work on carers:

- Social Work support for carers, 25 July 2016, Adult Principle Social Workers, Leicestershire County Council
- National Strategy for Carers, 29 July 2016, Department of Health & South West Carer Leads, Devon County Council
- National Carers Strategy (social workers), 4 August 2016, Department of Health, Skipton House
- SEEFA Round Table on the implications of the Carers Strategy for older people, 6 September 2016.

Discussion at these events raised similar concerns and suggestions to those presented in the analysis of responses produced by the Evidence Centre. A summary is included with this document.

Building on the call for evidence

The call for evidence was launched in preparation for a Carers Strategy. The announcement of a Green Paper on Care and Support for Older People presents an opportunity for a more fundamental approach to tackling the challenges carers face, by considering them alongside our strategy for social care.

We also recognise that there are specific actions needed to improve support for carers now and the Government is committed to further building and strengthening support for carers,
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particularly drawing on what carers told. That is why alongside this summary of responses we are publishing the Carers Action Plan. The plan will set out a cross-government programme of work to improve support for carers over the next two years.
Summary of findings

Call for evidence format
Individuals and organisations were invited to provide feedback about a variety of topics. Not every response commented on every topic. The questions most commonly responded to were about the impact of caring, valuing carers and quantitative questions that asked respondents to score the importance of various issues on a scale from 1 to 10.

When answering the questionnaire, respondents tended to focus on recounting their concerns and situations that had not gone well for them and their families. It was less common for people to describe things that had worked well or potential solutions.

People tended to give relatively short answers rather than detailed case studies. Although there were exceptions, most respondents reflected on personal, often negative, experiences.

Hardly any respondents commented on what carer support should look like in five to ten years. However, some did suggest improvements that might help them in the immediate future.

The following list highlights carers' most frequent requests:

- provide more information and training for health, social care and education workers to help them identify unpaid carers and provide information
- identify carers as early as possible, at the time the person cared for is diagnosed or in subsequent appointments
- make a directory of local services easily available to carers and keep it updated
- provide information and support using a variety of formats and approaches, to recognise the diversity of carers and their wide range of needs
- give carers access to consistent, good quality respite care (including house sitting services)
- give carers information about their eligibility for financial support
- give carers an appropriate level of financial support, set at a level that recognises the amount of time and effort they put into caring and the impact that this can have on other sources of income
- provide carers with someone to speak with regularly to air their concerns and ‘let off steam’, including peer support, counselling or a named link worker
- work with the voluntary and community sector to improve support
- raise awareness amongst employers, the public and professionals

The impact of caring
More than 5,000 carers provided feedback on this topic. They reported that caring had a significant effect on their physical and mental health, on their ability to pursue educational opportunities and to maintain full-time employment.

In other parts of the questionnaire, some recounted personal stories of how caring had influenced their relationships, made them feel isolated and depressed and reduced their overall
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sense of worth if they were not treated with respect. Carers painted a picture of having little time
to themselves and to sometimes feeling overwhelmed. They were also concerned about what
would happen to the person cared for if they was not available to support them.

Summarising of findings:

- People were asked to score the impact of caring on their physical and mental health, their
  education and their employment on a ten-point scale, where 10 represented the greatest
  impact. On average, people scored 8 out of 10.

- About half of carers said they had missed some educational opportunities as a consequence
  of their caring responsibilities (53 percent percent) and one-third said they had missed out
  on most or all educational opportunities (35 percent).

- One-third of carers said they had reduced their working hours in order to provide care (34
  percent percent) and half said they had left paid work to provide care (47 percent percent).

The round table hosted by SEEFA focused on the implications of the Carers Strategy for older
people. The group felt that the nature and impact of caring has changed, expressing the view
that many carers (particularly older carers) face unprecedented demands in terms of managing
complex and often long-term illness and disability in the family home.

The group also pointed to a growing population of adults with learning and other disabilities who
are now living in the community but are heavily dependent on ageing parents or other family

A number of focus groups expressed the view that the impact of caring came with a very high
financial and individual cost attached. One group drew attention to a report from the Royal
College of General Practitioners which found “all informal carers, at all levels of caring, were
more likely to report pain, depression and anxiety than non-carers”

In keeping with the findings, skills and employment were a focus of conversation at a number of
these events. Generally speaking, groups felt that more could and should be done to support
and protect carers in employment, including being clear with employers about their obligations
to their workforce) including to those who might have had to leave employment temporarily to
return to work.

Suggestions included: making the business case to employers to value carers; adjusting
mandatory government-led qualifications to be more ‘carer friendly’ and providing training to
carers (e.g. to avoid physical injury and develop resilience).

Identifying carers

More than 6,000 responses included comments on this issue. Carers and organisations said
that it was very important to have systematic and proactive approaches in place to identify them
and be able to gain information and ongoing support.

Half of carers who responded to this question said they had not received any help to identify
themselves. They felt that this was a real gap because it made them feel more alone and left
them unaware of the support available for them.

Some respondents said that it was important to identify carers sensitively because not everyone
may want to be called a carer and because the cared-for person may see this as a loss of
independence. Others said that there was a perception amongst some families and cultures that
caring was just something that people had to do as part of their family responsibilities and so might not be given a special label.

However, most people agreed that there were things that health, care and educational organisations and workers could do to help identify people as unpaid carers. The most commonly mentioned suggestions were:

- identifying carers through GP clinics (23 percent of responses to this question)
- training professionals to proactively ask people whether they are carers (14 percent)
- working with carers’ groups to identify carers (12 percent)
- registering people as carers when the cared for person is first diagnosed (8 percent)
- having a carers’ card or badge for identification (8 percent)

"It's important to be identified so you get the social care support. Registration via my GP's surgery was the easiest way. I could then get free flu vaccines and get information about being a carer" (Leena, East Midlands).

The focus groups produced similar ideas to the online, email and postal responses. One clear example of this was a suggestion that awareness-raising and training to help identify carers should be given to healthcare and other relevant professionals (e.g. teachers, medics and mental health staff). This was raised in a number of focus groups and in 14 percent of responses overall.

When considering ways to encourage carers to self-identify, suggestions were focused on finding practical incentives. This included considering ways to raise their pride and recognition to give them the confidence to seek support and to view this as a positive act.

In particular, the focus groups felt that carers needed a greater level of visibility across society as a whole. There was a desire to “rebrand” or innovate simpler and clearer ways to identify them, one recurring suggestion was the creation of a national symbol that could feature on a person's care record.

A number of the focus groups shared a common concern in that perceived support to be disproportionately balanced away from Black, Asian, mixed race and minority ethnic (BAME) carers. They felt more needed to be done to identify and support carers in these groups.

**Valuing carers**

More than 6,000 respondents addressed this issue. A similar number of carers said they felt valued and involved in the cared for person's care as said they did not. Whether they had felt well involved in the past or not, most respondents felt strongly that it was important that services valued and involved carers more in future. Carers themselves said that feeling respected and listened to was a high priority. They suggested that services for the person cared for should seek carers’ views and take those into account when making decisions. Some described negative impacts on their physical and mental wellbeing - and that of their families - when services had not done this. They also expressed the view that safety and support for the person cared for was also compromised.

The most common suggestions for valuing and involving carers were:

- asking them for their views, taking them into account in decision-making, and recognising them as experts by experience (28 percent responded to this question)
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- demonstrating that they are valued by providing appropriate financial support (8 percent)
- explicitly acknowledging their role and thanking them (7 percent)
- educating health and care staff to treat carers with respect (7 percent)

"It is essential that everyone involved in the care of a person is in communication with them and anyone caring for them. Carers who volunteer their care need to feel valued by professionals and helped with practical support and information" (Health professional, Eastern England).

Most respondents remarked on the importance of valuing carers. 39 percent of responders said they felt valued and involved in a person’s care whilst 45 percent felt they were not.

Group discussion in the focus group with social workers at Skipton House felt that events such as carers' dinner evenings were effective ways to make people feel valued. Social events that carers and the cared for can attend together were also seen as important.

On a more operational level, one group suggested that making sure carers were treated as expert partners was a central form of recognition. They also felt that their strengths and those of whom they care need to be recognised. It was also regarded as vital that carers are treated with respect, valued and listened to as having an active role in decisions about the cared-for person’s care. The need for approaches which support positive risk-taking to meet carers' needs and preferences was another suggestion around this theme.

Most groups felt that the way support is offered was especially important in helping carers feel valued. In particular, some groups expressed the view that one-to-one, open and person-centred conversations/assessments should be the norm rather than arm’s length or “tick box” exercises.

More widely, there was a feeling that action needs to be taken to combat stigma around caring which it was felt could lead to bullying. Groups felt that a culture shift in attitude and support by employers and wider society was needed. One group suggested recognising carers as a protected characteristic in equalities legislation to help achieve this.

Information and advice for carers

More than 6,000 respondents commented on this issue. About half of carers said they had received information about caring and the support available to them. Around the same proportion said they had not. Respondents felt strongly that it was important to provide better information. Most people commented about things that they would like to see happen in future, rather than things that had worked well for them in the past.

Suggestions focused on working with carer support groups and charities to disseminate information and the role that general practices, hospitals, pharmacies and other health services could play in proactively providing information. There was no most commonly preferred format for providing information, but it was suggested that a range of formats should be used to accommodate people with different needs and preferences. A number of people mentioned they had used online resources. Carers groups and charities were also a common source of information. The things that people most wanted information about were the availability of respite and sitting services, peer support groups and charities and community groups that may be able to help carers.

The most commonly mentioned helpful ways to provide information for carers were:

- information provision by carer support groups and charities (14 percent of responses)
• information provision by health services, particularly general practices (13 percent)
• providing information using a variety of formats and mechanisms, including online (11 percent), in groups (7 percent) and in written form (5 percent)
• providing information about respite care, sitting services, group support and links to charities and other sources of support (8 percent)

"Workshops - either refresher courses or workshops with information about caring, understanding the needs of the carer and coping with the stresses that come with caring for somebody. The workshops can also help carers find ways to cope with stigmatisation" (Michael, North West).

The Carers UK Conference felt it was important that information and advice for carers is both accessible and joined-up. Suggestions of how information and advice could be made accessible included the need to accommodate different language needs (including braille, plain English and large text).

This information would also need to be available in as many places as possible, preferably in different formats and, where possible, communicated in a fun and user-friendly way. This chimes with the range of suggestions that came up in the Call for Evidence with, for instance, 11 percent of respondents thinking it was important to provide information in alternative formats and across various channels, including online.

In order to make information and advice joined-up, people suggested; linking gov.uk pages for carers to other relevant topics, working with schools to identify younger carers and connecting information and service provisions for with carers with the cared.

Similar responses to the call for evidence were raised about GP practices at a number of the focus groups. It was felt that GPs needed to be able and ready to provide information and advice to carers. One of the groups pointed to GP surgeries that hosted carer clinics as an example of good practice. Social workers felt it was important for carers to be given social work advice which is both appropriate and realistic at the first point of contact. There was a concern in this instance that the first point of contact is often through an unqualified member of staff. It was also considered important for continuity that carers should be given a named social worker.

The Carers UK State of Caring Conference felt there was a need to promote the 'triangle of care' model nationally to make sure that people with serious mental health problems are included, informed and supported in the cared-for person's care.

Services and support for carers

Supporting adult carers

More than 6,000 respondents commented on this issue. Around half of adult carers said they had received support and half had not. Individuals and organisations felt it was a priority to improve support. Thinking about the future, responses said that accessible and affordable respite care or sitting services would significantly improve their lives. They said this would allow carers to have a break and to take part in other activities including support groups, employment or education.

There were strong feelings about what was perceived to be the limited availability of financial support for carers. Some felt it was unfair that the Carers Allowance is means tested and others
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said that it did not provide them with enough money to survive. This was felt to be particularly problematic when leaving paid employment to take on a caring role.

The most commonly mentioned support thought to be helpful for adult carers included:

- regular respite, sitting service or day care (19 percent)
- financial support and advice; e.g. personal budgets/direct payments (13 percent)
- information about how to be a carer and the support available (11 percent)
- mental health support or counselling (8 percent)

"Financial support to enable me to engage in activities which gives me a break is important for my wellbeing and needs to be flexible and responsive to my changing needs, anxiety and stress levels" (Carer, Eastern England).

Supporting young carers

About 1,000 respondents commented on this subject, though most of these were not current or past young carers.

Most respondents on this theme said they had not received any services or other formal support for young carers and had not had help to maintain their education or balance life outside caring.

Individuals and organisations thought it was important to support young carers and a number of responses said that it was potentially inappropriate for young people to have the responsibility of being a carer. The small number of young carers who responded said the things that would help them most were opportunities to spend time away from the person cared for, knowing they was in safe hands, and being able to take part in local leisure activities, including groups where they could share experiences with others and fun activities to help them relax and be with young people.

Access to transport such as lifts to and from services or free bus passes were thought to be important, as young carers said they did not have ready access. For this reason, very local and regular services were preferred.

The most commonly mentioned support that might help young carers, both in their caring role and to have a life outside caring, included:

- regular respite care to allow time for study and other activities
- peer support, forums and regular group activities with other carers to help share experiences, network, and have fun
- mental health support/counselling
- raising awareness amongst teachers and schools about young carers
- help to be identified as a young carer.

"My teachers allowed me to stay at school until the caretaker locked up at 5.30 so that I could study before going home to cook dinner, clean the house and tend to my four siblings and disabled mother. Flexibility is required" (Mary, Outside England)

The focus groups and other events felt carer-led support was an important area that the Carers Strategy should develop, with a particular focus on peer-support networks and carer-led projects. In keeping with this view, the call for evidence found that 22 percent of respondents
felt peer-support, forums and regular group activities with other carers were important to help young carers have a life outside caring. Community-led support, such as breaks for carers and neighbourhood networks of support were also raised by many respondents.

Financial support was discussed at the focus groups from a variety of perspectives. One group felt that personal health budgets for carers would be a good way to help support early intervention. On the issue of welfare support, it was felt that the high threshold for carers allowances and other benefits undermines more positive messages. The Carers UK conference felt that more needed to be done to support carers to access and apply for benefits that they are entitled to.

Among the views aired on formal financial support were: assessments should be both timely and flexible (i.e. there is no 'one size fits all' approach); carers shouldn't be subject to financial assessments; and local authorities should accept those completed by the third sector.

One group also raised concerns about the requirement under the Care Act for carers to be supported only by the local authority in the area they live. They considered this to be problematic, for example, if the carer lives in a different local authority to the person cared for. Discussion at the focus groups felt that respite and carer breaks needed to be tailored to individual circumstances and that respite should also be a break which could include vouchers and discount cards.

At the focus group of adult principle social workers, much of the discussion, was dedicated to the experience of carers in the real world, giving a particular focus to issues they come up against in practice.

For example, concerns were raised about a lack of 24/7 support for carers (reflecting on the fact that caring responsibilities aren’t limited to working hours). The focus group emphasised the need for improved technology for social workers to promote different and more flexible ways to support carers. It was felt that more support was needed for carers to understand the changes from health to social care funding (and back again) and how to challenge health decisions when needed. Continuing healthcare was raised as another area where it was believed more could be done to ensure that assessments are considerate of carers' needs.

Carer passports and carers lounges in hospitals were raised by most groups who felt they were important ways to support carers in hospitals so that they are easily identifiable and included in conversations and planning for the cared-for person's care.
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Who responded to the consultation?

In total, 6,532 responses were received from individuals (96 percent) and 270 responses were from groups or organisations (4 percent). A number of groups said their responses reflected the views of many carers or included summaries of surveys submitted by tens or hundreds of people.

Three quarters of individual responders were carers. They supported people with a wide range of mental and physical health issues. Two thirds said they had been providing care for five years or more (67 percent) and more than one third said they provided care for 100 hours or more each week (38 percent).

Individual responses were also received from health, care and education professionals, representatives from charities, people who received care and family members.

There was a good spread of responses from across England.

A note of caution is advised because only 223 groups or organisations provided their names and whilst these were labelled as organisational responses, not all may have been formally signed off by the organisations or groups in question.

In total, 5,891 responses stated they were from carers or groups containing or supporting them (87 percent). 911 responses were not.

Characteristics of individuals who responded

Of the 6,532 responses from individuals:

- 77 percent were from carers or former carers (5,007 responses)
- 3 percent were from people who had received care from a family member or friend (201 responses)
- less than 1 percent were from other family members of carers, such as carers’ children (31 responses)
- 10 percent were from health or social care professionals (638 responses)
- 9 percent were from other staff members of local authorities, the NHS or government departments responding as individuals, not on behalf of their organisation (567 responses)
- 8 percent were members of charities, carers’ groups or third sector organisations responding as individuals, not on behalf of their organisation (544 responses)
- less than 1 percent had other roles such as researchers, child care / school workers, legal advisors and business owners (38 responses).
Appendix 1- Breakdown of responses to the call for evidence

<table>
<thead>
<tr>
<th>Topic</th>
<th>Responses</th>
<th>Major trends</th>
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<tbody>
<tr>
<td><strong>Impact of caring</strong></td>
<td></td>
<td></td>
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<tr>
<td>Impact of caring on physical and mental health</td>
<td>5,675</td>
<td>The average perceived effect of caring on physical and mental health was 7.8 out of 10, where 10 was the greatest effect.</td>
</tr>
<tr>
<td>Impact of caring on education (scale)</td>
<td>3,069</td>
<td>The average perceived effect of caring on education was 7.8 out of 10, where 10 was the greatest effect.</td>
</tr>
<tr>
<td>Overall impact of caring on education</td>
<td>1,561</td>
<td>7 percent of carers said they had been able to fully pursue education opportunities, 12 percent said they were able to pursue education opportunities but had to study part-time, 53 percent said they had missed some education opportunities and 35 percent said they had missed most or all education opportunities.</td>
</tr>
<tr>
<td>Impact of caring on employment (scale)</td>
<td>4,444</td>
<td>The average perceived effect of caring on employment was 7.9 out of 10 where 10 was the greatest effect.</td>
</tr>
<tr>
<td>Overall impact on employment</td>
<td>2,852</td>
<td>19 percent of carers said they had been able to maintain full-time employment, 34 percent said they reduced working hours in order to provide care and 47 percent said they had left work to provide care.</td>
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<tr>
<td><strong>Identification as a carer</strong></td>
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<tr>
<td>Received help to identify as a carer</td>
<td>5,958</td>
<td>34 percent said they had received help to identify themselves as a carer, 50 percent said they had not and 16 percent were not sure.</td>
</tr>
<tr>
<td>Importance of identifying carers</td>
<td>6,646</td>
<td>The average perceived importance of identifying carers better in future was 9.5 out of 10, where 10 was very important.</td>
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</tbody>
</table>
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<table>
<thead>
<tr>
<th>Helpful ways of identifying carers</th>
<th>2,945</th>
<th>The most commonly mentioned ways to identify carers that people found helpful or suggested would be were:</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>- identifying carers through GP surgeries (23 percent)</td>
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<td>- training professionals to proactively ask people whether they are carers (14 percent)</td>
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<td></td>
<td>- working with carers’ groups to help identify people and encourage them to formally register as carers (12 percent)</td>
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<td>- registering people as carers around the time that the person cared for is diagnosed (8 percent)</td>
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<td>- having a carers’ card or badge for identification (8 percent)</td>
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<tr>
<th>Information and advice</th>
<th>Responses</th>
<th>Major trends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received information and advice about caring</td>
<td>6,086</td>
<td>48 percent said they had received information about caring and the support available, 43 percent said they had not and 9 percent were not sure.</td>
</tr>
<tr>
<td>Importance of providing better information</td>
<td>6,599</td>
<td>The average perceived importance of carers having better information in future was 9.6 out of 10, where 10 represented very important.</td>
</tr>
<tr>
<td>Ways of providing information and advice</td>
<td>3,866</td>
<td>The most commonly mentioned suggestions about helpful ways to provide information for carers were:</td>
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<tr>
<td></td>
<td></td>
<td>- information provision by carer support groups and charities (14 percent)</td>
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<td>- providing information in a variety of formats, including online (11 percent), in groups (7 percent) and in written form (5 percent)</td>
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- providing information about respite care, sitting services, peer support and links to charities and other sources of support (8 percent)

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<tr>
<th>Services and support</th>
<th>Responses</th>
<th>Major trends</th>
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<tbody>
<tr>
<td>Received services for adult carers</td>
<td>5,919</td>
<td>40 percent said they had received services or other formal support related to adult carers, 52 percent said they had not and 8 percent were not sure.</td>
</tr>
<tr>
<td>Importance of better support for adult carers</td>
<td>6,276</td>
<td>The average perceived importance of improving support for adult carers in future was 9.6 out of 10, where 10 was very important.</td>
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</tbody>
</table>
| Helpful types of services for adult carers | 3,639     | The most commonly mentioned services or support that might be helpful for adult carers in future were:  
- regular respite, sitting services and day care (19 percent)  
- financial support and advice including personal budgets and direct payments (13 percent)  
- information about how to be a carer and the support available (11 percent)  
- mental health support and counselling (8 percent) |
| Received services for young carers    | 604       | 21 percent said they had received services or other formal support for young carers, 67 percent said they had not and 12 percent were not sure. |
| Importance of better support for young carers | 1,492     | The average perceived importance of improving support for young carers in future was 9.6 out of 10, where 10 was very important. |
### Helpful types of services for young carers

<table>
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<tr>
<th>Services</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>- groups to share experience, including targeted groups for young carers supporting people with specific types of conditions (23 percent)</td>
<td>533</td>
</tr>
<tr>
<td>- respite care and sitting services (12 percent)</td>
<td></td>
</tr>
<tr>
<td>- local leisure and social activities with other young carers and non-carers (9 percent)</td>
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<tr>
<td>- mental health support or counselling, including bereavement support (9 percent)</td>
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<tr>
<td>- help to be identified as a young carer (9 percent)</td>
<td></td>
</tr>
<tr>
<td>- information provision through schools and educational establishments (8 percent)</td>
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<tr>
<td>- flexible educational support such as help to ask for extensions and careers planning (8 percent)</td>
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</tr>
</tbody>
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### Valuing carers

<table>
<thead>
<tr>
<th>Valuing carers</th>
<th>Responses</th>
<th>Major trends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extent to which carers feel valued and involved</td>
<td>6,102</td>
<td>39 percent said they had generally felt valued and involved by services supporting the cared for person, 45 percent said they had not and 16 percent were not sure.</td>
</tr>
<tr>
<td>Importance of valuing carers</td>
<td>6,586</td>
<td>The average perceived importance of services valuing and involving carers in future was 9.7 out of 10, where 10 was very important.</td>
</tr>
<tr>
<td>Ways of valuing and involving carers</td>
<td>3,169</td>
<td>The most common suggestions for valuing carers in future were:</td>
</tr>
<tr>
<td>- asking them for their views and taking them into account in decision-making (28 percent), care and discharge planning (8 percent)</td>
<td></td>
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<tr>
<td>- valuing carers through providing</td>
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</tbody>
</table>
- financial support (8 percent)
- explicitly acknowledging the role of carers and thanking them (7 percent)
- educating health and care staff about the role of carers (7 percent)
- letting carers know what information and support is available to them (6 percent)
- informing carers about what is happening (6 percent)

<table>
<thead>
<tr>
<th>Balancing life outside caring</th>
<th>Responses</th>
<th>Major trends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Received support for working carers</td>
<td>4,579</td>
<td>16 percent of adult carers said they had received support to balance their job with caring responsibilities and to have a life outside caring, 79 percent said they had not and 5 percent were not sure.</td>
</tr>
<tr>
<td>Importance of improving support for working carers</td>
<td>6,218</td>
<td>The average perceived importance of supporting adults to balance caring, paid work and life outside caring was 9.7 out of 10, where 10 was very important.</td>
</tr>
</tbody>
</table>
| Ways to help carers maintain employment | 2,805 | The most common suggestions about ways to help adult carers maintain employment and a life balance were:
- flexible working arrangements, part-time roles and more working from home (27 percent)
- availability of sitting services or respite care to allow carers to go to paid work or do other activities (23 percent)
- increasing awareness amongst employers about carers’ rights (18 percent)
- financial support (12 percent)
- legal rights, including paid carers’ leave (10 percent) |
<table>
<thead>
<tr>
<th>How can we improve support for carers?</th>
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</thead>
<tbody>
<tr>
<td><strong>Received support for young carers</strong> 549</td>
</tr>
<tr>
<td><strong>Importance of supporting young carers</strong> 1,204</td>
</tr>
</tbody>
</table>
| **Ways to support young carers with education** 426 | The most commonly mentioned services to help young carers have a life outside caring were: 
- regular respite care to allow time for study and other activities (31 percent) 
- peer support, forums and regular group activities with other carers (22 percent) to help share experiences and network (16 percent) 
- flexible support with education (11 percent) 
- awareness raising about young carers amongst educators (9 percent) 
- help to be identified as a young carer (7 percent) 
- school and community based personal mentors / career advisors (7 percent) |
| **Other experiences** | **Responses** 3,183 | **Major trends** 
Major issues that responders wanted the Department of Health to consider when developing the Carers Strategy included: 
- an emphasis on the financial difficulties associated with caring, including requests to increase the Carers Allowance and to make it
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<tbody>
<tr>
<td>available regardless of age or income</td>
<td>(13 percent)</td>
</tr>
<tr>
<td>- requests for better access to respite</td>
<td>(11 percent)</td>
</tr>
<tr>
<td>and day care</td>
<td></td>
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<tr>
<td>- the need for more signposting to</td>
<td>information and centralisation of the services available (9 percent)</td>
</tr>
<tr>
<td>information and centralisation of the</td>
<td></td>
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<tr>
<td>services available</td>
<td></td>
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<tr>
<td>- requests for more carers’ support</td>
<td>groups and peer support</td>
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</table>
How can we improve support for carers?

References