

State of Caring 2017



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State of Caring 2017

Carers UK carries out an annual survey of carers to understand the state of caring in the UK.

This year over 7000 people shared their experience of what it's like to be a carer in 2017.¹

This is the largest State of Caring Survey carried out by Carers UK to date.



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¹ As this report provides a snapshot of caring in 2017, only the responses of current carers have been used here. However, Carers UK will be drawing on the responses of former carers in other pieces of work throughout the year. See the appendix for more information about the survey.

Context: the state of caring in 2017

Debate on the balance of responsibility for care between individuals and the state was central in the run up to the 2017 General Election. The huge amount of care already provided by families and friends both practically and financially was not acknowledged enough in that debate, nor was the importance of supporting those people caring unpaid.



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A spotlight was shone on the inadequacy of the current system, on its unfairness and on the inconsistencies of how care for different health conditions is provided and paid for. Care for conditions like cancer and diabetes is largely paid for through the National Health Service whilst in contrast, conditions like dementia require social care services and these are subject to both a needs and a means test. All these issues are evident in the experience carers reported in response to our survey.

It is more than five years since the NHS in England began its programme of efficiency savings. A huge transformation is now underway in the way health and care are delivered which has as one of its aims achieving financial savings. NHS spending across the UK has not kept pace with demand from an ageing population living longer with complex health conditions and it is clear that spending on health and care will continue to be under considerable pressure across the UK.

In this context the enormous contribution of family and friends in the UK, the main providers of care, which is estimated to be worth £132 billion per year, roughly equivalent to the NHS budget, is more important than ever.

Yet, three quarters (73%) of carers responding to this year's survey feel that their contribution is not understood or valued by the Government. Nor do the majority feel the public value their contribution. This is consistent with recent polling of the public more widely which showed that the vast majority of the public (74%) think that carers are not sufficiently valued by society. These findings should act as a wake up call to policy makers and to the public.

Yet, rather than a health and care system which values and supports carers, our 2017 survey suggests that too often carers are being pushed into poor health through lack of access to practical support and breaks.

The value of unpaid care carers give in the UK



£132bn

The value of health spending in the UK



£134bn

Three quarters

73%



of carers responding to this year's survey feel that their contribution is not understood or valued by the Government.



Lack of social care funding is reflected in the failure of local authorities to consistently assess carers and put in place support. In England and Wales new legal duties to support carers have still yet to become a practical reality for carers. Whilst in Northern Ireland there is currently a power but no legal duty on Health and Social Care Trusts to provide services outlined in Assessments.

The absence of system incentives in the NHS and the repeal of the Carers Measure in Wales mean that the mechanisms to support carers consistently through primary care are not in place.

Evidence from carers on the financial impact of caring shows that far from having their contribution appropriately recognised by the social care and social security system, people providing unpaid care are struggling to make ends meet and, unable to protect their future financial security, are being made vulnerable to poverty and financial hardship both in the short and long-term.

The importance of flexible working to retain older workers and the need for support for people to enter or return to the workforce after time spent away has been consistently identified in Government strategies. Yet, the difficulty of remaining in work alongside providing care comes across strongly again in the 2017 survey.

It's clear that the way we value and support the contribution of carers is at the heart of addressing some of the current major challenges our society is facing. It is also of even more fundamental importance; caring and being cared for is part of being human and something which almost everyone will experience at some point in their lives. An action plan for supporting people well when they take on a caring role must be at the heart of the UK Government's agenda and the priorities of national, regional and local government across the UK. We are a caring society, and we should ensure that there is care for the carers.

Impact on carers' health and wellbeing



Caring can have a significant impact on health, with the pressures of providing care taking a toll on both carers' physical and mental wellbeing. Those providing round the clock care are more than twice as likely to be in bad health as non-carers.¹

The most recent GP patient survey found that 3 in 5 carers have a long term health condition, this compares with half of non-carers. This pattern is even more pronounced for younger adults providing care – 40% of carers aged 18-24 have a long term health condition compared with 29% of non-carers in the same age group². Carers' own experiences suggest that long term back and mobility problems are caused by long term physical stress from moving and handling without the right equipment or training. This impact is often exacerbated by carers being unable to find time for medical check-ups or treatment or being forced to put off treatment because of their caring responsibilities. Without proper support, carers are often pushed to breaking point and have to give up work, stop caring, or even go into hospital themselves.



It's very difficult to arrange health appointments to coincide with very short free windows of time



I have neglected my own health problems, putting off sorting them out, for fear that I would be hospitalised and therefore not able to care



² 2016 GP Patient Survey

The impact of caring on carers' health

6 out of 10 people (61%) said their physical health has worsened as a result of caring, while 7 out of 10 (70%) said they have suffered mental ill health. 13% said their health is no different as a result of caring.

People providing over 50 hours of care a week and older carers over the age of 65, were both more likely to say their physical health has worsened as a result of caring (67% and 65% respectively), while over three quarters (78%) of those providing care to a child with a disability said they have suffered mental ill health such as stress or depression as a result of caring.

Staying healthy as a carer

Carers reported a number of negative impacts of caring upon their wellbeing. 8 out of 10 people (78%) said they feel more stressed because of their caring role, and 7 out of 10 (72%) said caring has made them feel more anxious. 7 in 10 (69%) also said they find it difficult to get a good night's sleep because of their caring role.

Over half of people (54%) also reported that they have reduced the amount of exercise they take because of caring and 45% reported that they have found it difficult to maintain a balanced diet. Nearly half of respondents (46%) said they have suffered from depression because of their caring role.

People looking after a disabled child and those who are providing care to someone at the same time as bringing up a child without disabilities were more likely to report stress and anxiety as a result of caring than other groups. They were also more likely to say that caring had impacted upon them having a balanced diet and their ability to do exercise. People caring for a disabled child were also the most likely group to report having suffered from depression because of their caring role (54%).



7 in 10

69%



said they find it difficult to get a good night's sleep because of their caring

Over half

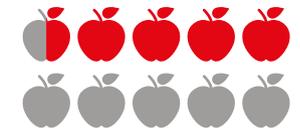
54%



reported that they have reduced the amount of exercise they take because of caring

Nearly half

45%



reported that they have found it difficult to maintain a balanced diet

Nearly half

46%



said they have suffered from depression because of their caring role

Support from GPs

In the last three years, the numbers of carers identified by GP practices has fallen, despite the promotion of good practice in some areas.ⁱⁱ Funding is not always consistent for promotion work and local improvements are not always sustained. On the one hand, the NHS often expects family to support other members, but on the other hand can fail to equip them with the knowledge and expertise to do so, and does not consistently recognise or support them.

When asked if their GP knows they are a carer, disappointingly, over two thirds of carers (68%) said that their GP knows but that they don't do anything different as a result. This rises to 73% for those who are providing over 50 hours of care a week, and 75% for those providing care for a disabled child.

Only 9% of all respondents currently providing care said that their GP knows and offers them extra support with their caring role and 8% said their GP knows they are a carer and provides some help but could do more to support them.

15% of people currently providing care said their GP does not know they are a carer. This rises to 2 out of 10 (20%) for those who are providing care whilst bringing up a child without disabilities and to one quarter (25%) for those who are in paid work whilst providing care.

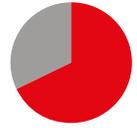
These results highlight the need to introduce a new duty on the NHS to put in place policies to identify carers and to promote their health and wellbeing.

What would make the most difference to health and wellbeing?

Respondents were asked what would make the most difference to improving their health and wellbeing. Regular breaks from caring was the most popular choice, with 2 in 5 (42%) placing access to breaks in their top three things. This was followed by good quality care services for the person they care for (35%) and a better income (32%).

Over two-thirds

68%



said that their GP knows they are a carer but that they don't do anything different as a result



I have suffered physical problems because of my caring role, mainly back and hands due to pushing a wheelchair, lifting and supporting my wife



Mental health is a big problem. The isolation is the hardest and the lack of understanding of my son's autism



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Time for a break



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Since the ground-breaking decision in 1999 to deliver carers' breaks funding to local authorities, government has continued to identify funding for carers' breaks which is welcome. Breaks are vital for carers to be able to deal with the physical and emotional strain of providing care and to support them to be able to continue in their roles. However, disappointingly, carers often report not receiving the support they need to take even a short break.

Transparency about how much breaks funding is allocated to providing carers' breaks at a local level and how this is spent remains an issue.

We asked carers when they last took a break from caring. Shockingly, many carers report not having a break for years. A quarter of people (25%) said they hadn't had a day off from caring for more than five years, while 4 out of 10 carers (40%) said they hadn't had a day off for more than a year. Having more than a day was still rarer, with over half of carers (58%) reporting not having had a weekend off in over a year and as many as 73% not having had a week off for over a year.

A quarter

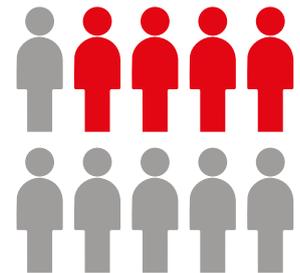
25%



said they hadn't had a day off from caring for more than five years

4 out of 10

40%



said they hadn't had a day off from caring for more than a year

Those spending 50 hours or more a week caring were most likely to report they had not had a day off from caring for over a year, with nearly half of people (47%) saying this, while 9 out of 10 (90%) of those caring for a disabled child said they had not had a full week off for over a year. People in paid work and those providing palliative care were more likely to have had a day off from caring within the last year than other groups (71% and 70% respectively). They were also more likely to report having had one day off in the last week, with a fifth of people in both groups stating this (21%).

The effect of not having a rest from caring is shattering, with carers describing being close to breaking point, desperate for some time to themselves, to sleep, recuperate, and see friends and family. Carers who reported not having had a break from caring within the last year, were also more likely to report having suffered mental ill health as a result of caring or that their physical health has worsened as a result of caring, with 73% and 64% stating this respectively, compared to 70% and 61% for all groups.

Barriers to getting a break

For those struggling to get a break from caring, the most common reasons that people gave were the costs of paying for or contributing to the cost of a break, or that the person they care for isn't willing to accept care and support from others, which 3 out of 10 people reported for each (31%). People caring for a disabled child were more likely to report that the costs of a break was a barrier (36%), while older people were the least likely group to report cost as an issue (21%).

Other common reasons for struggling to get a break across all groups included that the care needed for the person who is supported is not on offer (27%), not being confident in the quality of care available (19%), and not knowing how to get one (16%). For those who said that the care they need in order to take a break is not on offer, a lack of specialist support needed by the person they care for not being accessible was the most common reason.

People providing palliative care were most likely to report that the care needed for the person they support is not on offer, with almost a half of people in this group stating this (44%). They were also the most likely to say they weren't confident in the quality of care available (33%) and that they didn't know how to get a break (23%). Those caring for a child with disabilities were also more likely to struggle to find support services on offer for the person they care for with 1 in 4 (39%) reporting this.

Troublingly, only 13% of all groups said that they haven't struggled to access a break from caring.



I rarely get to see friends or even have an hour off let alone anything more



It would cause considerable distress to my husband if he was put into respite even for a short break



I would never dare to take a break away from caring as the standard of care can not be relied upon. The potential risk to the life of the person I care for is too scary to contemplate



I have tried and tried. I've not had respite since my son was 18, he is 25 this year. Social services tell me there aren't suitable places for him



The level of care needed is much more than the care package provides



I get regular breaks every month from my caring role, that helps me to go on providing the care that is needed for my son



What does a break mean to you?

We asked carers what having a break from caring means to them?



“Time to relax, get an undisturbed night’s sleep and concentrate on my other roles as wife, mum and granny”

“Just to have a complete day free would be magical”

“Lack of respite provision for our daughter is impacting on our physical and mental health as well as our marriage”

“It would allow me time to rest and recuperate. With my Son needing 100% 24/7 care, I have no time for my own health, care and social needs, and I can’t even remember what I enjoy doing. I lost a lot of friends after his birth and feel incredibly isolated so I do feel it is important to be able to invest some time on social relationships. It’s very easy to lose your identity when you are a full time carer for someone else and it’s incredibly easy to fall into depression. Breaks are vital for you to recharge your batteries and spend some time on your own needs”

“To sleep would mean a lot. To relax and not worry about the timing of food, toilet needs, medicines and to converse with people not linked to the health care service. Just to feel human and an individual again”

“So I can recuperate and then better care for the disabled person. To look forward to a break has the same effect as the break itself. It also allows me to spend time with my other children who miss out on a lot when I am caring for their brother along side them. I believe a break would benefit their wellbeing as much as mine”

“The world! It may improve my health and keep me caring. Funding for breaks is now gone for my local area and I cannot get them”

“Being able to know my mum is in a safe environment whilst taking some time away for myself would mean the world to me. I am unable to help my mother with a lot of things due to my own mental health, the cuts to many services have meant we are alone trying our hardest to help each other but often very unsuccessfully. We are both deeply in need of support”

“A few days of being able to really spend time with my husband so we can relax together. A chance to sleep a few nights without several interruptions to help Mum, a chance to actually deal with my own substantial health needs. A chance to be a person and not an unpaid servant on literally a 24/7 working day. I don’t resent caring, but I do resent having to jump through hoops to get even a proportion of the rights I would have if in paid employment”

Accessing practical support with caring



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6.5 million people in the UK provide unpaid care by looking after an ill, older or disabled family member, friend or partner, and 1.4 million people provide over 50 hours of unpaid care per week.ⁱⁱⁱ Yet often carers struggle for recognition and all too often go without the practical support they and the person they care for need from the wider health and care system with severe consequences. Public spending on adult social care in England has fallen by 8% between 2009/10 and 2016/17^{iv} and there has been a downward trend in the number of people, in particular older people, receiving a service^v – arguably with families picking up the shortfall or the older or disabled person going without any support at all.

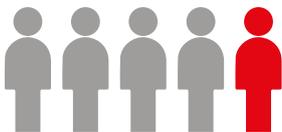
Practical support with caring

We asked carers about the practical support they receive or buy for caring. 77% of carers reported receiving some kind of practical support to help them care. However, almost 1 in 4 (23%) said they receive or buy no practical support to help them with caring. Even among those caring for 50 hours or more per week, 1 in 5 (20%) receive or buy no practical support to help them. These figures remain the same as last year.

Getting equipment in the home of the person they care for, such as a hoists, grab rails or easy-grip handles on taps, was the most likely form of support people receive, with nearly half of people (48%) reporting this. Almost a third (31%) said they get help from family or friends, which was broadly similar between groups. Technology like alarms, sensors or remote monitoring to help with caring is used by 25% of people. And one in 10 (12%) said they rely on a day centre that the person they support attends.

Only 28% said they buy or receive practical support from care workers coming in to help and as few as 16% said they buy or receive a break from caring.

Those caring for children under 18 with disabilities were most likely to be going without any support. A third (32%) said they did not buy or receive any practical support with caring. Sandwich carers, who are those providing care to someone at the same time as bringing up a child without disabilities, were also among those

1 in 5 

of those caring for 50 hours or more per week, receive or buy no practical support to help them

least likely to buy or receive practical support, with 28% of this group reporting they received none.

When asked how they feel about the practical support they might get in the future, 6 out of 10 people (63%) said they feel uncertain about what might happen and almost a third (29%) said they are worried that the support might be reduced. This was similar between groups. Only 8% of people said they were confident that the support they receive will continue. People providing care to a disabled child and sandwich carers were the least likely to say they were confident that the support they receive will continue (5%).

Changing levels of support

A third of people (34%) said they or the person they care for have experienced a change in the amount of care and support services they receive in the last year. Of these, almost 4 in 10 (39%) said the amount of care or support arranged by social services had been reduced and 13% said the care or support service was closed with no replacement offered. 7% said the amount of care or support reduced because the cost increased.

Out of those who reported a change in the amount of care they receive in the last year, people caring for a disabled child under 18 and round the clock carers were slightly more likely to report their care had been reduced, with 42% and 41% of those in this group stating this, respectively.

3 out of 10 people (29%) of those who reported a change in the level of support said that the amount of care or support arranged by social services had increased because the need for support increased.

This question has been asked consistently over the last few years and the evidence from carers shows a steady reduction in service provision, at times, with no alternatives. The compound effect of this is reflected in the overall social care provision statistics which demonstrate a reduction in the overall number of people receiving care. Most worryingly, some services are withdrawn completely, with no alternative offered.



The budget was cut so we have to find an extra £130 a month for provision



Almost a third

29%



said they are worried that the practical support they get might be reduced in the future

Only

8%



said they were confident that the support they receive will continue



We need more but cannot afford it



My son received direct payments. I accompanied him for many years to his swimming lesson and cubs. His PA started to take him to these activities about 15 months ago. This has allowed for me to give time to my other children. It isn't a break for me essentially but it helps as I would have had to choose one child's needs over another



Sam goes to a day service 5 days a week. I wouldn't cope if he didn't have this and neither would he





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Only 4 in 10

40%



said they are able to choose and have control of the services they receive



Mental health services have been cut to the bone, it's more difficult to get help as and when needed



When my son became 'an adult' his respite was reduced by a third. I was told "that's what happens when you become an adult"



Without good neighbours I would have no help



The needs are increasing, the help is decreasing



I have to fight for everything. I feel alone and unsupported



Choice and control of care and support services

Some people with care needs get a cash sum from their local authority or Health and Social Care Trust (in Northern Ireland) to pay for care and support services directly or receive a budget to choose the support services they want, although the local authority may arrange it. 27% of carers responding to the survey said they or the person they support received a direct payment or a budget to choose services they want.

When asked whether the carer and the person they care for have choice over what services they receive or buy using their Direct Payment, 46% of respondents who reported having a direct payment or a budget said they have a choice but that options are limited and they do not feel in control of the kind of support received. Only 4 out of 10 people (40%) said they are able to choose and have control of the services they receive.

More than 1 in 10 people (12%) said they have no choice over the services in place to support them.

Carers' experiences of carer's assessments



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Experiences of carers assessments in the UK

Across the UK, over 6 out of 10 carers (65%) reported having received an assessment of the impact of their caring role in the previous year. This was broadly similar across groups.

Of the 65% who reported having received an assessment in the last year, fewer than half (45%) said that their ability and willingness to provide care was thoroughly considered and reflected in the support they receive. Only a third (34%) said they felt that the support needed to look after their own mental and physical health alongside caring was thoroughly considered and reflected in the assessment process and subsequent consideration, while 3 out of 10 (32%) said that they felt their need to have regular breaks from caring was thoroughly considered.

Those providing palliative care were the most likely to say that their ability and willingness to provide care (68%) and the support needed to look after their own mental and physical health alongside caring (50%) was thoroughly considered and reflected in the assessment process and subsequent consideration. They were also the most likely to say that their need to have regular breaks from caring was thoroughly considered (40%). On the other hand, people caring for disabled children under 18, were least likely to say their ability and willingness to provide care and their own mental and physical health alongside caring was thoroughly considered, with only 31% and one quarter (24%) agreeing with this, respectively. This group was also least likely to agree that their need to have regular breaks from caring was thoroughly considered, with just 18% saying this.



I don't feel the assessment considered me as a person...I felt it was more about making sure I could carry on caring



As a parent carer of disabled children my local authority says I'm not entitled to an assessment



No support was offered or report on the meeting supplied. It would have been nice to have a reference letter of what to do should I become ill or should there be an emergency that requires the patient to be looked after by someone else at short notice



The Care Act and Children and Families Act in England

Obtaining an assessment

In England the Care Act, introduced in April 2015, should be making it easier for carers to get an assessment that looks at the impact of their caring role on all aspects of their life and what support they and their family need. It should also make it clearer for carers to find out about what is available to support them locally and whether they are entitled to local authority funded support.

Two years on now from its introduction, we asked carers whether they have been offered or requested a carer's assessment in the last 12 months. Just over one third of carers living in England (39%) who responded to our survey said they had either been offered (23%) or asked for (16%) a carer's assessment in the previous year. Those who hadn't asked or been offered (61%) may still have had an assessment (see below).

Older carers were most likely to have been offered an assessment in the last year (30%), while both older carers and round the clock carers, the most likely to have asked for one (18%). Those caring for a disabled child were the least likely to have been offered an assessment, with just 10% reporting this, while carers in paid employment were the least likely to have asked for an assessment (13%).

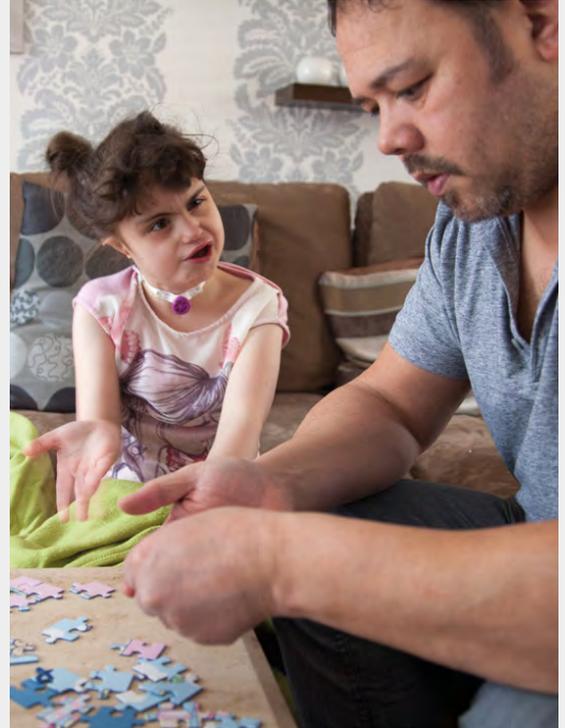
The Care Act only applies to assessments for adults caring for other adults. Slightly different rules apply to children who are caring and to those caring for children under 18.

The Children and Families Act 2014 requires local councils to assess parent carers on the appearance of need or where an assessment is requested by the parent. This is called a parent carers needs assessment. Despite this, evidence shows that parent carers are frequently being refused assessments.

“

I found that all the right questions were asked but ultimately when it came down to it there just isn't enough funding to implement anything that would help to any great extent

”



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“

Support I'd been offered in previous years was now not available despite my caring increasing due to cuts

”

“

When my daughter was under 18 I was told there was no point in having an assessment as there 'isn't any funding attached'. I have recently had an adult carer's assessment in preparation for 'transition'. It was over a month ago and I still haven't had formal response but been told I would be better off organising respite myself

”

Waiting for an assessment

68% of carers in England reported having received a carer's assessment in the last 12 months. Of these, 8 out of 10 people (81%) waited less than six months, with almost one in five (19%) waiting longer than six months. Overall, this appears to be an improvement on last year, when half of carers (50%) who had been offered a carer's assessment or had requested one, reported receiving an assessment within 6 months.

There were variations between different groups of carers. Of those who received an assessment in the last 12 months, 84% of older carers and 80% of those who provide care for more than 50 hours a week reported waiting for less than six months for their assessment. However, over a third (39%) of those caring for children with a disability reported having to wait more than six months to receive their carers assessment. Sandwich carers and people caring for someone with a mental health condition were also more likely to have waited more than 6 months, with 25% of people in both groups reporting this.

The survey suggests that in total, one quarter of people in England (25%) waited for six months for an appointment or have been waiting longer than six months. Again, this is a slight improvement on last year when a third of carers who said they'd been offered or requested an assessment (29%) said they have waited for more than 6 months or are still waiting 6 months later.

Shockingly, however, as many as 25% of people providing palliative or end of life care reported having waited or to be waiting for longer than six months for an assessment. While this is also an improvement on last year, when 39% of this group reported to have waited or to presently be waiting for more than 6 months to receive an assessment, it is still unacceptably high and more needs to be done to ensure that those providing care to people at the end of life receive a timely assessment and the support that they need to deliver care.

“

I still feel uninformed and in the dark about all services provided. What is the point of the assessment when it doesn't actually deliver any kind of help?

”

Experience of receiving an assessment

Of the 68% of carers in England who said they had received a carer's assessment in the last 12 months, over half (55%) said their ability and willingness to provide care was either not properly considered in their assessment or in the support they received (19%) or that they received some but insufficient consideration (36%).

Only a third (35%) felt that the support needed to look after their own mental and physical health alongside caring was thoroughly considered and reflected in the assessment process and subsequent consideration. A third (33%) felt that their need to have regular breaks from caring was thoroughly considered and reflected in the support they receive.

The Care Act in England brings in new rights around assessments for carers, but responses from carers show that this does not necessarily mean carers are getting the support the assessment identified them needing in practice. Even when carers reported that the assessment was thorough and that their needs were considered adequately, many resented going through the process and receiving no support as a result. As one carer explained,

“Assessment is a tick box exercise, no help is offered after this. You are left to get on with it”.

Carers' assessments are vital, but to be effective they must lead to positive outcomes and give carers the support they need to provide care, rather than just acknowledging it.

Only a third of carers in England

35%



felt that the support needed to look after their own mental and physical health alongside caring was thoroughly considered and reflected in the assessment process and subsequent consideration

Carers' experiences of discharge from hospital



As part of a patient's discharge, hospitals have a duty to consult the patient's carer about the discharge process. Of those filling out the survey, a third of carers (34%) said the person that they care for had been discharged from hospital within the last year. We asked these carers about their recent experience of hospital discharge. Disappointingly, responses show that the carer's needs and the support in place were not always properly considered in the discharge process, often leading to poor and distressing outcomes.

The majority of carers (58%) with experience of hospital discharge in the previous year said they were either not consulted about the discharge (23%) or were consulted but only at the last minute (35%). Many carers providing care for someone who had been discharged from hospital in the last year said they were discharged too early, with 23% stating that the person they care for was not ready to come home and 17% saying the support was not available for them to be at home. A further 1 in 10 carers (9%) reported that the person they care for was discharged too early and as a result readmitted to hospital in the following couple of months. These figures remain broadly unchanged from last year.

The majority

58% 

with experience of hospital discharge in the previous year said they were either not consulted about the discharge (23%) or were consulted but only at the last minute (35%)

1 in 10

9% 

reported that the person they care for was discharged too early and as a result readmitted to hospital in the following couple of months

A number of carers also described people having to stay in hospital longer than was necessary as a result of appropriate care and support in the community not being in place or as a result of poor care management in hospitals. Carers reported that the person they cared for could have come home much earlier and that staying in hospital longer than necessary had been detrimental to their wellbeing.

Overall, under half of carers (47%) said the timing of the discharge was just right. Carers for disabled children were most likely to report this (65%), whilst, worryingly, those providing palliative care were least likely to agree the timing was right, with only 35% reporting this.



There was NO communication from the hospital with me at any stage. On discharge I received no information about medication, a care plan....nothing. I find it very hard to cope as I feel voiceless



Our hospital staff were very understanding and involved me at every stage of my husband's discharge and made sure that I was happy and prepared and that all help that I may have needed was in place before he came home



They tried to discharge mum before her assessment. Forms were filled in on my behalf incorrectly. At no time was I asked if I could continue to care for my parent, my health was not considered



It was far too early, he was re-admitted within days of his discharge



It was right for my husband but I was tired out trying to sort out chores at home so I would have time for him as he needed lots of help and supervision with mobility



Mum was kept in far longer than needed just because they wanted her assessed by social services who couldn't do so for days. I felt that mum was neglected whilst she waited in hospital unnecessarily and that the delay was adversely affecting her. In the end I discharged her into my care



As a carer I was left to chase and co-ordinate services and supplies to avoid deterioration of patient health. I fear for anyone being discharged without help at home



We were unprepared for the practical requirements for the person's physical care. We needed much more information prior to discharge



Costs of caring

The UK's 6.5 million unpaid carers provide the majority of care for families, saving the economy an estimated £132 billion per year.³ Yet Carer's Allowance is the lowest benefit of its kind, at just £62.70 a week (2017/18 rates), and carers often report struggling financially. We regularly hear of families facing difficulties making ends meet and affording their basic living costs alongside the additional costs associated with caring. Financial constraints are made worse by many carers being forced to give up work as a result of their caring responsibilities, removing their opportunities to support themselves while they are supporting others.

We positively recognise the fact that the UK Government chose to protect carers' benefits by allowing it to rise in line with the Consumer Price Index whilst other benefits remained frozen. However, the fact that many carers also depend on means tested benefits that are frozen means that carers and their families are far from unaffected by this policy.

Almost half (48%) of carers responding to the survey reported living on a household income of less than £1,500 per month and nearly 4 out of 10 carers (39%) described themselves as struggling to make ends meet. As many as 8% of those responding to the survey said they were living in a household receiving under £500 in monthly income.

Those who provided care for over 50 hours a week were slightly more likely to be living on a low income, with the majority (52%) of this group reporting that their household monthly income was below £1,500, whilst sandwich carers and those providing care to a disabled child were most likely to describe themselves as struggling to make ends meet.

On the other hand, carers who were themselves in paid work or who lived in a household where someone was in paid work, were more likely than other groups to have a household income over £1,500 (67%), whilst older people were the most likely to say they can afford their bills without struggling financially (69%).

When we asked how carers who are struggling to make ends meet cope, a number of people reported cutting back on items and activities which are fundamental to their wellbeing, such as hobbies and leisure activities (53%), seeing friends and family (42%) and essentials, like food and heating (31%). Almost 1 in 10 of those who said they were struggling (9%) also reported cutting back on support services which help them directly with caring.



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We're treading a fine line, keeping our heads just above water



We had to declare bankruptcy and lost our house as a direct result of caring responsibilities when I gave up work. My son was too poorly at birth for me to be able to work



As I am currently in employment I can pay my bills but if I give up work to be a carer full time we will be on the breadline



"At 49 with no extra income, I am worried about the future. We are using savings we can't replace



³ Carers UK, University of Sheffield, University of Leeds (2015) Valuing Carers 2015; the rising value of carers' support

The methods a large number of carers are been forced to use to help them make ends meet:

30%



Their savings

26%



Credit cards

23%



Bank overdrafts

Very worryingly, a large number of carers reported being forced to use their savings (30%), credit cards (26%) or bank account overdrafts (23%) to help them make ends meet. Others reported borrowing from family or friends (17%). Altogether, over 1 in 5 (22%) carers struggling to make ends meet said they are in or have been in debt as a result of caring.

These coping mechanisms were reported to be the only way many carers could afford their basic living costs and the additional costs of caring, but they were also said to have a significant impact on stress and anxiety and they are unlikely to be sustainable in the long-run.

More should be done to ensure that carers and their families do not suffer financial hardship as a result of caring and that they have enough money to provide care and support without it being detrimental to their lives.



The costs of caring have surprised me. Extra heating, special foods, special loose fitting clothes, taxis. We are lucky enough to have savings but these are being depleted daily



I miss meals. I have been doing this for years. It's exhausting never been able to relax about money. The worry if they change the benefit system again and how will we cope?"



The Government has no understanding that so many carers have to use up all their savings and investments just to make ends meet. Carers are saving them millions and millions of pounds in caring for their loved ones, yet struggle to even receive a mere pittance of unacceptable levels of little or no benefits



We just try our best to live on what we have but it is very hard as we are always in arrears. The National Debtline has been great in helping us cope



I cannot afford hobbies or leisure activities and rarely see family or friends



Due to caring, my own old age which had been planned and saved for will be bleak and possibly homeless



Juggling work and care



Three million people, 1 in 9 of the workforce, combine caring for a loved one with paid work.^{vi} However, the significant demands of caring mean that many are forced to give up work altogether, due to a lack of rights, flexibility and high quality care services at home. Carers need to be supported so that they are able to juggle work and care and to enable them to return to work if they wish.

A third (37%) of carers responding to the survey reported currently being in paid work. As many as a quarter (25%) of those providing care for over 50 hours a week reported being in paid work.

Responses illustrate how caring takes a toll on people's employment opportunities, including career development, promotions and pay rises, as well as impacting upon carers' ability to work at all. And as many as 4 out of 10 carers (43%) said they had given up work completely to care, with 13% reporting that they had retired early to care.

1 in 5 of all carers (21%) said they had reduced their working hours to care. Nearly half of working carers (46%) said that they work the same hours but that their job is negatively affected by caring through tiredness, lateness and stress. 14% of all carers reported having had to take a less qualified job or have turned down promotion to fit around their caring responsibilities.

Having to work at the same time as providing care has a significant effect on people's health. Carers in paid work were more likely to have suffered mental ill health as a result of caring than some other groups, including stress and anxiety, with over 7 in 10 carers in paid employment (72%) reporting this. Over half

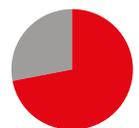
(55%) said their physical health has worsened as a result of caring. Two thirds (67%) said they found it difficult to get a good night's sleep, and half said they have reduced the amount of exercise they take (56%) and found it difficult to maintain a balanced diet (47%).

Carers in paid work are also the group for whom it is least likely that their GP knows they are a carer, with a quarter (25%) of those in paid work reporting this. This suggests opportunities for them to be better supported in their caring role and to help them look after their own health and wellbeing are being missed.

Of those who reported having a carer's assessment this year, responses suggest that the majority of carers in paid work are not being given the support they need by the local authority to help them juggle care with work. Over 7 in 10 carers (73%) said the need to combine paid work and caring was either not properly considered in their carer's assessment or in the support they received, or that this received some but insufficient consideration.

Over 7 in 10 carers

73%



said the need to combine paid work and caring was either not properly considered in their carer's assessment or in the support they received, or that this received some but insufficient consideration



I am totally worn out trying to balance work and care for my disabled daughter and family



I would *love* to be in paid work, even part time. I gave up a well paid career to look after my son. This has led to significant financial difficulties. I'd love more support to enable me to work



I do agency work instead of having a contract which gives me more flexibility but means I get no sick pay, pension contributions or professional training plus very limited holiday pay



I ended up with burnout as I was trying to deliver my caring role and work 50+ hours a week



I work a full day, but with adjusted hours to accommodate my caring role. I also use my annual leave entitlement on care related things such as medical appointments, organising care, covering shortfalls in care. I usually have to ask for several extra unpaid days when annual leave runs out each year. On occasions this unpaid leave has affected my pension entitlement



I had to leave a senior job in industry at the age of 50 and have found it difficult to find a senior part time job for a woman resulting in my earnings dropping drastically and putting me under financial pressure



My employer forced me to choose between taking on a permanent senior role or being perceived as not committed to the company and end my contract. I chose my mum. The financial suffering has been huge but I have some precious time with my mum who is late mid dementia, times I would have never had if I had chosen my career. But why should I have to choose? I saw young mothers at work given privileges I just wasn't allowed



We just try our best to live on what we have but it is very hard as we are always in arrears. The National Debtline has been great in helping us cope



I cannot afford hobbies or leisure activities and rarely see family or friends



I have ended up owing time and using unpaid leave due to having so much time off work this year



A contribution that is understood and valued?



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Carers make a huge contribution to the lives of those they care for and to our wider society. They provide invaluable support often at personal cost to their own mental and physical wellbeing, their relationships with family and friends, and to their own needs. Yet the majority of carers report feeling that their contribution is not understood and is not valued. Almost three quarters of people (73%) said they feel government does not understand their contribution or value it at all, while only 15% of people said their contribution is well understood and valued by health and care professionals, despite these being the very people who carers rely on for support.

Those providing more than 50 hours of care per week and those providing care to a disabled child were most likely to say government didn't understand or value their contribution at all (75%), while those providing care to a disabled child were also the most likely to say that health and care staff didn't understand or value their contribution at all (36%).



I want staff in health and social care to talk to me not ignore me. I want them to understand that I work part time so am not always available. I want them to understand that I am getting older. I want them to understand that I have a married life and friends whom I neglect



I feel that as a carer I only count as the cheapest form of care available. It starts and stops with that



The majority of carers also felt that their contribution is not understood or valued by the public and society more broadly and many said they don't feel their contribution is even understood or valued by those closest to them, with as many as 21% of people saying friends and family don't understand or value what they do at all.

The huge contribution carers make to the lives of those they care for and to society more broadly should be properly recognised. Carers should be better considered in the care and support that health and care professionals provide to the cared for person and their independent needs should always be addressed. Many carers reported that it was particularly difficult to feel valued by government and society when the money they receive for their caring is so little. At just £62.70 a week (2017-18 rates), Carer's Allowance is the lowest benefit of its kind, leaving many experiencing financial hardship, low self-esteem and feeling resentful that their invaluable contribution is not recognised. As one carer put it, "How can we say carers' contributions are valued when (if you qualify) we earn under £2 per hour?"

When asked about their expectations for the future, the majority of carers (53%) said they expect their quality of life to get worse in the next year. Only 5% of people said they expect it to get better.

Older people and those providing over 50 hours per week were more likely to say they expect their quality of life to deteriorate.



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I have never felt as depressed or undervalued as I do now



The tokenistic Carer's Allowance makes it plainly evident that society and government do not appreciate the practicalities, difficulties or hardship of caring for someone



In my experience social care workers take for granted that support will be given by other family members



I think the language used by politicians and the mainstream media has negatively contributed to how people who rely on benefits are viewed by much of the public



I feel very aggrieved at the pittance of an allowance I get for caring. It is so insulting and I feel so undervalued. I care 24 hours a day 365 days a year



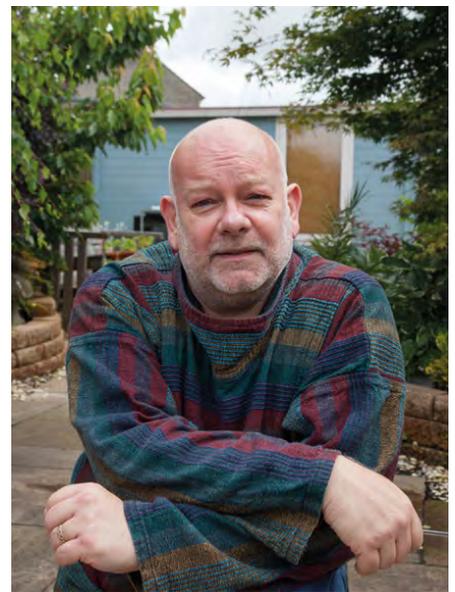
Recommendations

There is an urgent need for a cross government plan setting out how improved support for carers will be achieved with targets and milestones so carers can see the progress being made.

This should include measures:

To ensure that carers and our families do not suffer financial hardship as a result of caring:

- Carer's Allowance, just £62.70 per week on 2017/18 rates, needs to be raised significantly over the longer term and in the short term at least raised to the level of Job Seeker's Allowance (an increase of £10 per week) with equivalent increases to carer premia to ensure that those on the lowest incomes benefit from an increase.
- The earnings threshold for Carer's Allowance needs to rise year on year in line with the National Living Wage pegged at least to the equivalent of 16 hours a week. A taper should also be introduced.
- To auto-enrol carers in a second pension – a Carer's Pension that recognises the value of unpaid work and ensures that carers do not suffer financial hardship later in life.



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To ensure that there is sufficient funding so that older and disabled people get the care they need and which is affordable:

- An urgent new, sustainably funded settlement for social care and the NHS to make legal rights to support a reality and ensure that services are there when carers need them. This must include housing fit for caring and technology that supports caring.
- Good quality, reliable and affordable care services are needed to support the role of carers and ensure we get the breaks we need to care without putting our lives on hold and our health in danger.



To ensure carers are able to juggle work and care, returning to work if we wish:

- Introduce a new right to paid care leave in the workplace of between 5 to 10 days for carers in work.
- Support for carers and former carers who wish to stay in or return to work.
- Recognition that good quality, reliable and affordable care services are needed to enable us to juggle work and care.



To provide funding to enable carers to take the breaks we need:

- Increase and ring-fence funding for carers' breaks making it transparent so carers know what they are entitled to, and to ensure greater consistency in what is available



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To create a more 'Carer Friendly' NHS:

- A new duty for the NHS to put in place policies to identify carers and to promote our health and well-being – helping to build a carer friendly NHS.
- New measurements to monitor how GPs are identifying and supporting carers to make sure carers are able to look after their own health, are listened to about the care of the person we care for and are supported to care well.



Ensure we are all better prepared for caring and can get support early to look after our own health and wellbeing:

- Easily available advice and information for carers to help us plan, prepare and provide for care.



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About Carers UK

At times, caring can be profoundly joyful. There's nothing more natural and human than helping our loved ones get the most out of life.

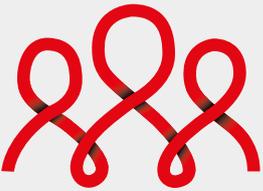
There's also nothing more difficult than focusing on someone else's needs without neglecting our own. Whether we're caring around the clock or balancing caring with work and family life, it can be exhausting. The 'system' can be bewildering. The emotions can be shattering.

However caring affects you, we're here.



Our vision is a world where carers feel respected, valued and supported for the huge contribution we make. Where the care we provide is not taken for granted.

We are focusing on three priorities to create the world we want for carers.

1. 

Battling for greater understanding and support for carers in our society, so we can all look after loved ones without putting our own lives on hold

2. 

Giving carers expert information and advice right from the start, so the answers are available for everyone who needs them

3. 

Building a network of carer positive employers, so no one has to give up work to care

Carers UK Adviceline

For expert advice and information about caring, contact the Carers UK Adviceline.

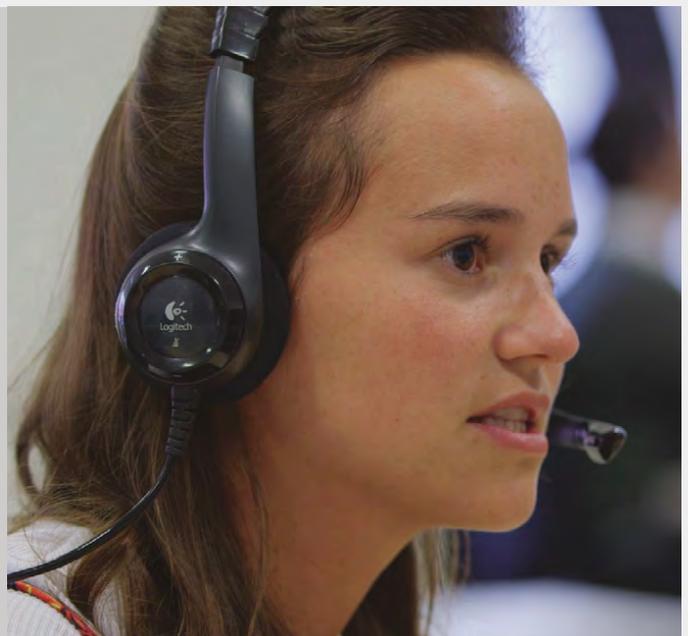
T 0808 808 7777

E advice@carersuk.org

Open Mon-Fri 10am-4pm

Listening service Mon & Tues 9am-7pm

carersuk.org



Appendix

A total of 7,286 carers and former carers responded to Carers UK's annual State of Caring Survey between March and May 2017.

Only responses for the current 6,607 carers who completed the survey are included in this report as it is designed to provide a snapshot of caring in 2017. However, Carers UK will be using the responses of former carers in other pieces of work throughout the year.

Compared to the carer population as a whole, respondents to this survey were more likely to be female and caring for a high number of hours every week.

Of respondents to the State of Caring Survey 2016 who are currently caring:

- 75% live in England, 10% live in Scotland, 7% live in Wales and 9% live in Northern Ireland
- 78% are female and 21% are male
- 26% consider themselves to have a disability
- Only 1% are aged 0-24, 4% are aged 25-34, 13% are aged 35-44, 29% are aged 45-54, 34% are aged 55-64, 15% are aged 65-74 and 4% are aged 75 and over
- 3% are lesbian, gay or bisexual.
- 19% also have childcare responsibilities for a non-disabled child under 18
- 37% are in paid work (46% full-time and 41% part-time)
- 33% have been caring 15 years or more, 15% for between 10-14 years, 23% for 5-9 years, 25% for 1-4 years and just 3% have been caring for less than one year
- 50% care for 90 or more hours every week, while 16% care for 50-89 hours, 23% for 20-49 hours and 11% care for 1-19 hours a week
- Most (76%) care for one person, 18% care for two people, 4% for three people and 2% care for four or more people

Endnotes

- i Census 2011
- ii Carers Week (2016), Building Carer Friendly Communities, Research report for Carers Week 2016
- iii Census 2011
- iv The Health Foundation (2017) Election briefing: NHS and social care funding: Three unavoidable challenges.
- v ADASS 2016 Budget Survey
- vi Census 2011



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