

State of Caring 2016



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State of Caring 2016

Carers UK carries out an annual survey of carers to build a picture of the state of caring in the UK.

This year over 6,149 people shared their views and experiences on what life is like for carers in 2016.¹

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



¹ As this report provides a snapshot of caring in 2016, only the responses of current carers have been used here. However, Carers UK will be using 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 2016

Our latest calculation of the value of unpaid care in the UK shows that the contribution of the UK's carers is growing and is now worth a staggering £132 billion.² That's the equivalent of spending on the National Health Service.

So how is this huge contribution being recognised and what support can carers expect in return?

New legal rights for carers across the UK for support with social care services suggest the growing contribution of carers is increasingly recognised by governments and policy makers. In 2016 these rights are at different stages of implementation.

In England an early picture is emerging of what new rights mean in reality within the context of continued reductions to social care spending expected to result in a shortfall of £3.5 billion by the end of this Parliament and an NHS struggling to meet savings targets.³ The results show that the spirit of the Care Act 2014 and the Children and Families Act 2014 have not become a reality for all – and carers are struggling to get the support from health and care services that they need to care, work and have a life outside caring.

The survey shows evidence of public services creaking under pressure – charging is up, the right services are harder to find and vital support is cut or under threat, leaving many carers anxious about the future and their ability to continue to care.

Despite saving money for the UK economy, caring still comes with a high personal cost for the many carers who are struggling to make ends meet, finding it hard to stay in touch with friends and family, seeing their own health and wellbeing suffer, or needing more support to stay in work alongside caring.

For many in England, Wales and Northern Ireland, the impact of welfare reform changes continue to be felt as changes to Housing Benefit and the localisation of council tax reduction continue to bite. The prospect of further reductions to Employment Support Allowance and help with housing costs threatens greater financial insecurity for many families in the future. A commitment to exempt carers entitled to Carer's Allowance from the benefit cap will bring relief to some.

The freezing of some benefits and the negative Consumer Price Index inflation measure keeping carer and disability benefits at the same level this year mean families receiving social security will struggle with any increase in the cost of living.

For carers to feel that the care they give is truly valued and that choosing to provide care doesn't mean putting their own lives on hold, more must be done to put in place the financial, practical and workplace support that they urgently need.

Newly elected representatives in Scotland, Wales and Northern Ireland considering their priorities for the next electoral term and the Westminster Government considering the shape of its new cross government strategy to support carers must put carers' priorities at the heart of their policy making.

The value of unpaid care carers give in the UK



The value of health spending in the UK



² Carers UK, the University of Sheffield and the University of Leeds (2015) Valuing Carers 2015 – the rising value of carers' support, S. Yeandle, L. Buckner

³ Nuffield Trust, Health Foundation, Kings Fund (2015) The Spending Review: what does it mean for health and social care?

Practical support

Without practical support with caring from health and care services, carers cannot get the time they need to look after their own health and maintain relationships with others. Replacement care for the person they support is essential in enabling carers to juggle work, study or have hobbies and interests alongside caring, or to manage care with other family responsibilities such as childcare.

Without this support, carers are often pushed to breaking point and have to give up work, stop caring, or even go into hospital themselves.

8 out of 10 (78%) carers buy or receive some form of practical support with their caring role, be that equipment, technology, a break from caring or help from family and friends. However, 1 in 5 carers (20%) who are providing 50 hours or more of care each week are receiving no practical support with their caring role.

1 in 5

20%



of those providing 50 hours or more of care each week **are receiving no support with their caring role.**



“

The care agency pulled the care from my mother with only seven days' notice. I was forced to accept direct payment as no alternative care agency could be found.

”

“

Direct payment increased slightly but still not enough to cover the level of care required.

”

“

The amount of 'free time' has been cut following the withdrawal of council funding to Mencap. Our son was able to go away for one or two weekends per year and attend two social clubs, two evenings each week during term time. This is no longer available.

”

“

Less respite per year means having less quality time with my husband. Day care has been reduced so having to care for more hours, feeling tired and stressed.

”

“

The social worker who assessed my wife said all direct payments in the borough were being reduced. We discussed the needs and were advised we would be informed of any change. Without warning or notification the budget was cut by 30% immediately.

”

Type of support

Almost half of carers (48%) have practical support in the form of equipment in the home of the person they care for, such as hoists, grab rails or easy grip handles. Nearly a quarter (24%) use technology to help their caring role and 29% have practical support from care workers. Nearly a third (29%) of carers surveyed have help from family or friends, showing the importance of a support network.

Almost 1 in 5 carers (18%) have practical support in the form of a break from caring for themselves. 22% of carers surveyed have a Motability vehicle, which enables them to get out and about with the person they care for. For those caring for someone with a learning disability, day centres continue to be an important source of support with 1 in 5 carers (19%) looking after someone with a learning disability using a day centre.

Reduction in support

A third (34%) of respondents to our survey said that they or the person they care for has experienced a change in the amount of care and support services that they receive. More than half of those reporting a change (59%) said the amount of care and support they receive had been reduced because of cost or availability of services.

This includes 12% who have cut down on the amount of care and support they get because the cost has increased or their personal budget no longer covers it, and 13% said that the care or support service was closed and no replacement was offered.

Paying for support services

Less than 1 in 10 (9%) carers reported that they have been asked to pay for support services for themselves, although over a quarter (27%) of those receiving care have been asked to pay. In just 7% of cases both the carer and the person they care for said they had been asked to pay. In over half (57%) of cases where the carer and the person they care for qualify for services, they do not have to pay for these. Most of these respondents were on means-tested benefits and extremely low incomes.

For those who are asked to make a financial contribution towards the cost of care and support, nearly half (47%) say they struggle to afford to pay for it.

“

Transition from child to adult services resulted in a significant reduction even though her needs are the same.

”

More than half

59%



of those reporting a change say **the amount of care and support services they receive has been reduced because of cost or availability.**

“

Care workers now come more frequently but are provided by a private company rather than council. The quality of care provided has gone down since this happened with little continuity due to so many different care workers coming in and virtually no communication from care provider's head office regarding times of attendance, care worker names etc. This means I am basically on call 24/7 in case they don't turn up or do what they are supposed to do.

”

Nearly half

47%



of those being asked to contribute to the cost of care say **they struggle to afford to pay for it.**

Experiences of carers' assessments

Across the UK, 31% of carers responding to our survey reported having an assessment of the impact of their caring role on them in the previous year.

Only a minority of those having an assessment in the last year (35%) were told how to get all the information and advice about their caring role they felt they needed, with 1 in 5 (22%) saying they received little or no helpful information or advice and felt they did not know where to go for support with caring.

Those providing 50 hours or more of care a week are twice as likely to be in bad health⁴ as those not providing care yet, high numbers of carers felt that their assessment did not look sufficiently at the impact of caring and support needed to look after their own health and have a break from caring. Only a third (35%) of carers who had an assessment in the last year felt that the support they need to look after their own mental and physical health alongside caring was properly considered. Two thirds (68%) of carers felt that their need for replacement care to have a break from caring was either not considered or not thoroughly considered in their carer's assessment.

Only a third

35%



of carers who had an assessment in the last year **felt that the support they need to look after their own mental and physical health alongside caring was properly considered.**

⁴ Census 2011

One year on:

The Care Act 2014 and Children and Families Act 2014 in England

In England the new 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.

Obtaining an assessment

We asked carers in England whether they have been offered or asked for a carer's assessment in the last 12 months. Half of carers (50%) living in England who responded to our survey had either been offered (28%) or asked for (22%) a carer's assessment in the previous year. Those who haven't had one in the last 12 months could have already had one, or have not yet been offered or requested one.

Older carers are much more likely to have been offered their assessment (39%) compared to 20% requesting one. On the other hand, those caring for a disabled child under 18 were more likely to have asked for their assessment (22%) than have been offered one (13%).



Well over a third

39%



of carers in England caring for someone at end of life **waited or have been waiting for at least six months for a carer's assessment.**

Waiting for an assessment

Of carers who have been offered a carer's assessment or have requested one, half (50%) received an assessment within 6 months but nearly a third (29%) waited for more than 6 months or are still waiting 6 months later.

There were variations between different groups of carers. Older carers were more likely to have an assessment more quickly with 55% of older carers offered or requesting an assessment receiving one within 6 months and 25% waiting longer than six months.

Those supporting someone with a mental health condition were slightly less likely (48%) to have received an assessment within six months. The survey suggests that alarming numbers of those providing care for someone with a palliative or end of life condition are waiting for 6 months or longer for a carer's assessment. Well over a third of carers (39%) for someone at the end of life waited or have been waiting for at least six months. This includes nearly a quarter (23%) who are still waiting 6 months later. Only 42% received a carer's assessment within 6 months of being offered one or requesting one.⁵

There was also a difference in the timeliness of assessments depending on whether a carer requested an assessment or was offered one. This was particularly stark for parents of disabled children under 18 who are more likely to request an assessment than other groups of carers.

Of those carers who requested a carer's assessment (rather than being offered one) 34% have waited or have been waiting for more than 6 months. This rises to 48% of those caring for a disabled child under 18. 17% of all carers who have requested a carer's assessment are still waiting 6 months later.

For those carers who were offered an assessment, a quarter, (25%) have waited or have been waiting for more than 6 months, rising to 28% of those caring for a disabled child under 18.

⁵ The sample size of black and minority ethnic carers who had received a carer's assessment in the last year was too small to include findings on.

“

I requested a carer's assessment and council refused it, said I did not have a right to one as I was caring for child not an adult!

”

“

I had to wait almost a year to get an assessment

”

“

I had to fight for a social worker but got an assessment immediately and finally got some support although it's still not at the correct level.

”

“

Waiting a year has made the situation much more difficult and my need for help considerably greater. I definitely feel the length of time waiting has had a detrimental effect on my mental health.

”

Nearly a third

29%



of carers in England who have been offered a carer's assessment or have requested one **have waited for more than six months or are still waiting six months later.**

Experiences of receiving an assessment

Looking at the assessment approach, over half (53%) of carers felt that their ability and willingness to provide care was not properly or insufficiently considered in their assessment or the support they received.

Only a third (36%) of carers felt that support to look after their own health, both mental and physical, was thoroughly considered as part of the assessment process and only a third (33%) felt their need to have regular breaks from caring was properly considered.

6 in 10 (63%) felt that the support they need to provide care for others (such as non-disabled children) was not sufficiently considered. This rises to 74% for those whose main caring role is for someone with disabilities or serious illness who is under 18.

The area which most carers found was not properly considered as part of the assessment or the support received was the support needed to juggle care with training or education. This was followed by support needed to remain in or return to work alongside caring – in fact 74% of working age carers did not feel that this was sufficiently considered as part of the assessment.

Support following an assessment

21% of those who had an assessment said they received little or no helpful information or advice and felt they did not know where to go for support with caring. 45% felt they got some but not all the information they needed.

11% of those who had an assessment in the previous year said they had been asked to pay for services to support them as a carer and 35% reported that the person they care for has been asked to pay towards their services.

Almost half (47%) of carers say that it is struggle for them to afford the cost of care whilst 8% of carers pay for care because the person they support cannot afford it.

Whilst the Care Act in England brings in strong new rights around assessments for carers, it does not mean in practice that carers are feeling the benefit. The strong message that came through in the feedback was that carers feel their assessment might look at their need for support but this did not mean they received support as the outcome of their assessment.

Many carers felt that the money or services is not there for the local authority to provide them with the support their assessment found them to need so the assessment ended up feeling like a tick box exercise. It is fundamental that carers' assessments lead to positive outcomes and give carers the support they need, rather than just acknowledging their need.

“

The assessment is just a piece of paper and I have no help.

”

“

I was told I was lucky to be able to work at all, that I should ask my employers (who are very tolerant already) to schedule me in a way that enables time with my partner. I stressed this absolutely would not meet our needs and was immediately rejected for any help around the house.

”

“

Lots of good ideas but no support is really available and if you cannot get care for the disabled person none of it can happen – no funds.

”

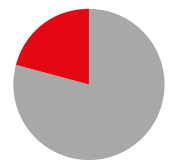
“

All assessment areas were considered by my assessor but due to cuts there was no support they could practically offer me. I was listened to but there was no positive outcome.

”

1 in 5

21%



of carers in England who had a carer's assessment said they **received little or no helpful information or advice and did not know where to go for support with caring.**

NHS – experience of hospital discharge

As part of a patient's discharge, hospitals have a duty⁶ to consult the patient's carer about the discharge process. Of those filling out the survey, 31% care for someone who had been discharged from hospital in the previous year. We asked these carers about their recent experience of hospital discharge. A quarter (25%) of the carers of those who have been discharged from hospital at least once in the previous year report that they were not consulted about the process.

Significantly, nearly 6 in 10 carers (57%) said that they did not feel that they had a choice about providing care to the person following their discharge from hospital.

The survey suggests that a failure to consider the carer's needs or the support in place at home is having distressing and counter-productive consequences. Over half (55%) of those completing the survey who care for someone discharged from hospital in the previous year said that they were discharged too early. Worryingly, 1 in 10 (11%) carers said that because the person they care for was discharged too early, they had to be readmitted to hospital in the following couple of months.

Many carers also described instances where a lack of support from social care and community health services meant the person they cared for had to remain in hospital longer than necessary to wait for support at home to be put in place.

Nearly 6 in 10

57%



said that they **did not feel that they had a choice about providing care to the person following their discharge from hospital.**

1 in 10

11%



of carers said **because the person they care for was discharged too early, they were readmitted to hospital within a couple of months.**

“

No additional help was offered. I got three hours' notice and she was a two hour journey away. I don't drive so had to beg for help from a neighbour.

”

“

Several hospital stays have been far longer than medically necessary due to the failure of social care provision.

”

“

My son was discharged home to an empty flat and he didn't have a key to get in. They put him in a taxi and sent him on a 30 minute drive home. There was nobody to let him in for over three hours and it was raining heavily and he had no coat. I could do nothing as I was 150 miles away.

”

“

I had to fight long and hard for the social services and the hospital to recognise that my sister was not ready to be discharged from the hospital. They have no idea about her disability. Only through fighting did she receive adequate care after discharge from hospital.

”

“

My mother's discharge was delayed by about four or five days whilst the continuing health care package of home care was put in place.

”

⁶ In Scotland existing protocols around hospital discharge will be replaced by a duty to consult carers coming into place with the Carers (Scotland) Act 2016

Carers' finances

Despite their valuable contribution, carers are not being protected from financial hardship. Taking on a caring role often results in sharp reduction in household income, especially when leaving work or reducing hours to care – this can be particularly catastrophic if they are caring for a partner who has also left work as a result of illness or disability.

Despite the growing numbers of people providing more hours of unpaid care, support for carers and their families from the social security system continues to be reduced. Freezes on most working age benefits combined with low inflation as measured by the Consumer Price Index means that carers and their families see no increase in their benefits this year, leaving them without the scope to manage rising costs.

Carers UK's year-long Caring & Family Finances Inquiry found that carers can face higher utility bills, higher transport costs, higher shopping bills, spending on care services and even the cost of home adaptations.⁴

Forthcoming changes to reduce Employment Support Allowance for the work capability group and a further four year freeze of working age benefits mean many carers will again be hit hard.

Those responding to the survey are managing on low incomes with over half (51%) of them managing on a gross household monthly income of less than £1,500.

44% are struggling to make ends meet rising to nearly half (48%) of those caring for 35 hours or more per week. A quarter of carers (26%) report that they have been, or are currently, in debt as a result of their caring role.

Two thirds

64%



of carers who are struggling to make ends meet **cut back on seeing friends and family to cope.**

“

Whilst I can manage the bills, this is at the expense of holidays and other activities we used to enjoy.

”

“

I constantly worry about bills and wake up early feeling anxious about money. We have some savings but I am now in my 60s so I'm worried about depleting them.

”

“

It is a real struggle, week on week, month on month, year on year.

”

“

When my savings, which I dip into each month, have gone then the debt will accumulate.

”

“

The increased stress has left me with depression, high blood pressure and anxiety. Headaches, low self-esteem, emotionally crippled. All hidden behind a smile.

”

“

The constant worry about money means that you can never be off your guard... you can never relax. You are always worrying and you never feel you can enjoy life.

”

⁷ Carers UK (2014) Caring & Family Finances Inquiry: UK Report

As a result of financial strain many carers are being forced to make impossible decisions about spending to get by. Of those struggling to make ends meet, nearly half (48%) are cutting back on essentials like food and heating and 1 in 6 (16%) are falling into arrears with housing and utility bills. Others are borrowing money on credit cards (35%), taking out loans (13%) or borrowing from friends or family (30%).

Over a third (37%) of carers struggling to make ends meet are using up savings to get by suggesting that their ability to manage is unlikely to be sustainable in the longer term.

Financial hardship is putting further pressure on carers' ability to get practical and emotional support with their caring role as 13% of those struggling financially are cutting back on practical support with caring and nearly two thirds (64%) are cutting back on seeing friends and families, increasing the isolation that many carers experience.

Worry about finances has a knock on impact on carers' own health too. Across all carers, whether they are currently struggling financially or not, the numbers who report a level of worry about finances that affects their own health is high at 43%. Three quarters (73%) of those struggling to make ends meet report that worry about their finances is affecting their health.

Three quarters

73%



of carers who are struggling to make ends meet **say worrying about their finances is affecting their health.**

“

I sometimes skip meals so other family members eat.

”

“

Caring for someone and looking after our baby is a massive physical and emotional drain. Adding to this the stress of becoming increasingly in debt and the knowledge that continuing along this path will end in eviction and the inability to pay bills, eat and heat the property causes stress for me and directly impacts on my partner's health and wellbeing.

”

“

I am constantly on edge waiting for 'that' phone call or 'that' letter in the post or the debit card declined at the supermarket checkout.

”

“

It is a constant worry that adds to the stress and anxiety that I already have as a carer. It also means that when I do have 'time off' my partner and I can't afford to 'make the most of it'. We haven't had a holiday away from home since I started caring and even a weekend visit to my in-laws has to be carefully planned and saved for.

”

Caring and work

1 in 9 people in the workforce are juggling care with paid work, yet many face a lack of understanding from colleagues and managers.⁵ Working carers are looking for a mixture of support; from understanding and flexibility at work to reliable, affordable care services that give them peace of mind that the person they support is being well cared for. Without this and the information and support to coordinate care, working carers are ending up stressed and anxious without access to the time they need for themselves as well as feeling isolated from their colleagues.

Many working carers find they go months or even years without a real break. Of full-time or part-time employees responding to our survey, 7 in 10 (70%) have used their annual leave to care and almost half (48%) have done overtime to make up hours spent caring.

Many carers leave work altogether when they feel they cannot cope any longer, and many more reduce their hours, turn down promotion or take lower paid, flexible work that can fit around their caring responsibilities. Half (49%) of carers responding to our survey have given up work to care. Nearly a quarter (23%) reduced their working hours while 17% have had to take a less qualified job or turned down promotion to fit around caring.

The continuing opportunity costs for carers and their employers are stark.

Among those currently in paid work, 2 in 5 carers (39%) have taken a less qualified job or turned down a promotion. Half (50%) have reduced their hours to care suggesting that among those currently juggling work and care, many have already taken steps to reduce paid work and will have limited choices if their caring responsibilities increase.

7 in 10

70%



of working carers **have used their annual leave to care** and almost half (**48%**) have **done overtime to make up hours spent caring**.

“

I had to reduce my hours at work as there were no care facilities for my son.

”

“

I had to reduce my working hours because of my mum's health and now only work 11 hours per week and I am not entitled to any financial help. I gave up a wonderful job that I loved with an excellent salary.

”

“

I would have liked to work but feel the choice has been taken away by my role at home.

”

“

I just cope with the stress and the guilt and work all hours I can to make up for it.

”

“

My caring role had an impact on my employers considering me for promotion – it was very frustrating, as I knew I was more than capable of a different role.

”

“

My career choices were limited because of my caring role. I gave up jobs I loved because they couldn't fit round caring role.

”

⁵ Census 2011


Top three things that carers say would have helped them remain in work alongside caring

54% 

More support from care workers coming to the home of the person they care for

45% 

Support with household chores such as help with shopping

34% 

Support with managing or coordinating care

Of those who gave up work, retired early or reduced working hours, 69% said the stress of juggling work and care was a contributing factor, 31% said it was because there are no suitable care services and 21% said care services are too expensive. 16% said that the leave available from work was insufficient to be able to manage caring alongside work and 18% were unable to negotiate suitable working hours.

What would make the difference in enabling more people to remain in work alongside caring? Carers who have given up or reduced hours to care were asked to name the top three things they felt would have helped them stay in work. More support from care workers coming to the home of the person they care for was the top choice of most carers (28%) and 54% of carers put it in their top three. 45% of carers put support with household chores such as help with shopping as a top three priority and one third (34%) put support managing or coordinating care in their top three. This underlines that it isn't only those providing personal care that are seeing an impact on their ability to stay in work but also those arranging and organising care for loved ones.

Responses from carers who have received a carer's assessment this year suggest that support with remaining in work is still not being sufficiently considered when local authorities look at the support that carers need. Nearly a third (31%) of working carers felt that the support they need to manage work and care or to return to work was not properly considered in their assessment.

These findings should inform commissioners of care and carer support services who are looking to shape a local market of care services that meet the needs of carers and those they support.



“

Night duty was the only shift I could work. It meant I earned more than the allowed threshold meaning I lost Carer's Allowance, so worked for very little extra.

”

“

It's impossible to afford enough care to cover all the holiday periods.

”

Carers' expectations and priorities

In the next year, half (54%) of carers expect their quality of life to get worse, while only 6% think it will get better.

Carers UK wants to see carers' priorities reflected in the agendas of all the UK's legislatures and in the new cross-government Carers Strategy in England.

- 1** Improve financial support so that carers and their families do not suffer financial hardship as a result of caring.
- 2** Greater investment in social care and health funding is urgently needed to ensure that new legal rights for carers being introduced have the finances behind them to make life better for carers. Carers UK is calling for a sustainable funding settlement to meet the needs of our ageing society.
- 3** Improve carers' health. Carers UK is pressing for a duty on NHS to identify carers and measures to make hospitals and other health settings more carer friendly and to increase funding for carers' breaks.
- 4** Strengthen rights for carers who want and need to juggle work with care with more statutory rights to time off from work to care.



54%



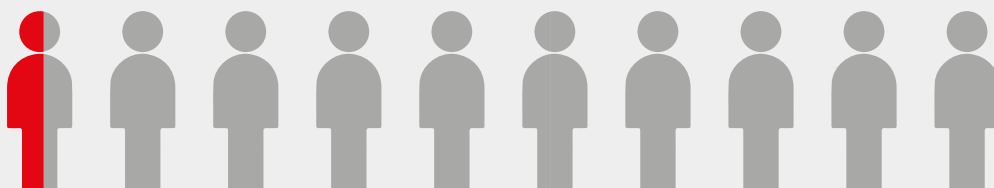
Half of carers **expect their quality of life to get worse** in the next year.

As well as a long term policy agenda to improve support for carers, action on the following in the next year would make a difference to carers' lives:



- New governments in Scotland, Wales and Northern Ireland to commit to putting carers at the top of their policy and legislative agendas.
- The NHS building on existing carer friendly policies by introducing carer passports in every hospital trust or board and ensuring GP practices are identifying and improving carers' quality of life.
- NHS trusts jointly reviewing hospital discharge practices with local authorities/Health & Social Care Trusts and community health services to ensure that carers are identified, consulted and properly supported when the person they care for leaves hospital.
- Local authorities/Health & Social Care Trusts reviewing their practices to support carers, including waiting times for assessments and how information and advice could reach carers earlier and more quickly for example, by exploring digital communication methods.
- Governments setting out clearer expectations of how quickly a carer's assessment should be carried out.
- Many more local authorities/Health & Social Care Trusts and employers working with Employers for Carers and Carer Positive in Scotland, for example, to boost workplace support for carers supporting carers to remain in and return to work.
- Any new policy decisions on older and disability welfare policies to consider the impact on carers and carers' incomes to ensure that they support caring rather than penalise carers for looking after relatives and close friends.
- In light of the rise in the National Minimum Wage, the earning threshold for carers should be increased with a commitment to align future increases.
- As one of the UK's largest employers the NHS has a key role to play from the individual GP practice, to the largest NHS Trust or board, in supporting staff to stay in employment. A similar role could be played by the care industry in looking after its own care workers to retain valuable staff.
- Regulations and guidance for the Housing and Planning Bill should ensure that the needs of carers are recognised in changes to housing policy in England.

Only **6%**



of carers expect their **quality of life to get better** in the next year.

Appendix

A total of 6,149 carers and former carers responded to Carers UK's annual State of Caring Survey between March and April 2016.

Only responses for the 5,682 current carers who completed the survey are included in this report as it is designed to provide a snapshot of caring in 2016. 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, disabled themselves and caring for a high number of hours every week.

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

- 78% live in England, 9% live in Scotland, 8% live in Wales and 5% live in Northern Ireland
- 78% are female and 22% are male
- 26% consider themselves to have a disability
- Only 1% are aged 0-24, 4% are aged 25-34, 12% are aged 35-44, 27% are aged 45-54, 35% are aged 55-64, 17% are aged 65-74 and 5% are aged 75 and over
- 19% also have childcare responsibilities for a non-disabled child under 18
- 31% are in work (14% full-time and 17% part-time)
- 35% have been caring 15 years or more, 16% for between 10-14 years, 24% for 5-9 years, 23% for 1-4 years and just 3% have been caring for less than one year
- 52% care for 90 or more hours every week, while 16% care for 50-89 hours, 21% for 20-49 hours and 10% care for 1-19 hours a week
- Most (75%) care for one person, 19% care for two people, 4% for three people and 1% care for four or more people



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