

State of Caring 2015



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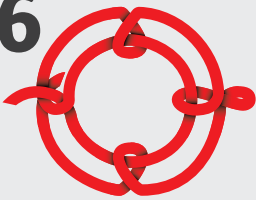
50
years of making
life better

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State of Caring 2015

Carers UK carries out an annual survey of carers to build a picture of the state of caring in the UK. This year over 4,500 people shared their views and experiences on what life is like for carers in 2015.¹



¹ As this report provides a snapshot of caring in 2015, 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 2015

Over the next five-year Parliament, 10.6 million people will take on a new caring role for a disabled, older or seriously ill relative or friend.² In 2015, the 50th year of the carers movement and the 50th anniversary of Carers UK what can carers expect and what are their experiences?

Caring is something that, increasingly, affects us all at some point in our lives, whether we find ourselves looking after someone we love, or we need some support ourselves; it is a normal part of life. However, caring without enough support in place can have a huge impact and it is taking its toll on millions of families throughout the UK. Whether caring is full-time, or it is part of a stressful mix of work and other family responsibilities, many carers find they don't have the time or energy to maintain relationships, stay in work, or look after their own health and wellbeing.

Our rapidly ageing population and longer life expectancies mean that the number of older people in need of care and support is estimated to outstrip the number of working age family members able to provide it as early as 2017.³ The number of people caring around-the-clock is already growing rapidly; there has been a 25% increase in the number of carers providing 50 or more hours a week of unpaid care in just 10 years.⁴

More of those born with disabilities are surviving into adulthood and later life and many are surviving serious illness like cancer or stroke yet the number of us living with long-term conditions is increasing creating new demands for our health and care service.

This demographic challenge requires a clear and urgent response from national and local government, health and care services and employers. Carers' huge contribution to society needs to be recognised and more must be done to put the financial, practical and

workplace support in place that they urgently need. Without this support, more and more carers will reach breaking point, with devastating results for families and our health and care system which has to step in when they cannot continue to care any longer.

Despite this, economic and societal circumstances continue to put pressure on families. Difficult economic conditions have led to a reduction in spending in critical public services like social care. Spending on social security has also slowed as the implementation of the Welfare Reform Act has reduced the number of carers receiving the main carers' benefit, Carer's Allowance. The introduction of criteria for Housing Benefit in the social sector and the localisation of support with Council Tax has left many carers struggling with the cost of living.

Yet, legislative change across the UK is giving carers the strongest ever recognition and right to support from the care system and UK party political manifestos have all included commitments to improve the lives of carers.

To make these rights a reality and fulfil these commitments, the experiences of carers must be listened to and a new dialogue must begin about how the Government, employers and society can better support families who care. This report provides a snapshot of what caring is like in 2015 for millions of people across the UK, setting out the impact that caring has on their lives and the evidence to inform this dialogue and policies that can make a real difference to carers.

² Carers UK (2014) Need to know; Transitions in and out of caring: the information challenge, based on analysis by Dr Michael Hirst, Social Policy Research Unit, University of York

³ Pickard, L. 'A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032', Ageing and Society (2013)

⁴ Census 2011 and Census 2001, Office for National Statistics

Practical support

Practical support with caring, such as help from care workers in the home or replacement care for the person they care for, is essential for many carers to be able to work alongside caring if they want to, juggle other family responsibilities such as childcare and to have a life of their own outside their caring role. Without this support, carers are often pushed to breaking point and have to give up work, stop caring, or even go into hospital themselves.

New rights for carers in the Care Act 2014 and Children and Families Act 2014 in England and forthcoming legal change in Wales and Scotland, should make it easier for carers to access the essential help and support they need.⁵ However, there is clear evidence that the number of carers receiving carer's assessments and services to help them care is falling, despite the rapid increase in the number of carers.⁶

Almost a third (32%) of respondents to our survey said that they or the person they care for have experienced a change in the amount of care and support services that they receive. Of those, a third (33%) said it was because they didn't need the service anymore or that the amount of support they receive has increased.

However, 42% said the amount of care and support arranged by social services has been reduced, 12% 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.

Over half (55%) of carers say that they are worried about the impact of cuts to care and support services over the next year.

Over half of carers

55%



say that they are **worried about the impact of cuts to care and support services over the next year.**

⁵ In Wales the system continues to operate on current Community Care legislation until the Social Services and Well-being (Wales) Act come into force in April 2016. In Scotland the Scottish Parliament is considering new legislation, the Carers Bill. In Northern Ireland the Carers and Direct Payments Act (NI 2002) places a requirement on Health and Social Care Trusts to make sure carers know about their right to a carer's assessment.

⁶ HSCIC RAP returns

“

The local authority responded to my breakdown and assessed Mum for residential care as I could no longer cope. They were wonderful... Now I can enjoy the time Mum has left and can walk away when her dementia means she becomes emotionally aggressive towards me.

”

“

I have an additional care worker to feed my wife her evening meal, which I prepare, thus enabling me to enjoy a hot meal at the same time.

”

“

Play schemes and youth clubs have all closed. Respite care has been reduced. This has had a huge impact on my daughter's ability to socialise and I am simply tired all the time now.

”

“

I have had a stroke and my own care needs have changed. I am now disabled but I still get no support.

”

“

My daughter has a number of days per year respite. This is a vital part of our and her life. The break for both parties is essential. However with the continuing local government cut backs it is very uncertain whether we will get any respite in the future.

”

Quality of care

It is not only access to care services which is important for carers. Carers UK's research⁷ has shown that the quality of social care services is also crucial. Carers need to know that their parent, child or partner is in good hands when they are at work, providing childcare or taking some time for themselves. If services are unreliable or poor quality then arrangements break down, leaving carers to pick up the pieces.

Over half (53%) of carers responding to our survey have experience of social care services such as home care or respite care. Of these, 27% report positive experiences of these services (7% excellent and 20% good) while 21% report negative experiences (8% bad and 13% terrible). Half say that their experiences have been mixed (42%) or fair (10%).

This shows that there is lots of good care out there which can make a big difference to people's lives, but that there is also far too much poor quality care which carers cannot rely on. In fact, a third (33%) of carers with experience of social care services say that they have refused or stopped using a service altogether because of concerns over quality.

Over a quarter

27%



of carers with experience of social care services such as home care or respite report **positive experiences**.

A third

33%



said that they had **refused or stopped using a service altogether because of concerns over quality**.

“

The last time my son was put into respite care he was neglected and abused. I was supposed to have had a week's leave but ended up sleeping just 23 hours in 7 days because my son kept ringing me, begging me to come and get him. I had to arrange a taxi for him in the end and cut the break short.

”

“

Home care [quality] depends on the individuals. Some are great but it is just a job to some. The training doesn't seem to be adequate and many care workers seem to be overworked so there is a very high staff turnover and this leads to poor care.

”

“

Carer workers are good but on zero-hour contracts. The service providers just don't care.

”



⁷ Carers UK (2014) Quality of care and carers: How quality affects families, employers and the economy

Health and wellbeing

Without the right support in place, carers often find their own health and wellbeing suffering as a result of the care they provide. By putting their loved one first, carers can put their own needs last, struggling to find time to exercise, eat healthy meals, see friends and family, or even see the doctor. This year's survey has again found that this is having a knock-on impact on carers' physical health, mental health, and relationships with others.

82% of carers report that caring has had a negative impact on their health, 2% more than in 2014. Three quarters (74%) of carers find it difficult to get a good night's sleep (5% more than last year) while nearly half (47%) struggle to maintain a balanced diet. Four in ten (41%) have experienced an injury or their physical health has suffered as a result of caring.

This has consequences for carers' mental health, with a worrying 84% saying they feel more stressed, 78% saying they feel more anxious, and 55% reporting that they have suffered from depression as a result of their caring role – significantly more than in 2014.⁸

Over three quarters (76%) of carers responding to our survey are concerned about the impact of caring on their health over the next year.

Over three quarters

76%



of carer are **concerned about the impact of caring on their health over the next year.**

“

The last full night's sleep I had was in 2009. I have torn ligaments in my leg and I've damaged my back and both knees. I'm mentally exhausted and depressed, very isolated and lonely.

”

“

I suffer from depression and anxiety. Trying to juggle work, being a mum and the additional needs of two kids on the spectrum has had a knock-on impact on my own wellbeing and coping ability.

”

“

At present I am recovering from a cancer operation and still have to care for my husband as he won't go into respite care.

”

“

I have lost weight over the last 12 months and most of my clothes are falling off me. This has not helped my self-esteem. I feel both mentally and physically exhausted.

”



⁸ In 2014, 82% said they felt more stressed, 73% felt more anxious and 50% stated they were affected by depression

Isolation and loneliness

Carers UK's research⁹ has found that many carers experience social isolation and loneliness as a result of caring. This may be because they cannot afford social activities anymore, because caring without enough support means they do not have the time to see friends and family, or because it feels like no-one understands what they are going through.

This is reflected in the State of Caring Survey 2015, with well over half (62%) of those carers who are struggling to make ends meet saying they are cutting back on seeing friends or family to save money.

Over half (53%) of respondents say that they are concerned about the impact of caring on their relationship with the person they care for over the next year and 3 in 5 (61%) are worried about the impact their caring role will have on relationships with their friends and family over the next year.

Three in five

61%



are worried about the **impact their caring role will have on relationships with their friends and family** over the next year.

“

We don't go out much anymore. My husband can't walk far now so beloved country walks are no more. Stairs are a barrier and the wheelchair is hard to push and hurts my back. If my husband is not feeling well, I don't sleep well for fear of him wandering off in fugue state. I'm feeling trapped in the house.

”

“

I'm worried about becoming more isolated and finding it increasingly difficult to maintain relationships.

”



⁹ Carers UK (2015) Alone and caring: Isolation, loneliness and the impact of caring on relationships

Financial hardship

When people take on a caring role they often face a steep drop in income if they have to leave work or reduce their hours to care – sometimes a double loss of salary if they are caring for a partner who also has to give up work as a result of their illness or disability.

This is often coupled with a steep rise in expenditure as a result of the additional costs of caring and disability. 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.¹⁰ This is combined with the impact of welfare reform which has hit many families hard.

Nearly half (48%) of carers who responded to our survey are struggling to make ends meet. Worryingly of those struggling to make ends meet, 41% are cutting back on essentials like food and heating, 26% are borrowing from family and friends and 38% are using up their savings to get by – suggesting that the squeeze on carers' finances is not sustainable in the long term.

Of carers responding to our survey, 45% say that financial worries are affecting their health. Over half (52%) are worried about the impact of cuts to social security over the next year and a similar number (54%) are worried about their finances.

Nearly half

48%

of carers are **struggling to make ends meet.**



“

I get very stressed if anything needs repairing in the house or the car because I need to try to find the money to pay for it.

”

“

The shock of living on benefits meant that I got myself in trouble with household bills as I wasn't prepared for the big financial difference...

”

“

I spend as little as possible. I only buy reduced food where I can. I had been saving for a house since I was 18, so all that money has been used up by caring. I have no life. I only spend what I must and it depresses me to live like this.

”

“

We have no savings left, no private pension or life insurance. We are older and feel the cold but are frightened to put the heating on and my wife and I are in bad health

”

“

Our life is less than it would have been without the loss of income caused by illness and disability, and my partner's loss of employment. We are not struggling but we have made cutbacks and manage our needs carefully

”

¹⁰ Carers UK (2014) Caring & Family Finances Inquiry: UK Report

“

At the end of this week I had £6.50 left in my bank account! If it was not so serious it would be laughable.

”

“

I am selling things I own to pay for needed care items.

”

“

Caring has used up all of the saving we had for our retirement

”



Caring and work

Over three million carers in the UK combine work with their caring responsibilities, including over two million who are working full-time.¹¹ It can often be extremely difficult to juggle these responsibilities. When there is a lack of support to help with caring at home or a lack of understanding and flexibility at work, it can lead to stress and anxiety, absence, tiredness, isolation and loneliness.¹²

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, over two thirds (68%) have used their annual leave to care and 46% 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 (51%) of carers responding to our survey have given up work to care and 12% have retired early to care. A fifth (21%) reduced their working hours while 13% have had to take a less qualified job or turned down promotion to fit around caring.

Of those who gave up work, retired early or reduced working hours, 65% said the stress of juggling work and care was a contributing factor, 30% said it was because there are no suitable care services and 22% said care services are too expensive. 15% 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.

Six in ten (60%) working carers are worried about their ability to remain in work over the next year.

Six in 10

60%



working carers are **worried about their ability to remain in work over the next year.**

“

I am unable to work due to my caring role. It is not my daughter who has this impact on me, but the lack of support we both get from family, society and services.

”

“

Because of caring, I have not been able to get a job for nearly twenty years. I am now 54 and really want a job, but my health is now so shot through because of caring...I feel there is no prospect of me ever getting another job in my life and consequently I will have nothing live to on in my own old age.

”

“

I keep trying to work – by giving up on sleep and time off I do manage to produce a handful of projects a year, but never enough to pay the bills.

”

“

I had to give up full-time work after working for 34 years due to severe depression and anxiety; my caring responsibilities were a significant factor.

”

“

I do feel that the stress and worry I have doesn't help in my job but I try to carry on as normal.

”

¹¹ Census 2011, Office for National Statistics

¹² Carers UK and Employers for Carers (2015) Caring and isolation in the workplace: Impact report and recommendations

Making life better for carers

Priorities for the new Government

In the State of Caring Survey 2015, Carers UK asked carers to choose only one issue that they would like the new Government to make a priority.

Two in five

40%



respondents said that the **most important thing for the new Government is to ensure carers and their families do not suffer financial hardship as a result of caring.**

Three in ten

29%



carers say that the biggest issue for them to **ensure there is sufficient funding for the social care system so that older and disabled people get the care they need.**

Carers also left messages that they would like to give the new Government. These included:

“

Please look at increasing Carer's Allowance so that carers no longer feel worthless.

”

“

Realise that carers do the job out of love and devotion but need support to do this.

”

“

Not everyone was born into a financially secure family and we want to be seen as an important part of society, not a football to be kicked around.

”

“

Please ensure that local government has sufficient funds for affordable or free care which is of good quality and which is closely aligned to health services. And please, please see that hospitals are equipped to deal with elderly and disabled people and actually notice that they are different and need extra help

”

“

Caring should be an essential part of the nation's fabric. Care, concern and respect for others must be the cornerstone for a nation's health and its subsequent wealth.

”

Government priorities (cont.)

In the next year, half (50%) of carers expect their quality of life to get worse, while only 5% think it will get better.

52%

of all carers responding to our survey **are worried about cuts to social security**



55%

are worried about cuts to care and support services



60%

of working carers **are worried about their ability to remain in work**



76%

are concerned about the impact of caring on their health



54%

are worried about their finances



Carers are clear that more must be done to make sure they have the financial and practical support in place that they need to care safely and well, work if they want to, juggle other commitments such as childcare, maintain relationships, and to live a life of their own

outside of their caring role. Government must take urgent steps to make carers a priority now and over the next Parliament to meet the demographic challenge and ensure that by 2020 all carers have reason to be optimistic about their future.

Taking forward priorities for carers in the next Parliament

Carers are clear that they are looking to the new Government to bring forward policies that will make a positive difference to their lives. All political parties made commitments for carers as part of their 2015 election manifestos and Carers UK wants to see these promises become a reality and is pressing for changes to:

1

Improve financial support so that carers and their families do not suffer financial hardship as a result of caring

Carers need more, not less financial support and Carers UK will campaign for urgent measures to improve the level and structure of Carer's Allowance

2

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

Greater investment in health and social care funding is urgently needed to ensure that new 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 ring-fence spending on carers' breaks.

4

Strengthen rights for carers who want and need to juggle work with care

Carers UK is seeking the introduction of a statutory right to period of Care Leave so employees can take 5-10 days extra leave for their caring responsibilities.

A total of 4,935 carers and former carers responded to Carers UK's annual State of Caring Survey between February and April 2015.

Only responses for the 4,572 current carers who completed the survey are included in this report as it is designed to provide a snapshot of caring in 2015. 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 2015 who are currently caring:

- 78% live in England, 10% live in Scotland, 8% live in Wales and 5% live in Northern Ireland
- 78% are female and 22% are male
- 27% consider themselves to have a disability
- Only 1% are aged 0-24, 5% are aged 25-34, 16% are aged 35-44, 31% are aged 45-54, 31% are aged 55-64, 13% are aged 65-74 and 3% are aged 75 and over
- 22% also have childcare responsibilities for a non-disabled child under 18
- 31% are in work (13% full-time and 18% part-time)
- A third (34%) have been caring 15 years or more, 17% for between 10-14 years, 24% for 5-9 years, 22% for 1-4 years and just 2% have been caring for less than one year
- The majority (56%) care for 90 or more hours every week, while 17% care for 50-89 hours, 20% for 20-49 hours and 8% care for 1-19 hours a week
- Most (77%) care for one person, 17% care for two people, 4% for three people and 2% care for four or more people.



Carers UK
20 Great Dover Street
London SE1 4LX

T 020 7378 4999

E info@carersuk.org

carersuk.org



@carersuk



/carersuk

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