

State of Caring 2015



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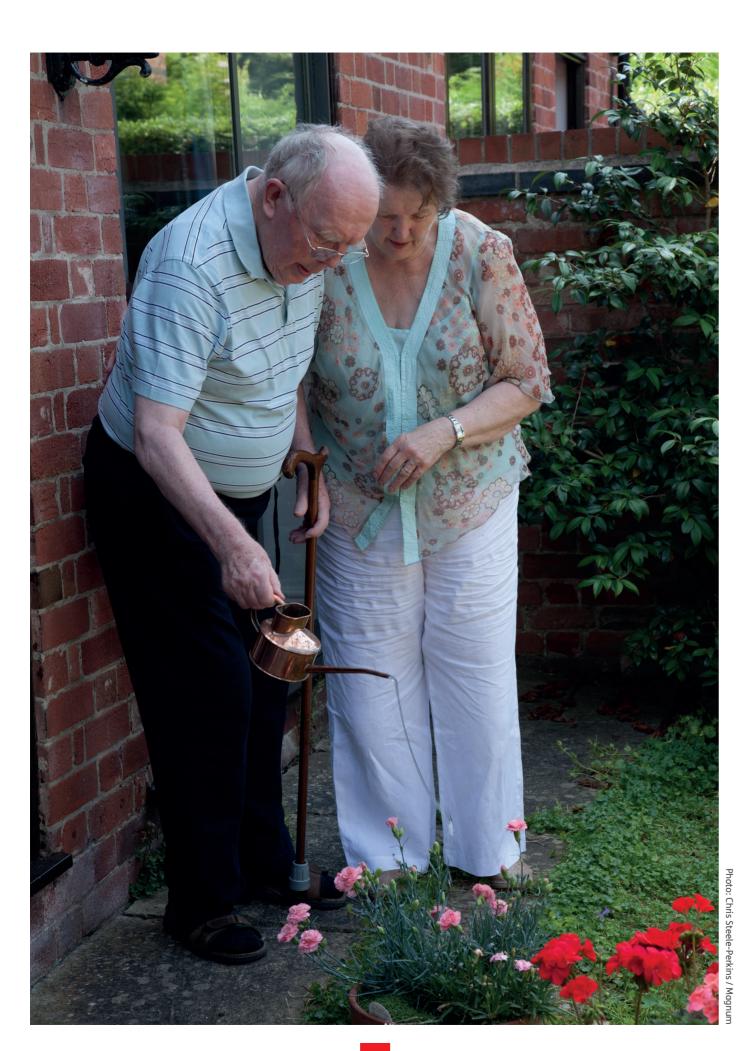
Carers UK carries out an annual survey of carers to build a picture of the state of caring in the UK. 294 people in Wales shared their views and experiences on what life is like for carers in 2015.¹



Photo: Chris Steele-Perkins / Magnum

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 in Wales 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 life is like in 2015 for carers across Wales, 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 Wales will come into force in 2016 in the Social Services and Well-being (Wales) Act 2014. This should make it easier for carers to access the essential help and support they need. 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

In Wales, 35% of respondents 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, almost a third (31%) said it was because they didn't need the service anymore or that the amount of support they receive has increased.

However, 43% said the amount of care and support arranged by social services has been reduced, 8% 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 14% said that the care or support service was closed and no replacement was offered.

Over half (51%) 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



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

I get three days of day centre but I can only get mam there once a week.

I referred myself to the Social Services Department three years ago. They picked up the case one year ago and still no package of support in place.

My son's use of daycentre will be ending soon. I do not know what will be offered instead.

We no longer receive appointments from the Memory Clinic. I've phoned twice but nothing has happened. There is no 'joined up' thinking and/or link with our GP.

I tried to get help from the local authority and from my GP but was told all they can do is provide a list of care agencies that would require payment.

Some care providers we have used in the past have not had the expertise needed to provide the right service to meet my son's needs.

"

Quality of care

It is not only access to care services which is important for carers. Carers UK's research⁶ 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 (55%) of carers responding to our survey have experience of social care services such as home care or respite care. Of these, 11% report positive experiences of these services (3% excellent and 9% good) while 9% report negative experiences (6% bad and 6% terrible). A third say that their experiences have been mixed (28%) or fair (6%).

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, just under a quarter (24%) of carers with experience of social care services say that they have refused or stopped using a service altogether because of concerns over quality.

They have a tendency to be unreliable and will not take advice from hospital clinics.

No continuity. All we want is regular visits from care workers and our morning call to be at 8am instead of 6.40am.

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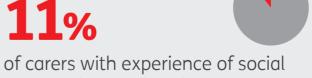
We are left to struggle on.

22

I was told by social services that no help is available.

The care worker who attends is excellent but our experience with social services to get the care has been poor.

A tenth



care services such as home care or respite report positive experiences. A quarter



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

5 HSCIC RAP returns

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⁶ 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.

80% of carers report that caring has had a negative impact on their health, 1% more than in 2014. Three quarters (73%) of carers find it difficult to get a good night's sleep (3% more than last year) while over half (51%) struggle to maintain a balanced diet. Four in ten (36%) 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 87% saying they feel more stressed, 79% saying they feel more anxious, and 56% reporting that they have suffered from depression as a result of their caring role – 6% more than in 2014.8

Over three quarters (75%) of carers responding to our survey are concerned about the impact of caring on their health over the next year.

Three quarters

75%



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

44

I do not have enough time to do everything that needs to be done, therefore I get stressed.

"

66

I am getting close to depression and all the doctor says is 'go for a walk'. That's OK if you can leave the person you care for!

22

44

My blood pressure has rocketed.

"

66

I have no time to myself at all any day.

"



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 just under half (47%) 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 (56%) 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.

66

I felt very depressed, anxious and lonely.

"

4

People get tired of you having to cancel and stop inviting you.

"

66

Caring has altered my relationships with friends and neighbours.

71

66

Caring is my life. I have no room for anything for me, like hobbies.

22



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

Three in five



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

(

 $^{^{\}rm 8}\,$ In 2014, 83% said they felt more stressed, 78% felt more anxious and 50% stated they were affected by depression

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 adaptions. This is combined with the impact of welfare reform which has hit many families hard.

Over half (53%) of carers who responded to our survey are struggling to make ends meet. Worryingly of those struggling to make ends meet, 36% are cutting back on essentials like food and heating, 17% are borrowing from family and friends and 32% 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, 48% say that financial worries are affecting their health. Just under half (46%) are worried about the impact of cuts to social security over the next year and over half (57%) are worried about their finances.

Over half 53%

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

66

It takes very careful budgeting with no luxuries.

"

66

Paying for additional care is expensive and has reduced my ability to finance my own old age, whatever my health.

71

66

We live on benefits and have to always be careful what we spend money on. We never go out socially.



66

All our savings have gone and I have been selling sentimental items left to me by my mother and father which I will never be able to replace.

"

66

I manage my bills but that is all. There is nothing for replacing household items and clothes.

"



Photo: Chris Steele-Perkins / Magnum



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, just under half (44%) have used their annual leave to care and 28% 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 14% have retired early to care. A fifth (18%) reduced their working hours while 14% 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, 64% said the stress of juggling work and care was a contributing factor, 32% said it was because there are no suitable care services and 21% said care services are too expensive. 18% said that the leave available from work was insufficient to be able to manage caring alongside work and 12% were unable to negotiate suitable working hours.

Almost a quarter (23%) working carers are worried about their ability to remain in work over the next year.

Almost a quarter

23%

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

11 Census 2011, Office for National Statistics

66

My role was terminated due to illness/stress, caused mainly by caring role.

"

66

I was offered an early retirement deal by my employer and could take my pension early.

"

66

My partner's health is too variable to work at the moment.

"

66

I HAD to care full time. I didn't want to but had no other option.

"

Making life better for carers Priorities for the new UK Government

In the State of Caring Survey 2015, Carers UK asked carers to choose only one issue that they would like the new UK Government to make a priority. This is what carers in Wales told us:

Just under half

44%

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

27%

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:

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

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66

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

"

66

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.

"

44

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

"

66

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.

"

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

Government priorities (cont.)

In the next year, half (53%) of carers expect their quality of life to get worse, while only 4% think it will get better.

47%

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









51%

are worried about cuts to care and support services



23%

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



75%

are concerned about the impact of caring on their health



58%

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.

Appendix

A total of 294 carers across Wales responded to Carers UK's annual State of Caring survey between February and April 2015.

Only responses for the 294 current carers who completed the survey are included in this report as it is designed to provide a snapshot of caring in Wales 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:

- 81% are female and 19% are male
- 32% consider themselves to have a disability
- Under 1% are aged 0-24, 7% are aged 25-34, 14% are aged 35-44, 32% are aged 45-54, 32% are aged 55-64, 11% are 65-74 and 3% are aged 75 and over
- 25% also have childcare responsibilities for a non-disabled child under 18
- 28% are in work (17% full-time and 11% part-time)
- A third (36%) have been caring 15 years or more, 15% for between 10-14 years, 20% for 5-9 years, 25% for 1-4 years and just 3% have been caring for less than one year
- The majority (58%) care for 90 or more hours every week, while 16% care for 50-89 hours, 20% for 20-49 hours and 8% care for 1-19 hours a
- Most (77%) care for one person, 16% care for two people, 3% for three people and 3% care for four or more people.





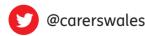
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