

State of Caring 2018



About the research

A total of 542 carers and former carers responded to Carers UK's annual State of Caring survey between March and May 2018.

Only responses from the 514 people currently providing care who completed the survey are included in this report as it is designed to provide a snapshot of caring in 2018.

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 2018 who are currently caring:

- 82% identify as female and 18% identify as male.
- 29% consider themselves to have a disability.
- 1% are aged 0-24, 4% are aged 25-34, 13% are aged 35-44, 31% are aged 45-54, 31% are aged 55-64, 15% are aged 65-74 and 5% are aged 75 and over. As fewer 1% of carers currently providing care who are under 18 took part in the survey, we have not explored results specifically for this group in the report.
- 4% are lesbian, gay or bisexual.
- 23% also have childcare responsibilities for a non-disabled child under 18.
- 31% are in paid work (45% full-time and 55% part-time).
- 33% have been caring 15 years or more, 15% for between 10-14 years, 22% for 5-9 years, 24% for 1-4 years and just 3% have been caring for less than one year.
- 56% care for 90 or more hours every week, while 17% care for 50-89 hours, 18% for 20-49 hours and 3% care for 1-19 hours a week.
- Most (74%) care for one person, 20% care for two people, 4% for three people and 2% care for four or more people.

As not all respondents completed every question in the survey, a number of the figures given in this report, including those presented in this Appendix, are based upon responses from fewer than 514 carers. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.

State of Caring 2018

Carers Wales, as part of Carers UK carries out an annual survey of carers to understand the state of caring in the UK each year.

In Wales a total of 542 people shared their experience of what it's like to be a carer. This is the largest State of Caring survey carried out by Carers Wales and Carers UK to date.



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Context: The state of caring in Wales in 2018

As we mark the 70th anniversary of our National Health Service, the shape and sustainability of our health and care system are understandably in the spotlight. Too often missing from this debate is the role family and friends play. It is frequently forgotten or, perhaps worse, taken for granted that the majority of care provided doesn't come from the NHS, social services or from care homes. It comes in the form of unpaid care which relatives, friends and neighbours provide, estimated to be worth £8.1 billion a year in Wales¹. As future funding and service models for health and social care statutory services are debated, that unpaid carers need to provide care, without putting their own lives on hold, must be at the heart of these debates.



A far greater role for the NHS itself in identifying and supporting carers must be given priority. The Carers Strategies (Wales) Measure was repealed during the legislative process for the Social Services and Wellbeing (Wales) Act 2014 and new strategic planning duties were placed on Local Health Boards and Local Authorities to work together in the Future Generations Act.

For 4 out of 5 carers their first point of contact with any statutory agency is generally within a primary care setting². We feel that the vital role within the NHS has now been lost in identifying carers to signposting them to support.

The Welsh Government's new A Healthier Wales Plan³ encourages care closer to home that will undoubtedly impact on family carers. It is imperative that carers are considered, are told about their rights and receive a comprehensive assessment of their needs which includes what aspects of care they are able and willing to do.

Healthcare staff are in a unique position to identify those who are in a caring role and direct them to support. As this research shows, this is a key priority for carers along with having the right information and equipment to enable them to care well and enable them to get regular breaks from caring

¹ Carers UK, University of Sheffield, University of Leeds (2015) Valuing Carers 2015 - the rising value of carers' support

² Carers Strategies (Wales) Measure 2010

³ <https://gov.wales/newsroom/health-and-social-services/2018/fund/?lang=en>

Rather than being given the financial and practical support to care, evidence from our previous State of Caring survey showed that many carers are finding breaks increasingly hard to access, 4 out of 10 (40%) of unpaid carers said they had not had a day off in over a year. Having more than a day was even rarer with 1 in 6 (62%) saying they had not had a weekend off in over a year and 83% said they had not had a week off in over a year.

Continuing rises in living costs, coupled for many with year on year freezes on means tested benefits means that for those struggling the most, making ends meet is getting more difficult. A welcome change from the Scottish Government means that carers in Scotland who receive Carer's Allowance will see an increase in the amount they get as it rises to the same level as Jobseeker's Allowance. Carers Wales and Carers UK continues to press for at least the equivalent rise for the rest of the UK with equivalent increases to carer premia to ensure that those on the lowest incomes benefit.

For those combining work and care, seeking work alongside caring or looking at returning to paid work after a period away for caring, there continues to be many challenges. Both employers and politicians are increasingly realising the need to support working carers.

Funded by the Welsh Government, the Wales Hub of Employers for Carers has been recently established by Carers Wales to support organisations based in Wales to be more carer-friendly.

There are more than 180,000 carers in employment in Wales so it is critical for employers to consider the impact this has on the individual, the workforce, the business and the economy.

Employers for Carers can help employers to support and retain the 1 in 9 people in the workforce.

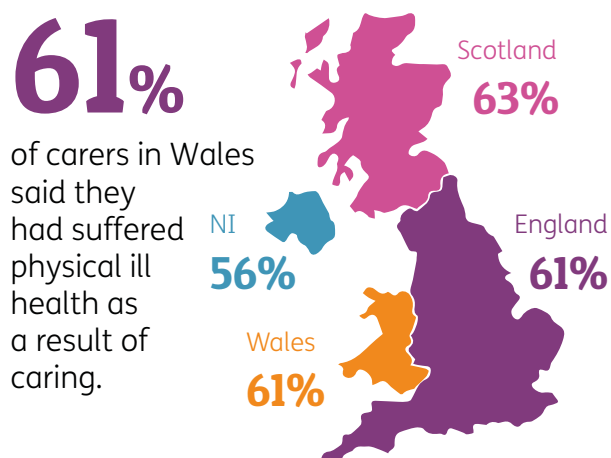
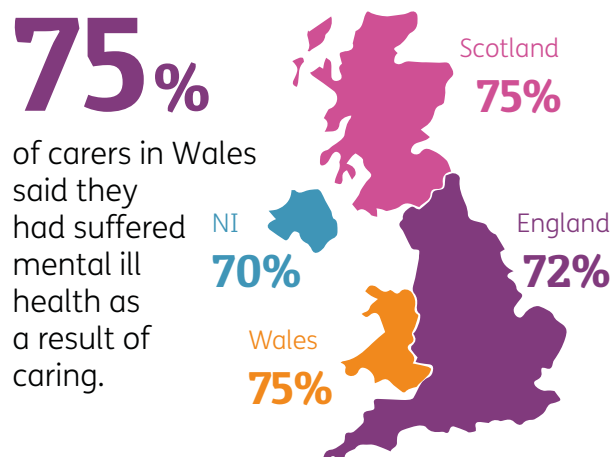
Members of Employers for Carers can access:

- Practical guides on supporting carers in your workforce
- Expert consultancy and training services
- The latest information on legal changes and employment policy
- Tips and guidance from other employers

It is vital we put in place what families and friends caring every day need to enable and support them to care without putting their own lives on hold. The weight of evidence and experience provided by the carers responding to this survey sets out clear priorities for action which our national and local governments, the NHS and employers must now take forward.



The impact of caring on health and wellbeing



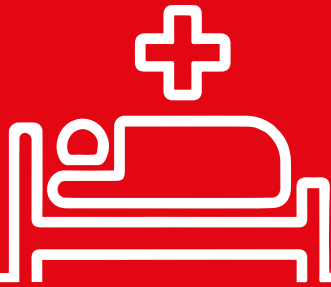
The support provided by Wales' unpaid carers is worth an estimated £8.1 billion per year – almost the Welsh Government's budget for health and social care in Wales.⁴ Yet the cost of caring on individuals is often high, taking a toll on carers' emotional and physical health. The NHS and social care sector relies on family and friends, but we regularly hear carers say that they feel little attention is paid to them in terms of being identified, valued and supported.

Three quarters (75%) of respondents to the State of Caring 2018 survey who are currently providing care said they had suffered mental ill health such as stress or depression as a result of caring, while well over half (61%) said their physical health had worsened as a result of caring.

⁴ Carers UK, University of Sheffield, University of Leeds (2015) Valuing Carers 2015 - the rising value of carers' support

The NHS at 70

This year, the National Health Service is turning 70 years old. We asked carers to choose their top priorities for what the NHS should be doing for carers over its next 70 years.



Overall, carers were most likely to prioritise the following:

- Routinely identifying and supporting carers
- Recognising and valuing the knowledge that carers have and treating them as partners in care
- Giving carers the right information, training and equipment at the right time to be able to care well and safely, and
- Making sure GPs offer more to carers and routinely register them

68% of carers in Wales said their GP was aware of their caring responsibilities. 34% were offered a free flu jab but 50% said they were not offered any further advice, information, support or where to could go for help.

What carers want from the NHS



Valuing the role of carers by ensuring we are appropriately supported



Listen. We know just as much as you... sometime we are right too



Acknowledge carers contribution and support it



Listen to us! Really listen, not just listen and then disregard what we say



Be recognised for the fantastic work we do. Be given regular respite



Work closer with in-house NHS departments so less duplication of trivial paper chasing and quicker responses to carer issues



Practical support with caring

Practical support from health and care services is essential for carers, helping them to manage their caring responsibilities and to maintain their health and wellbeing.

We asked carers what type of support they receive or buy. The most common support that carers reported was equipment in the home of the person they care for, such as hoists, grab rails or easy-grip handles on taps which over half (53%) of respondents said they receive or buy. Other leading practical support that carers reported receiving or buying included:

- Help from family and friends (29%)
- Technology like alarms, sensors or remote monitoring (29%)
- Practical support from care workers coming in to help (25%); and
- A motability vehicle (22%)

Despite a number of carers buying or receiving this practical support, however, these figures also reveal the large numbers of carers who are missing out on help. Indeed almost a quarter (22%) said they receive or buy no support to manage their caring responsibilities.

We know that in some instances carers refuse health and care support because of concerns over quality, suitability or not wanting or needing help. Disappointingly, a quarter (25%) who responded to the State of Caring survey this year said that they had refused support because of quality or suitability.



Tried to get away for a short break, but my husband not confident for me to go



My son had a PA who took him out for 6 hours a week for me to have respite. This is no longer in place since February



I worry about how well my mother and mother in law will be looked after when I'm not here



The sort of care I provide could not be duplicated, I would not be able to relax



Family members give me occasional breaks



a quarter

25%



of carers who responded to the State of Caring survey this year said that they had refused health and care support due to concerns over quality

Experiences of carers needs assessment



A Carers Needs Assessment provides an important opportunity for carers to get access to information, help and support from their local authority.

Disappointingly 61% of respondents told us that they have not been offered or requested a carer's assessment in the last twelve months.

This figure and carers experiences very much echoes what carers told us about their experiences of Carers Assessments in our Track the Act Briefing 3⁵. 54% of carers who responded to the Track the Act survey 2018 said they had not been offered or requested a carers needs assessment.



Social Services were obstructive when I cared for three disabled people and refused to do a carer's assessment



I think it was just taken for granted. The Assessment seemed to be focussed on my husband's main needs but not mine. I thought the Assessment was for me the carer, so was a bit confused



The Assessment wasn't done as we didn't want to do it over the phone and the assessor didn't seem to care that we'd prefer a visit. I don't think they'll call anymore

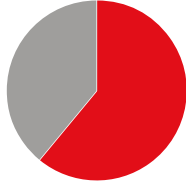


⁵ Track the Act Briefing 3 – Monitoring the 2nd year of implementation of the Social Services and Well-being (Wales) Act 2014 – Carers Wales 2018

The majority
of respondents

61%

said they had not
been offered or requested a Carer's
Assessment in the last 12 months



CC

The Assessment was quite thorough but what it lacked was the possibility of hands-on support for carers especially at a time of crisis, a shoulder to cry on as it were, with some practicalities. The actual person who did the assessment was very caring, sympathetic and efficient

DD

Over half of carers

54%

who responded to the Track the Act
survey 2018 said they had not been
offered or requested a carers
needs assessment



CC

Nothing, but nothing has changed following the 'chat' I had with the social worker. No cognisance was taken of the fact that I am 75 and still picking up the tab which is having huge financial, physical and emotional effect on me

DD



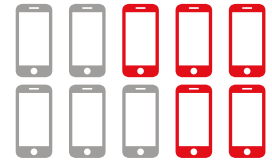
Support from technology

We asked carers whether they were aware of any technology that can support them with care and caring. Across Wales, almost (40%) of carers said that they were aware of this kind of technology. Half (49%) of respondents, meanwhile, said that they or the person they care for uses technology to support their caring and/or care.

Across all groups, using the internet as a source of information was the most commonly used form of technology with 85% of carers reporting this. 41% said that they used the internet as a form of communication or online support.

Almost half

49%



of respondents said that they or the person they care for uses technology to support their caring and/or care.

85%



of carers said using the internet as a source of information was the most commonly used form of technology



Costs of caring

Despite the huge contribution that carers make to our society, Carer's Allowance remains the lowest benefit of its kind, at just £64.60 a week for a minimum of 35 hours (2018/19 rates). We regularly hear from carers and their families who are facing difficulties making ends meet and who are struggling to afford their basic living costs alongside the additional costs that are associated with caring.

Over a third of carers (34%) responding to our survey described their financial situation as 'struggling to make ends meet'.

Only half (48%) of carers in Wales said that they could afford their bills without struggling financially.

For those struggling financially 57% said they had to cut back on hobbies/leisure activities, 57% said they cut back on luxuries and 41% said they cut back on seeing family or friends.

Having to cut back on hobbies, leisure activities, and seeing family and friends can have a significant effect upon a person's wellbeing. More should be done to ensure carers have an adequate income to support themselves and to ensure that providing care does not jeopardise people's health and wellbeing and have a detrimental impact on carer's health.



Managing at the moment but am concerned



I manage because I have to but cannot afford holidays or to replace my car



I constantly juggle money and stress



I am forced to find part time work to afford the extra costs of my partners disability but this means I go for periods of time without any income that would be considered mine



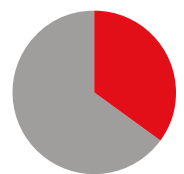
We cut our cloth accordingly, living very differently than when my husband was well and we were both employed



Over a third of carers

34%

described their financial situation as 'struggling to make ends meet'



Juggling work and care



Carers' financial situations are often negatively affected by the impact of caring on their ability to participate in paid work. Across the UK, 2.3 million adults report having given up work to care at some point in their lives and almost 3 million have reduced their working hours.⁶ Many carers face a lack of understanding from colleagues and managers. Working carers need a mixture of support, ranging 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 looked after.

1 in 3 of the carers who responded to our survey (31%) reported being in paid work. Women who responded to the survey (33%) were significantly more likely to be juggling their caring responsibilities with paid work than male carers 29%.

40% of carers in Wales reported that they had given up work to provide care, with a further 14% saying that they had reduced their hours of work in order to support the person they care for. 20% said they had taken a less qualified job or turned down a promotion as a result of their caring responsibilities or that they had retired early in order to provide care. 11% said that they work the same hours as they did before they started caring but that their job has been negatively affected by it as a result of tiredness, lateness or the impact of stress.

Only 4% of carers responding to our survey said that caring has had no impact upon their capacity to work.

⁶ YouGov and Carers UK (2013).



Overall those carers struggling to make ends meet 52% and those caring around the clock 48% were the most likely to report having given up work to care.

“

I had a temporary flex arrangement with my employer but I was informed that it would not work for the business and I would have to leave July 2018 after a member of staff returns from maternity leave

”

“

As my own boss I can be flexible with working but it means there is no income if I'm not working

”

“

There is no support available at all, in fact it has been made quite plain that time off for caring is not approved of

”

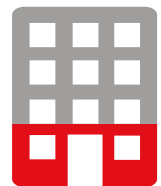
“

No carers policy. Equalities might be considering one. There is a policy for every damn thing but not for carers. Was told that existing various policies meet needs. Ummm no!

”

Overall, two fifths of carers

40%



reported that they had given up work to provide care, with a further 14% saying that they had reduced their hours of work in order to support the person they care for

Expectations of the future

We asked carers about their expectations for the future in terms of the practical support they receive with caring, their health and wellbeing and their ability to provide care, and their quality of life.

In terms of practical support with caring, as many as 1 in 4 carers (27%) said they are worried that the support they currently buy or receive might be reduced, while almost two thirds of carers said that they do not know what might happen with the support they currently buy or receive (65%).

When we asked carers about their expectations for their own health in the future, troublingly, the majority (55%) said that they expect their physical health to get worse in the next two years.

Carers expectations for their mental health and wellbeing were similarly discouraging, with over half of carers (57%) saying they expect their mental health to get worse in the next two years.

Those struggling financially to make ends meet 67% and those providing round the clock care 61% were also more likely than other groups to say they expect their physical health to get worse. Carers who said they were struggling financially to make ends meet were the most likely group to expect their mental health to get worse in the next two years (66%).

We asked carers about how they thought their mental and physical health would affect their ability to provide care in the future. Almost half of carers responding to the survey (45%) said they expect that they will be able to provide less or no care in the future because of poor current or future physical health, while over one third (37%) of carers said they expect that they will be able to provide less or no care in the future because of poor current or future mental health.

In terms of their quality of life in the future, disappointingly, (46%) said they expected their quality of life to get worse in the next 12 months. Only 9% said they expected it to get better.



I love to care but feel things are getting worse with no support



I have had to give up my caring responsibilities due to the strain it was putting on my health. I was at breaking point



The unpredictability of my son's needs alongside me having developed mental and physical health problems are all interlinked



I know I need to stay strong and healthy but it isn't always possible. It may be because I've too much to do



It will make it harder to continue to care but I will take more pain relief and continue as there is no choice



I worry that if my physical health deteriorates the whole family structure will collapse



Almost half of carers

46%



said they expected their quality of life to get worse in the next 12 months.

Only

9%



said they expected it to get better.



I am not young and ageing process will reduce my ability to provide care to the same extent



My mental health has suffered considerably. I now take anti-depressants to cope with stress and anxiety on a daily basis. I don't sleep well and worry constantly



Recommendations

The care provided by Wales' 370,000 carers cannot be taken for granted. Welsh Government must take the lead in coordinating action across local government, the NHS and employers in Wales. Welsh Government should also put pressure on the Westminster Government for non-devolved issues affecting carers in Wales. Carers will judge the strength of government commitments by concrete actions.

Deliver a Health Service in Wales that recognises, values and supports carers

- A new statutory duty on the NHS to put in place policies to identify carers and promote carer's health and wellbeing. Ensure that all staff are trained to know about carers and how to signpost and support them.
- Increase early identification and signposting via primary care to ensure carers are better prepared for caring and can get support early to look after their own health and wellbeing, easily available advice including information to help carers plan, prepare and provide care.
- An urgent and significant increase in funding for care services is needed now or the role of families and friends caring will become increasingly unsustainable as carers are pushed to breaking point. It will have financial implication for health and social care if carers needs are not recognised and met.
- Consideration of new funding models for social care and the priorities for future NHS spending must have carers' contribution, both financial and practical, at their heart to deliver sustainably funded health and care system that is fairer for families.



Give carers a break: Provide funding and choice of quality services to enable carers to take the breaks they need

- Increase and ringfence funding for carers' breaks making it transparent so carers know what they are entitled to, and ensure greater consistency in what is available. A choice of appropriate and good quality care must be available or carers cannot get the breaks with or without the person they care for to look after their own health and wellbeing.



Ensure carers are able to juggle work and care and provide carers with support to return to work alongside or after caring:

- Create a new right to paid time off work to care of at least 5-10 days.
- Put in place tailored support for carers looking to return to work, including recognising the skills carers have developed through our caring role.
- Work with employers to include carers in health and wellbeing support at work.
- Recognise that good quality and affordable care services are an essential part of enabling carers to remain in or return to work alongside caring.



Ensure that carers and our families do not suffer financial hardship as a result of caring

- Carer's Allowance, just £64.60 on 2018/9 rates, must be raised across the rest of the UK to at least the level of Job Seeker's Allowance, as has been done in Scotland, with equivalent increases to carer premia to ensure that those on the lowest incomes benefit. In the longer term, financial support for carers must be increased significantly.
- 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 so carers don't have to choose between Carer's Allowance and keeping in touch with the workplace. 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 they do not suffer financial hardship later in life.



Our mission is to make life better for carers



We give expert advice,
information and support



We connect carers so
no-one has to care alone



We campaign together
for lasting change



We innovate to find new ways
to reach and support carers





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