

State of Caring 2017



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State of Caring 2017

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

This year 400 people across Wales shared their experience of what it's like to be a carer in Wales.¹ All quotes contained in this report are from the Welsh respondents who completed the survey.



¹ This report provides a snapshot of caring in 2017, only the responses of current carers have been used.

Context: The state of caring in Wales in 2017

Debate on the balance of responsibility for care between individuals and the UK state was central in the run up to the 2017 General Election. However, the huge amount of care already provided by families and friends both practically and financially was not acknowledged enough in that debate, nor was the importance of supporting people who are caring unpaid. This is important in the context of how much funding Welsh Government is given by the UK to fund the devolved services in Wales.



A spotlight was shone on the inadequacy of the current system, on its unfairness and on the inconsistencies of how care for different health conditions is provided and paid for.

The lack of recognition by the Westminster government has a financial knock on effect for health and social care services which are delivered in Wales through devolved powers by the Welsh Government.

In this context the enormous contribution of family and friends in Wales, who are the main providers of care, is estimated to be worth £8.1 billion per year.² It is more important than ever that carers are understood and valued by Governments across the UK. Yet 72% of carers in Wales who responded to this year's survey felt that their contribution is not understood or valued.

This is also consistent with recent polling of the public more widely which showed that the vast majority of the public in Wales (72%) think that carers are not sufficiently valued by society.³ These findings should act as a wake-up call to policy makers and the public.

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

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

³ Building a carer friendly society – Carers Week Research 2017

The estimated
value of
unpaid care
in Wales



£8.1bn

The value
of health
spending
in Wales 2017



£6.85bn

72%



of carers in Wales who responded to this year's survey felt that their contribution is not understood or valued.



Lack of social care funding is reflected in the failure of local authorities to consistently assess carers' needs and put in place support. The Social Services and Well-being (Wales) Act 2014 has now been in place for a full year and through our Track the Act survey Carers Wales has seen little evidence that it has improved the lives of the 370,000 carers across Wales.⁴

Evidence from carers on the financial impact of caring shows that, far from having their contribution appropriately recognised by the social care and social security system, people providing unpaid care are struggling to make ends meet and are unable to protect their future financial security.

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

It is clear that the way we value and support the contribution of carers is at the heart of addressing some of the current major challenges our society is facing. It is also even more fundamentally important that caring and being cared for is something which almost everyone will experience at some point in their lives. Supporting people when they take on a caring role must be a priority of national, regional and local governments across the UK.

⁴ Carers Wales – Track the Act Briefing 2 – September 2017

Impact on carers' health and wellbeing



Caring can have a significant impact on health, with the pressures of providing care taking a toll on both carers' physical and mental health. Those providing over 50 hours of care each week are twice as likely to be in bad health as non-carers.

In Wales 59% said their physical health has worsened as a result of caring, while 7 out of 10 (70%) said they have suffered mental ill health.

People providing over 50 hours of care a week were more likely to say their physical health has worsened as a result of caring (58%), while three quarters (75%) of those providing care to a child with a disability said they had suffered mental ill health such as stress or depression as a result of caring.



I recently had a tumour removed from my leg which had been there a long time. Because my husband takes priority, I gave up telling the GP about the pain I was in until it meant going in to have surgery immediately



I have not ticked any of the boxes, because they don't touch the surface of how caring affects individuals. I recently told someone that I feel so tired most of the time that I have forgotten what it's like to feel normal. I don't know how this affects my health, but I worry that I may one day have a stroke



Difficult to get a good night's sleep - long term sleep deprivation is the cause of all my health issues



I need two knee replacements but get morphine to cope instead



The overall impact of being a carer means I am as housebound as my husband is. It's very difficult when someone totally relies on you, even though you are very happy to love and care for that person. There is no freedom



Staying healthy as a carer

Carers reported a number of negative impacts of caring upon their wellbeing. 8 out of 10 people (77%) said they feel more stressed because of their caring role. Almost 7 in 10 (65%) also said they find it difficult to get a good night's sleep because of their caring role.

Over half of people (53%) also reported that they have reduced the amount of exercise they take because of caring and 47% reported that they found it hard to maintain a balanced diet. Over half (52%) said they have suffered depression because of their caring role.

Support from GPs

When asked if their GP knows they are a carer, disappointingly, almost three quarters (73%) said that their GP knows but that they don't do anything different as a result.

12% of people currently providing care said their GP does not know they are a carer and this rises to 25% for those who are in paid work and providing care.



I have had severe anxiety and nearly had a breakdown due to stress of work and caring. I do feel less stressed now I have given work up but more anxious and hopeless about myself. I feel I should be more confident but feel too tired all the time. The future scares me that who will take over when I'm gone



I used to suffer in the nights as I would be anxious of checking on mum, I would find it hard to sleep. But, I introduced some exercise and whenever I get a 20 min block I try to some cardio to increase my fitness I have also introduced weight training to help my strength albeit on a low level



We have all become quite socially isolated. Very worn down and tired



Nearly two thirds

65%



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

Over half

53%



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

Nearly half

47%



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

Over half

52%



said they have suffered from depression because of their caring role

Almost three quarters

73%



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

Taking a break from caring

Breaks are vital for carers to be able to deal with the physical and emotional strain of providing care and support. It helps them to continue in their caring roles. However, disappointingly, carers often report not receiving the support they need to take a short break.

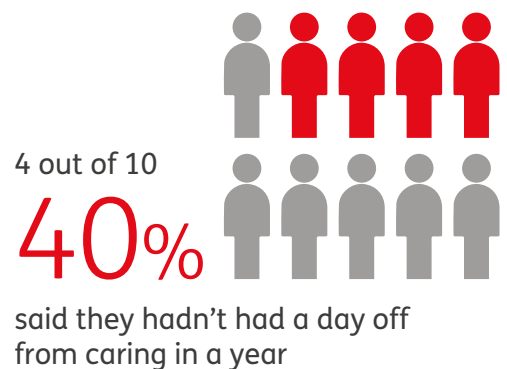


We asked carers when they last took a break from caring.

4 out of 10 carers said they hadn't had a day off in a year. Having more than a day was rarer with (62%) reporting they have not had a weekend off in over a year and as many as 8 in 10 carers (83%) not having had a week off for over a year.

Those spending 50 hours or more caring were most likely to report they had not had a day off from caring for over a year with 42% of people saying this.

The effects of not having a rest from caring is shattering. Carers describe being close to breaking point. Carers are desperate for some time to themselves to be able to sleep, recuperate and see friends and family. Of those carers who reported not having a break from caring within the last year 70% said they had suffered mental ill health and were more likely to report that their physical health 64% has worsened.



“

I have not had a break/holiday or a single day off in 17 years

”

Barriers to getting a break

For those who said they were struggling to get a break from caring, the most common reasons that people gave were that the person they are caring for is not willing to accept care and support from others (30%), the care and support needed for the person is not on offer (28%) and the cost of paying for or contributing to the cost of a break (28%).

Troublingly only 8% of all respondents said they haven't struggled to access a break from caring.



Mum doesn't get a break due to lack of confidence to leave dad with anyone else, even her daughters! She would like to go away with him once he is well enough but can't find accessible breaks. She doesn't have the energy to do it all: packing, driving and all the running around she would have to do as dad is paraplegic



Was told a few years ago he wasn't disabled enough to get respite. Sister may have him overnight but that's usually a last minute thing that doesn't last 24 hours - perhaps 3 times in the last year - not!



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



A rest for my brain from the constant stress



The breaks I take are short because taking longer breaks away from my husband are stressful due to the worry. The only real holiday I have is with him when I care for him 24 hours but have a break from my other responsibilities



Have been on waiting list for 3 years for overnight respite. Told it will not be available in the foreseeable future



I have no money to go on a break anyway, the government has removed my husband's PIP and therefore my Carers Allowance. We are destitute



The respite is through a charity and is only short term



What does a break mean to you?



“Having a break means a lot but you cannot get away from the feeling of guilt. Then you get back to reality and caring. Your break seems non-existent”

“Relaxing , feeling normal can go and do anything without having to think ahead all of the time, recharging one’s self”

“Time to recharge our batteries and have some quiet time together”

“I have frequent short breaks as my husband can cope for several hours on his own. It means I can go to classes, talks, concerts, plays and social events that I enjoy. I come home refreshed”

“It helps me relax and do some exercise. I have a 18 year old son who is about to start university. He needs my attention as well. He is at a crucial time in his life. He is so lovely and patient. He tries to play games with his granny. However there can be jealousy if I spend too much time with my son. The break for me is so important”

“It gives me time to deal with my own health problems and issues”

“Break from loneliness and routine”

“Quality time”

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

“I accept my responsibilities to my husband... we marry for better or worse. I need my own space to keep sane (having our own space was the norm before he became ill)”

“It means so much to me. The fact that one can relax or do something for myself which may be something simple would be so uplifting. It is very hard being a carer. To know what to do for the best is difficult as we are not trained like nurses for example. When it’s your family and you see them struggling with even a simple task it’s very hard to think about going on holiday”

“Just that, a break to do as I please without feeling guilty”

“Not having to think about food for my mother every day and going away with my husband on our own”

Accessing practical support with caring

370,000 carers in Wales provide unpaid care by looking after an ill, older or disabled family member, partner or friend and 103,594 provide over 50 hours of unpaid care per week.⁵



Carers often struggle for recognition from the wider health and care system and all too often are not identified or signposted to appropriate sources of information, advice and support.

Getting equipment in the home of the person being cared for, such as hoists, grab rails, easy grip handles on taps was the most likely form of support people receive with almost half (47%) reporting this. A quarter (25%) use technology like alarms, sensors or remote monitoring to help with caring. Only 24% said they buy or receive practical support from care workers coming in to help.

One in 5 (20%) of those caring over 50 hours or more a week do not receive or buy practical support to help them.



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

⁵ 2011 Census

Carers' experiences of carer assessments

The Social Services and Wellbeing (Wales) Act 2014 came into force in April 2016 and with it came important new rights for carers.

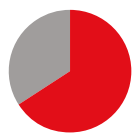


The Act places a set of new duties on councils:

- Unpaid carers in Wales have equal legal rights for support as the people they look after.
- There is a legal duty on councils to meet a carer's eligible needs following a carer's needs assessment.
- Councils must ensure that they have information, advice and assistance services in place and clearly signposted so carers can get the right information at the right time.
- There is a legal duty on councils to make sure there are a wide range of relevant community services and activities available in the local area for information services to signpost people to.
- Councils are now also required to promote the well-being of both, people 'in need' and of their carers.

However only 19% of carers in Wales responding to this survey said that during the last year had been offered a carer's needs assessment and only 15% had requested one. 66% of carers in Wales said they had not been offered or requested an assessment.

66%



of carers in Wales said they had not been offered or requested an assessment.

“

I have tried to access help, but it isn't available, social services were useless! I do pay for him to attend a private tutor to help with his educational needs, and book him onto free courses. Barnardo's have helped a little by including him in some activities, but this is only 2 hours a month

”

Support in the future

When asked how they feel about the practical support they might get in the future, 64% said they feel uncertain about what might happen and almost a third (27%) said they were worried that the support might be reduced.

Almost a third

27%



said they were worried that the support might be reduced in the future



“

Used to have respite for my daughter but since she turned 19 the services and the places they offer are not right for my daughter

”

“

I do not receive any help from anyone. I pay a lady to take my son out 16 hours a week. That is the only break I get, well if you can call it a break as I run around like an idiot doing the things I can't do when my son is here

”

“

I have two hours a week during which someone from a charity takes one of my cared for shopping but we have to pay for the travelling costs. They do not provide the care on Bank Holiday

”

Costs of caring

The UK's 6.5 million unpaid carers provide the majority of care for families saving the economy and estimated £132 billion per year (£8.1 billion in Wales).⁶ Yet Carer's Allowance is the lowest benefit of its kind, at just £62.70 per week (2017/2018 rates) and carers are often struggling financially.



Carers Wales regularly hear from families facing difficulties making ends meet and affording their basic living costs alongside the additional costs associated with caring and disabilities. Financial constraints are often made worse by carers being forced to give up work or reduce their working hours as a result of their caring responsibilities.

Almost half (47%) of carers responding to the survey reported living on a household income of less than £1500 per month and four out of ten (43%) described themselves struggling to make ends meet.

When we asked carers who are struggling financially how they cope, a number of people reported cutting back on items and activities which are fundamental to their wellbeing, such as hobbies and leisure activities (56%) and seeing friends and family (40%).

Worryingly some carers reported being forced to use their savings, credit cards or bank account overdrafts to help make ends meet.

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

Almost half

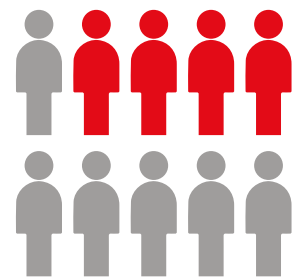
47%



of carers responding to the survey reported living on a household income of less than £1500 per month

4 out of 10

43%



described themselves struggling to make ends meet

⁶ Carers UK, University of Sheffield and University of Leeds (2015) Valuing Carers 2015 – the rising value of carers' support



I sell personal belongings to make extra cash



I can JUST afford my bills!!



Budgeting ensures bills etc are covered but there are no extras such as holidays. Income covers necessities and 0% credit cards are used to cover unexpected costs



I've had to take out a debt management plan due to getting into debt caring and having to reduce overtime to care



Although I can pay my bills I can't afford to buy in respite care



I am managing to pay bills but struggle to afford other everyday things like clothes, household purchases or days out due to the cost of care



We manage by budgeting monthly and going without luxuries



Juggling work and care

Three million people, 1 in 9 of the UK's workforce,⁷ combine caring for a loved one with paid work. However, the significant demands of caring mean that many are forced to give up work altogether, due to lack of rights, flexibility and high quality care services at home. Carers need to be supported so that they are able to juggle work and care and also to enable them to return to work if they wish.



Almost a third (29%) of carers in Wales responding to this survey reported currently being in paid work. Almost a quarter (24%) of those providing care for over 50 hours a week reported being in paid work.

Responses illustrate how caring takes a toll on people's employment opportunities, including career development, promotions and pay rises, as well as impacting upon carers ability to work at all and almost half (47%) said they had given up work completely to care.

Having to work at the same time as providing care has a significant effect on people's health. Carers in paid work were more likely to have suffered mental ill health. With 78% reporting they were more stressed and 67% reporting they were more anxious. 50% of respondents said their physical health has worsened as a result of caring. 51% respondents said they found it difficult to get a good night's sleep and 52% said they have reduced the amount of exercise they take, 46% found it difficult to maintain a balanced diet.

Almost half

47%

said they had given up work completely to care



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

⁷ Census 2011



I am considering options to take either reduce my working hours or early retirement as the time spent supporting my mother in her care home is becoming too much for me



My health has suffered due to the work involved in my caring 24/7 I get no help or break from my daily caring as it is my husband I care for, my love for him makes it worthwhile



I left work because my employer was unwilling to offer me the flexibility to accommodate my caring responsibility



My mental health deteriorated in the last year and I'm now taking time out of work to recover myself



I gave up a legal career to care for my mother on a full time basis. I have had no choice but to go back to full time employment in a less qualified role but with less stress to be able to work closer to home and look after my mum. Financially, I could not survive as I did not qualify for benefits other than Carer's Allowance



Worked up till 18 months ago, and struggled to work part time before that due to my caring role



Had to find a job nearer my home as my son had so many appointments and was sometimes ill in school and had to be collected, but that meant a significant cut in pay



I work 8am-5pm and feel I am continually torn but as the only wage earner I know my job is important and more stress would be caused to my husband if we did not have my earnings



Recommendations

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

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

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



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

- There needs to be an urgent and sustainably funded health and social care system to make carer's legal rights a reality and ensure that there are adequate services in place when carers need them. This must include housing fit for caring and technology that supports carers.
- Good quality reliable and affordable care services to support carers, including adequate and sustainable community services to support carers in line with the new Social Services and Well-being (Wales) Act.
- Adequate good quality flexible replacement care must be made available so that carers are able to have a break and look after their own health.



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

- Introduce a new right to paid care leave in the workplace between 5 to 10 days for carers in work
- Support for carers and former carers who wish to stay in or return to work
- Recognition across Government that good quality, reliable and affordable care services are needed to enable carers to juggle work and care
- Ensure working carers are identified and given information about their employment rights as well as a right to a carer's needs assessment



- Encourage and assist employers to support carers in their workforce through carer friendly policies and working practices, via the development of a Welsh Employers Award Scheme

To provide funding to enable carers to take breaks

- Increase and ring-fence funding for carers' breaks, so there is more transparency and consistency in what is available, enabling carers to know what they are entitled to.
- Ensure that there are enough respite and replacement carers services available to meet carers needs.
- Ensure that carers are consulted with and fully engaged in deciding the future shape of replacement care services.



To create a more 'carer friendly' NHS

- A new duty for the NHS to put in policies to identify carers and to promote carers' health and well-being.
- New measures to monitor how GPs are identifying and supporting carers to ensure that carers can look after their own health.



To ensure carers are better prepared for caring and can get the information and support early on

- Increase efforts to identify carers and ensure that they are signposted to appropriate support and services.
- Protect and resource local carers support services and commission more services in line with the needs identified in the local population assessments to manage increasing demands on their services.
- Ensure that adequate monitoring is taking place to ensure local councils are meeting their legal obligations.



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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