State of Caring 2019

Each year, Carers UK carries out a survey of carers to understand the state of caring in the UK.

This is the largest State of Caring survey carried out by Carers UK to date and across Wales almost 600 carers and former carers shared their experiences of caring.

This report provides a snapshot of caring in 2019 by only including the responses from the 580 people who are currently providing care.

About the research

Carers UK carried out an online survey between March and May 2019. Carers Wales is part of Carers UK and across Wales a total of 582 carers and former carers responded to the survey – we have only included responses from the 580 people who are currently providing care in this report.

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 survey:

- 83% identify as female, 16% identify as male, 1% identified as other.
- 30% consider themselves to have a disability.
- 1% are aged 0 – 24, 3% are aged 25 – 34, 11% are aged 35 – 44, 28% are aged 45 – 54, 38% are aged 55 – 64, 15% are aged 65 – 74, and 5% are aged 75 and over.
- 13% identified as lesbian, gay or bisexual.
- 1% described their ethnicity as black or minority ethnic.
- 18% also have childcare responsibilities for a non-disabled child under 18.
- 35% are in paid work (51% full-time and 49% part-time).
- 34% have been caring for 15 years or more, 14% for between 10 – 14 years, 24% for 5 – 9 years, 25% for 1 – 4 years, and just 3% have been caring for less than one year.
- 51% care for 90 or more hours every week, while 16% care for 50 – 89 hours, 23% care for 20 – 49 hours, and 10% care for 1 – 19 hours a week.
- Most (75%) care for one person, 17% care for two people, 6% for three people, and 2% care for four or more people.

As not all respondents completed all the questions 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 580 carers but never less than 100. This, together with the sample sizes of different groups, should be taken into consideration when reading the results.
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Context: The state of caring in Wales in 2019

Recent polling published by Carers UK has suggested there could now be as many as 400,000 adult carers in the Wales¹, compared to 370,000 adult carers recorded in the 2011 Census. Improving support for carers whether it’s practical or financial must be at the heart of how we address our ageing population.

There have been a number of positive developments for carers in the last year. These include:

- £50m invested in the integrated care fund to deliver joined up care closer to home. £15m of the allocated money is being invested in services to support people with learning disabilities, children with complex needs and carers;
- £1m funding to Welsh local health boards to support partners to work together to secure better support for carers around raising carers awareness across GP practices in Wales and improving support for carers in relation to hospital discharge;
- £3m recurring funding to support respite;
- £95k to third sector organisations to take forward Ministerial Priorities:
- Supporting life alongside caring;
- Identifying and recognising carers;
- Providing information, advice and assistance;
- Work to improve data collection from local authorities about the support provided to carers.

But even with these developments, carers and the people they care for still face economic and societal pressures. Despite additional investment, there are services in Wales that are reaching crisis point, with unpaid carers facing the consequences of local cuts to budgets and delayed funding solutions. The results of this year’s survey show clearly why system-wide reform is needed to ensure carers are properly supported and able to have a life alongside their caring responsibilities.

Carers’ support in Wales is valued at £8.1 billion a year², however this comes with high personal costs. Many carers are suffering from loneliness and social isolation, need support to help them stay in work and are facing their own health problems as a result of their caring role. This is in addition to the financial cost of caring; with almost half (45%) saying that they are struggling

¹ Carers UK (2019) Juggling work and unpaid care, Yougov polling
² Carers Uk (2015) Valuing carers – based on 2015 carer projection
³ Carers Uk (2019) Juggling work and unpaid care, Yougov polling
to make ends meet and 68% reporting that they regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for.

A higher state pension age means that people are working for longer and are more likely to be working alongside caring. Increasing numbers of employers are recognising the importance of supporting carers in their workforce to continue working, so they can retain talented staff rather than incurring the costs of recruiting and retraining new employees. But with workplace support still very varied across the country, nearly half a million people across the UK have had to give up work over the past two years as a result of caring. This equates to around 600 people every day.

This shows that there is much to be done to increase support for carers and that many carers have serious concerns about the future. Two thirds of carers (66%) told us that they have focussed on the care needs of the person they care for, not their own needs, and just under half (44%) of those who aren’t yet retired are not able to save for their retirement. This brings to light the reality of the impact of caring on a carers’ ability to plan for their future retirement and their own care needs. Action must be taken to support them.

The Welsh Government has previously committed to valuing, recognising and supporting carers, but if this is truly to become a reality then carers’ voices, opinions and experiences must be heard, listened to and acted on. It is of paramount importance that even in the current challenging financial and political climate across the UK, the Welsh Government must focus on supporting carers and ensuring a sustainable future for our health and social care system.

This report contains a snapshot of what caring is like in 2019, capturing the impact that caring has on carers’ lives in Wales and makes policy recommendations that could improve this.

Financial pressure

Many carers face very difficult financial situations due to their caring responsibilities, despite the valuable contribution they make to society. Carers often find their own income affected by caring (for example because of having to give up work or reduce their hours to care) and this can be compounded if their partner or another family member has also had to leave work due to their illness or disability.

When asked how they would describe their financial situation, almost half (45%) carers say that they are struggling to make ends meet. This is an increase of 11% from 2018 when 34% said that they were in that situation, showing that even more carers are facing financial hardship.

Carers who have been caring for more than 15 years and those who care for more than 35 hours a week are less likely to say that they are struggling to make ends meet, with 42% and 41% saying that respectively. However, over half of carers who are receiving Carer’s Allowance (56%) say they are struggling to make ends meet.

Almost half

45%

of carers say that they are struggling to make ends meet

Over half

56%

of carers who are receiving Carer’s Allowance say they are struggling to make ends meet

I am digging into my savings to provide their needs

Just about making ends meet

I manage to pay the bills but we never have holidays and have very limited social lives. I constantly cut back to make sure we live within our means. We have an interest only mortgage and we don’t have savings
Only 4 in 10 of all carers (41%) say that they can afford their bills without struggling financially and 23% have been in debt as a result of caring while 8% cannot afford utility bills and 4% cannot afford their rent/mortgage payments.

Carers who are struggling financially often have to make difficult decisions and cut back on spending. Of those carers who are struggling to make ends meet, 47% are relying on their savings and 33% are using credit cards. A third of carers who are struggling financially (32%) are using their bank account overdraft facility, 13% are falling into arrears with utility bills and 6% are falling into arrears with their housing costs i.e. rent or mortgage payments.

Many carers find that cutting back on household spending is an essential part of balancing their budget. Whilst 86% have cut back on luxuries, more than half of carers (54%) have also had to cut back on essentials like food and heating.

4 out of 5 carers who are struggling financially (81%) have had to cut back on hobbies and leisure activities and 61% have cut back on seeing family and friends. 13% have even had to cut back on the support services which help with caring. 6% of carers who are struggling to make ends meet have said that they have used food banks and 3% have used pay day loans.
Practical support with caring

Carers make a huge contribution to the lives of those they care for and to our wider society. Despite this, too many are going without the support they need and all too often they are going without any support at all. This year’s survey found that one in five carers (21%) buy or receive no support with caring. Whilst these figures in this section are largely similar to last year, there is still a large level of unmet need, with many carers struggling without any support at all.

Carers were asked what type of practical support they receive or buy. The most popular type of support was equipment in the home of the person they care for (like hoists, grab rails or easy-grip handles on taps) with 49% receiving or buying this.

Carers also reported receiving or buying the following types of support:

- Help from family or friends – 33%
- Technology (eg alarms, sensors or remote monitoring to help with caring) – 29%
- Practical support from care workers coming in to help – 25%
- A Motability vehicle – 26%
- A break from caring – 19%
- Use of a day centre for older/disabled people – 13%
- Help with other household chores (eg shopping or cleaning) – 8%
- Help managing or co-ordinating care – 5%
Almost three quarters of carers don’t receive any cash sum for either themselves or the person they care for.

68% said they regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for.

A quarter of carers worry that the practical support they receive might be reduced in the future.

In this year’s survey we asked carers about spending their own money on support. Shockingly, over two thirds of carers (68%) regularly use their own income or savings to pay for care or support services, equipment or products for the person they care for.

When asked how they feel about the practical support they may receive in the future, only 1 in 10 (9%) carers say that they are confident that the support they currently receive will continue in the future. A quarter of carers (23%) worry that the support might be reduced and two thirds (68%) don’t know what might happen.

Carers were asked if they or the person they care for get a cash sum, from their local authority or health body to pay for care and support services directly (e.g. a direct payment or personal budget). Almost three quarters (74%) carers don’t receive any cash sum for either themselves or the person they care for.

However 19% said the person they care for receives a cash sum, 4% said they receive a cash sum in their own right as a carer and 4% said both they and the person they care for receive a cash sum.
Technology

Carers responding to the survey were asked if either they or the person/people they care for use any technology to support care and caring. Three quarters of carers (75%) reported using one or more types of technology. Using a more inclusive definition of technology in this year’s questions meant a considerable increase in the number of people using technology compared with 2018 when 49% of carers reported using it to support them to care.

Of those carers who use technology, the internet was the most popular type with 84% using it as a source of information and 41% using it as a form of communication or online support.

Remote health care such as online GP appointments, repeat prescriptions, online video consultations or online mental health services was another popular way to use technology with 18% of carers saying they use this.

20% of carers who use technology said that they used remote monitoring and alerts such as motion sensors, fall detectors, personal alarm, GPS trackers, whilst 10% use medication management tools such as medication dispensers or medication reminders.

6% of carers are using environmental monitoring such as heating and lighting control, door video systems, or smart appliances. 13% of those who use technology use vital signs monitoring such as blood pressure monitors, blood glucose monitor, and heart rate monitors.

3% of carers are using apps, including those which help with pain management, mood management and care co-ordination.

The figures above however may not be a true representation as those who completed the survey did so online and for that reason will be more inclined to have access to and be able to use technological solutions.

Nonetheless, these figures show that there are still significant opportunities to increase the numbers of carers who use technology to help them in their caring role.
Carer’s Assessments

Carer’s Assessments in Wales

The Social Services and Well-being (Wales) act 2014 gives all carers a legal right to an assessment from their local authority or the local authority where the person they care for lives. The assessment should consider the impact that caring has on an individual and consider all aspects of their life and what support a carer needs.

28% of carers in Wales reported that they had an assessment, or a review of their assessment, in the last 12 months. In 2016, when we last asked this question in this way, 31% of carers had received an assessment.

Out of all carers who received an assessment in the last year, 84% waited less than six months for this assessment but 16% waited longer than six months.

28% of carers in Wales reported that they had an assessment, or a review of their assessment, in the last 12 months

“"My latest carers report says they will not supply me support as a carer, until I consent to an assessment of my needs, as I’m housebound. I don’t want an assessment of my needs. I just want a one night of respite - there are 12 listed in my child’s care plan, but they won’t provide them. My Local Authority are forcing me to care. I’ve tried to commit suicide twice because they won’t help me with my severely learning disabled autistic child. My child is violent and aggressive""

“"The Authority, due to limited budgets, I assume, provides minimum support and expects carer to do the rest. 7 hours of care a week out of 168 for a 101 year old with many health issues. How does that allow a carer to work or have a social life? Impossible!""
Barnardo’s Family Support worker is helping me access services, recently got Team Around the Family but neither have been able to help me get a carers assessment which I’ve been trying to access for over 4 years

Same again - had a carer needs assessment, as recommended by the carers assessor, but told have been assessed as having no eligible needs because I work five hours a week as a cleaner
Experiences of assessments

The majority of carers who had been assessed / reassessed in the last year felt that their needs were not given sufficient consideration. Respondents were most likely to say that the suitability of their housing for continuing their caring role was taken into consideration, but only 41% of carers said this happened. Even fewer carers said that other aspects of their needs had been thoroughly considered:

- Carers’ ability and willingness to provide care was only thoroughly considered and reflected in support in 36% of assessments;
- Only 25% of carers felt that their need for support to look after their own physical and mental health alongside caring had been thoroughly considered;

Just over a quarter (27%) said their need to have regular breaks from caring was considered.

41% of carers said that the suitability of their home for continuing their caring role was taken into consideration in their carer’s assessment

Just over a quarter of carers

27% said their need to have regular breaks from caring was sufficiently considered in their carer’s assessment

Only

25% of carers felt that their need for support to look after their own physical and mental health alongside caring had been thoroughly considered

Nothing was going to change. Carers assessment person suggested I see the Dr about my knee, but she couldn’t give me any advice on how to get an appointment “oh you will have to try and get one when the new respite care for your son starts.” Was the helpful advice I received!

I have asked for a carer’s needs assessment but got a letter saying they were overwhelmed and I would be put on a waiting list
Costs, cuts and closures

When asked about changes in care and support services over the last year, 30% of carers reported that they had experienced a change in the amount of services that they receive. Of these carers who experienced a change, for 15% this was because the amount of care or support arranged by social services was reduced, whilst for 11% of respondents the care or support service was closed with no replacement offered. 6% of respondents reduced the amount of care or support received because the cost increased and 4% reduced the amount of care or support received because the personal budget no longer covers it.

However, 29% of respondents who experienced a change to the amount of care or support arranged by social services saw an increase because the need for support increased and for 4% of carers there was an increase even though the needs stayed the same.

Of all carers responding to the survey, 11% reported that they or those they support received less care or support services during the previous year due to a reduction in the amount of support from social services.

“More burden on me to supplement the reduced care provided by social services”

“Of all carers responding 11% reported that they or those they support received less care or support services during the previous year due to a reduction in the amount of support from social services”

“Had to pay towards care could not afford to budget so tight”

“Never got offered any care, I ended up getting a friend to help 2 hours a week”

“The local authority has been excellent in its help and increased funding when needed”

“We got private care in as more reliable”

“Want too much money for services. On low income so cannot afford it plus a lot of services have been cut or finished”
My GP contacted Social Services, as I had been unable to get respite for my son for over 16 months, and needed to increase my dose of antidepressants.

Day centre closed for refurbishment, will reopen but only for dementia patients.

I have not felt lonely but I do regret that I am unable to do the things that I would like (I do not have the time) I also think I am less interesting because so much of my 'spare time' which used to be my leisure time- is now spent as a carer.

We moved to a neighbouring council 2 months ago and they have cut the care package by over half.

Told last week that my carer for my own personal care (I look after my husband’s personal care) was being stopped, with no notice or explanation as to why. This has been a very important factor in my emotional well-being and feeling of being supported in my role as carer. Now, it’s suddenly stopped!!
Support for emergencies and contingency planning

Many carers worry about what will happen in case of an emergency where they are unable to care or the person they care for needs urgent treatment.

Carer’s assessments, which carers are legally entitled to, should already consider support needs should emergencies arise.

Planning for contingency and emergencies

The survey asked carers about emergencies and found that only 1 in 6 (16%) have had a conversation with an NHS professional (eg a GP or a nurse) about what to do if the condition of the person they care for deteriorates, or they are no longer able or willing to provide care for them.

Carers experiences of talking to NHS staff are varied with some saying that there is excellent support available while others have struggled to have the issue taken seriously or don’t know where to start with this conversation.

I have discussed Advance Care Plan with my family and them having power of attorney for me

Only one in six carers

16%

have had a conversation with an NHS professional (eg a GP or a nurse) about what to do if the condition of the person they care for deteriorates or they are no longer able or willing to provide care for them

Lack of nursing respite in the area. Was unable to have respite for me to travel to a family funeral because there is nothing in place for anything unexpected. Fearful should I become ill and there is no one to look after my dad
Emergency hospital admissions

Just over a third of carers (38%) said that the person they care for had been admitted to hospital in an emergency (an unplanned admission) at some point in the last 12 months.

Of carers who’d had an emergency admission for the person they care for, 30% felt that the admission could have been prevented if they’d had more care and support for the person they care for and 20% felt that more support for them as the carer (breaks from caring) would have prevented the admission.

Over a quarter (28%) felt that higher quality care for the person they care for would have prevented the admission whereas 12% felt adaptations in the home of the person they care for would have made a difference. 13% felt that the emergency admission could have been prevented if they had access to a district nurse.

1 in 10 carers (10%) felt that following a previous discharge from hospital, not enough time was taken to put in place adequate care and other arrangements that could have prevented the subsequent emergency admission. 7% of carers thought that telecare or telehealth services (e.g. monitoring equipment, alarms and sensors which remotely check the health of an older, sick or disabled person and that they haven’t wandered, had a fall or accident) could have prevented the emergency admission and a further 8% thought replacement care when the carer needed medical treatment would have prevented it. 1% of carers thought it could have been prevented if they’d had access to a hospice.

Although I recognised and accepted my role as a carer, it has not always been made clear what help is available. Caring does put on a lot of strain but it is something you learn to live with and don’t realise how it impacts on your life until an emergency occurs.

We have some aids, though they were supplied by the NHS for me. I have mobility problems due to MS and also poor vision.

Since my father was recently discharged from hospital without any care package put in place, I arranged, through my GP an emergency care package which is due to end shortly.

30% of carers felt that an emergency hospital admission could have been prevented if they’d had more care and support for the person they care for.

13% felt that the emergency admission could have been prevented if they had access to a district nurse.

Sometimes he can get transport to and from hospital appointments, but ONLY because I am caring for another family member in the same house.

I care for my daughter full time. When my daughter was discharged from hospital to be cared for at home, I was told there would be an emergency bed in our local hospital where she could go in an emergency and care would still be provided by her team who provide her care at present. However, this has not happened in reality. There are no beds in our local trust for my daughter as she needs a bed to recommence a medication that has been stopped and now can only be recommenced whilst in hospital. My daughter is looked after by mental health services in the community.
Planning for the future

For many carers, whether their caring responsibilities start suddenly following a diagnosis or they develop over time as an older relative needs more support, they can find their future plans affected – in particular their future retirement plans.

Planning for retirement

We asked carers who are not retired about how they intend to pay for their retirement. The most common source of income for retirement was a state pension with 74% of carers expecting to use this.

Other sources of money which carers are planning to use for retirement include:

- Workplace pension (37%)
- Personal savings (11%)
- A main home you could downsize from (12%)
However, one in five carers (21%) don’t know how they are going to pay for retirement. Carers who are over 50 and therefore closer to retirement age, are less likely to say they don’t know how they are going to pay for their retirement with 19% of over 50s saying this compared to 28% of under 50s.

Carers who are not retired and are struggling to make ends meet are less likely to have made financial plans for the future – 26% don’t know how they are going to pay for retirement.

Carers who are not yet retired were also asked about their future plans and 51% said that they are not able to save for their retirement. This rises to 73% of carers who are regularly using their own income or savings to pay for care or support services, equipment or products for the person they care for. 66% of those who describe their financial situation as struggling to make ends meet are not able to save for retirement. Almost two thirds of those who are receiving Carer’s Allowance (67%) are not able to save for retirement.

Some carers are saving or have saved less for their retirement with 12% saying they did this because their working hours were reduced. 15% said that they have saved less or were saving less because their short-term financial needs are too great to afford to save for the long term.

Only 16% responding to the survey said that their ability to plan or save for retirement had not been affected by caring.

21% don’t know how they are going to pay for retirement

51% of carers said that they are not able to save for their retirement

I don’t think of myself just the person I care for
Planning for carers’ future care needs

Almost two thirds of carers (63%) say that they have focussed on the care needs of the person they care for and not on their own needs.

Over third of carers (35%) say that they worry about their care needs in the future but cannot do anything about it. For carers who have been caring for over 15 years this is even higher with 39% reporting that they worry about this but cannot do anything about it.

Only 2% of all carers feel that they have prepared for any care needs they may have in the future for themselves.

Almost two thirds of carers

63% say that they have focussed on the care needs of the person they care for, and not on their own needs.

Am scared my savings that were supposed to sustain my husband and I in old age are already being used to support my adopted children’s needs and will not last us out. We do not live luxuriously and never holiday or leave the kids.

Hopefully I will die before I need any care. I really have no time or energy any more.

Your own life stops as a carer.
Caring can have a significant impact on health, with carers often finding that both their mental and physical health are affected. When asked about how their health is in general, carers described their physical and mental health as follows:

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<tr>
<th>All carers</th>
<th>Very good</th>
<th>Good</th>
<th>Fair</th>
<th>Bad</th>
<th>Very Bad</th>
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<tr>
<td>Physical health</td>
<td>6%</td>
<td>27%</td>
<td>46%</td>
<td>17%</td>
<td>5%</td>
</tr>
<tr>
<td>Mental health</td>
<td>5%</td>
<td>27%</td>
<td>43%</td>
<td>2%</td>
<td>5%</td>
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Given the immense personal cost that comes from providing round-the-clock care, it is surprising that carers who care for more than 50 hours a week reported better health with 20% reporting bad or very bad physical health and 23% reporting bad or very bad mental health.

Carers who have been caring for over 15 years reported poorer health with 22% describing their physical health as bad or very bad, but only 22% describing their mental health as bad or very bad, which is below the average in the table above.

Last year we asked if any what has been the impact of caring on your health with multiple answers including my health is no different as a result of caring, my physical health has worsened as a result of caring, I have suffered ill health eg stress or depression as a result of caring, my mental health has improved as a result of caring as a result of caring was 75% and physical health worsened as a result of caring was 61%.

When asked about physical exercise, 82% of carers responding to the survey said that they are not able to do as much physical exercise as they’d like to do.

The need for the NHS to routinely identify and support carers was a top priority for carers across every nation except Scotland where legislation and measures are already in place to ensure carers are identified.

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Due to the rounding configuration, these statistics equal 101%
Caring has impacted on my own health both mentally and physically, I now suffer with raised blood pressure and anxiety, being around illness constantly does impact on your state of mind.

I try to incorporate exercise in my daily routine by going up and down stairs a bit more often, doing some extra stretches etc when carrying out normal household duties. Generally being aware of keeping as fit as I can.

82% of carers responding to the survey said that they are not able to do as much physical exercise as they’d like to do.

I care but it has affected my health. I am ill but have to keep going I do not know what the future holds.

Other people don’t understand the emotional toll being a carer has.
I am losing a lot of sleep, I am on antidepressants, I have thoughts of suicide and lack of self worth.

I know that physical exercise would help my mental health, but physically I am run down and mentally lacking in motivation to do anything, as I am often just too exhausted.

I am given 5 hours respite time per week, not consecutively. In that time I have to do everything. Appointments, shopping, collections etc. this leaves barely enough time to get to where I have to go, do the business and then get home. I am clock watching all the time and nervous about getting back on time.

No spare time, no spare money to join gym/go swimming etc.

I am unable to have the time or the freedom to do any exercise as I am either caring or working. Spare time (with a sitter) allows me to do shopping, going to the bank, solicitor or whatever needs doing.

Not being able to work or exercise has had a huge impact on my physical and mental health.

Missing out on family gatherings has left me feeling isolated, lonely and alone. Family members don’t come anymore because of my husband’s behaviour.

Can’t be bothered, my ‘get up and go’ has got up and gone.
Juggling work and care

More working carers responded to the survey than in previous years – in 2019 35% of respondents were juggling paid work with caring compared to 31% in 2015.

Recent research by Carers UK\(^6\) found that the number of those juggling work and care could be far higher than previously thought – around 223,000 in Wales. This is one in seven of all workers. There are different numbers of people who are juggling work and care in the different employment sectors for example it has been estimated that one in five of the NHS workforce in England is an unpaid carer\(^7\).

Over a third (35%) responding to the survey reported being in paid work. These working carers can be broken down as follows:

- 46% are full-time employees
- 39% are part-time employees
- 5% are self-employed full-time
- 10% are self-employed part-time

Carers often find that it can be a struggle to balance their responsibilities in work with their caring responsibilities.

42% of all carers reported that they had given up work to care and 17% had reduced their working hours. 1 in 6 carers (16%) said that they work the same hours but their job is negatively affected by caring, for example because of tiredness, lateness, and stress. 13% of carers said that they have had to take a less qualified job or have turned down a promotion to fit around their caring responsibilities. Just over 1 in 10 carers (11%) said that they had retired early to care. Only 4% of respondents of all ages said that caring has had no impact on their capacity to work.

Carers Wales is working with forward thinking employers to improve carers support in the workplace. Welsh Government has recognised that carers need to be supported and funded Carers Wales to launch a Wales Hub for Employers for Carers in June 2018.

The Carer Confident benchmarking scheme also assists employers to build a supportive and inclusive workplace for staff who are, or will become, carers and to make the most of the talents that carers can bring to the workplace. For more information visit employersforcarers.org

\(^6\) Carers UK (2019) Juggling work and unpaid care, Yougov polling
I am holding down a full time job as well as a caring time but not sure for how much longer

I have changed jobs and put my career on hold to care

As I am able to have flexi in work I work longer hours to have a day off in the week

I will be retiring soon to care

The feeling that other people do not understand me or what I’m going through has been and is isolating and very lonely

I keep trying to work in various jobs, but keep failing due to care role

Balancing work and caring is extremely difficult

I work for a carer friendly employer who were very supportive when my role was more intense a couple of years ago

I have reduced my working hours and my job is still negatively affected by caring (tiredness, stress, juggling both in order to keep my job)

I have managed to continue working full time and caring. As I have financial commitments however I do find myself feeling very tired at times. I have to use my annual leave to take days off work when I feel the pressures of work and caring becoming quiet stressful

My LA will not provide me support so I can take up employment. I’m being forced to care

I have to work to earn money but my boss is not at all understanding and I have taken sick leave and now am frightened to take any more

I’m fortunate to work in a very progressive organisation that has complete flexibility with working hours. When I look after my brother for days at a time, i work remotely from the home where he lives. Before, I had to travel an hour each way to my old job and stress about him being home alone while I was at work.
Concrete action needs to be taken across all levels of Government in order to put in place the support that carers need urgently in the shorter term. The Government also needs to consider the longer term and there needs to be efficient and effective planning to ensure the sustainability of the health and social care system. Carers should not be left to pick up shortfalls in care and have to put their own lives on hold.

**Recommendations**

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

- Carer’s Allowance, just £66.15 on 2019/20 rates, must be raised across the rest of the UK to the same level as 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 staying in work.

- 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.

**Deliver a National Health Service that recognises, values and supports carers**

- Across the NHS in Wales there need to be policies in place to identify carers and signpost them to appropriate sources of information and advice.

- All staff should be trained to know about carers and how to support them.

- The roll out of A Healthier Wales should ensure integrated services where carers are routinely identified and supported.
Ensure enough funding and services are available so that carers are able to easily access quality and affordable care so that they are able to have a life alongside their caring roles.

- 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 by a lack of support.
- 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 a 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 we need:

- Increase and ring-fence funding for carers’ breaks. Funding should also be 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 so carers get the breaks they need for their own health and well-being.

Ensure carers are able to juggle work and care, if they wish to, 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 well-being 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.
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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