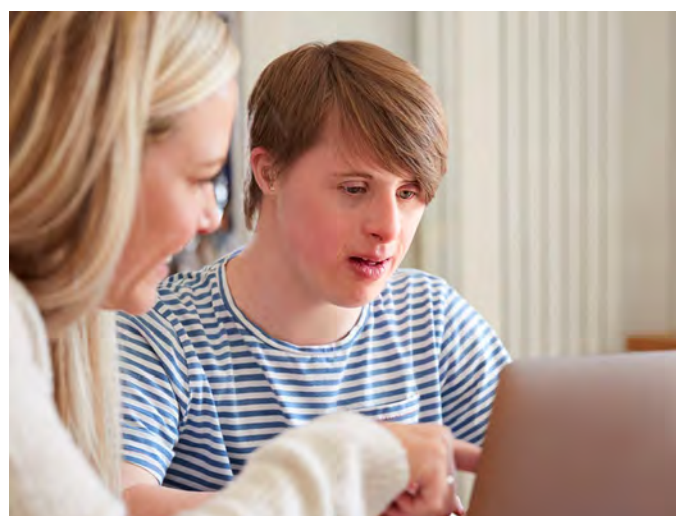


State of Caring 2021: Wales Briefing

A snapshot of unpaid care in Wales



State of Caring 2021

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

Over **700** carers and former carers 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 to date.

About this research

Carers UK carried out its annual online State of Caring survey between August and September 2021. A total of 740 carers in Wales, who are currently providing care, responded. Compared to the carer population as a whole, respondents to this survey are more likely to be White British, female and caring for a high number of hours every week. As not all respondents completed every question in the survey, a number of figures given may be drawn from a sample size of fewer than 740.

Responses from 740 carers in Wales represents a record level of engagement for a State of Caring survey in Wales. Carers Wales would like to thank each and every carer who contributed to this survey. Your experiences will be used to help build a society that recognises and supports carers more.

Thank you

Carers Wales would like to thank each and every carer who contributed to this survey, from those who helped us develop and test the survey to every single person who took the trouble and time to tell us about their experiences. Your experiences will be used to help build a society that recognises and supports carers more.

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State of Caring in 2021: context

During 2021 the hundreds of thousands of unpaid carers across Wales were under immense strain, often bearing the burdens of overstretched and under-resourced health and social care systems still dealing with the effects of the COVID-19 pandemic. Unpaid carers have seen their physical and mental health deteriorate, their services disrupted, and their careers curtailed if they are in employment.

Before the pandemic it was estimated that there were 487,000¹ people in Wales providing care to a family member or friend who required support due to age, illness or disability. The care unpaid carers provide is diverse; from undertaking medical interventions, medicine management and personal care such as washing to making meals, organising and transporting loved ones to doctor's appointments, as well as organising access to formal care services and looking after their loved one's emotional and mental well-being.

As the pandemic struck the number of unpaid carers in Wales increased dramatically to as many as 683,000², with unpaid carers saving the NHS in Wales and other public services £33 million every day of the pandemic. This equates to £12 billion over a year³, greater than the Welsh Government's annual spend on the NHS. Unpaid carers are the third pillar of the health and social care system. They have kept the health and social care system going through the pandemic, but carers feel their efforts are still too often overlooked by politicians, the media, and the public at large.

Carers have seen their physical and mental health deteriorate as they have provided more care with less support during the pandemic, and over 7 in 10 carers have been unable to take any breaks at all since March 2020⁴, with many also not having access to breaks before then⁵.

Carers in Wales were struggling long before the pandemic, leaving carers, and those they care for, with insufficient support. Our *Track the Act* series of annual evaluations, conducted since 2016, has found that the legal rights of carers in Wales to information, assessments and support contained within the Social Services and Well-being (Wales) Act 2014 have consistently not been delivered according to the carers who responded to our annual surveys⁶.

Against this backdrop, urgent action in Wales is needed to support carers. Pre-pandemic services must be fully reinstated and additional services put in place to help carers recover from the pandemic.

Long-term and substantial reform to social care is long overdue. Autumn 2021 saw the announcement of the UK-wide Health and Social Care levy, and the commitment within the Welsh Government and Plaid Cymru *Co-operation Agreement*⁷ to explore the creation of a National Care Service for Wales. If policy makers recognise the importance of carers in social care reform, these developments could provide some hope for carers in Wales moving forward.

This was the state of caring in Wales in 2021. If the health and social care systems are to recover, they must value and put in place support services for carers to enable them to carry on. 2022 must begin with urgent action to meet the needs of unpaid carers who have gone above and beyond during the pandemic.

1 Carers Week: Carers Week 2020 Research Report (2020)

2 *ibid*

3 Carers Wales: Unpaid carers in Wales have saved £33 million every day of the pandemic (2020)

4 Carers Week: Breaks or breakdown Carers Week 2021 report (2021)

5 Carers Wales: State of caring 2019 (2019)

6 Carers Wales: Track the Act Briefing 5: Monitoring the 4th year of implementation of the Social Services and Well-being (Wales) Act 2014 (2020)

7 Welsh Government: The Co-operation Agreement: 2021 (2021)

Carers' finances



Caring often results in additional costs for unpaid carers, from equipment and care costs to increased expenditure on utilities and transportation.

Many carers also feel they must reduce their hours at work to balance caring duties with employment, compounding financial pressures as their income is cut.

When asked to describe their current financial situation, 36% of carers in Wales said they were struggling to make ends meet. 23% are, or have been, in debt as a result of caring and a further 8% cannot afford utility bills such as electricity, gas, water or telephone bills. 40% of carers with financial concerns said they were cutting back on hobbies or leisure activities, and 28% said they were having to see friends and family less, demonstrating how financial pressures can add to the isolation and poor wellbeing experienced by many carers.

Over a third of carers (36%) said their financial situation had deteriorated since the COVID-19 pandemic began. Caring can be expensive and 65% of unpaid carers are spending their own money on care, support services or products for the person they care for. Carers in Wales are spending on average £109.75 per month on caring, or over £1,300 per year. There is a clear financial penalty to stepping in to care for a loved one.

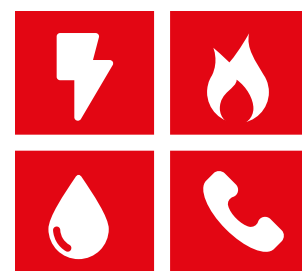
Energy bills have soared across the UK, and 11 million households have on average faced an increased fuel bill of £139, rising to £153 for another 4 million households that use prepayment meters. Alongside the removal of the £20 uplift to Universal Credit, the end of the furlough scheme⁸ and concerns about increasing inflation, there is widespread concern around personal finances and carers are no exception.

Indeed, carers are more likely to be in financially precarious situations and less able to cope with these additional costs. Two-thirds (66%) of carers said they were spending more on bills or shopping compared with before the pandemic, demonstrating how vulnerable carers are to increases in the cost of living this winter. Over a quarter of carers (26%) are also having to spend more on equipment or products for the person they care for.

Looking to the future, less than half of carers (45%) are confident they will be able to manage financially over the next 12 months, while 55% of carers are worried about the impact caring will have on their finances. 71% are worried about their ability to save and plan for the future, strongly suggesting that many carers face immense barriers to improving their financial situation.

8% of carers
cannot afford
utility bills

like electricity, gas,
water or telephone



23%

of carers

did not feel
confident

that they will be able
to manage financially
over the next year



Table 1: How carers who are struggling financially said they were managing:

Cutting back on luxuries	42%
Cutting back on hobbies or leisure activities	40%
Cutting back on seeing family and friends	28%
Using savings	25%
Using credit cards	19%
Using an overdraft	17%
Cutting back on essentials like food and heating	16%
Borrowing money from family and friends	15%

⁸ BBC News: Energy price cap: Millions of households face higher gas and electricity bills (2021)

Support and services

Carers often need practical and emotional support to enable them to provide the care their loved ones need while also looking after their own health and wellbeing. Support for carers can range from paid care workers who assist with practical tasks such as bathing and dressing, to local voluntary or third sector groups who provide information and services which enable carers to have a break from their caring role

These can include things like sitting services that look after the cared for person as well as short breaks or respite opportunities for the carer. In 2019, before the pandemic, 21% of carers in Wales received no support at all for their caring role⁹. Since then, the situation has become more serious due to the COVID-19 pandemic.



9 Carers Wales: State of caring 2019 (2019)

In 2021, carers in Wales reported that there were many barriers to accessing services. Two in five carers (40%) say they are unaware of services and sources of support for carers in their local community. This presents compelling evidence that the legal duty on local authorities to proactively offer carers information and advice contained within the Social Services and Well-being (Wales) Act 2014 is not being fulfilled in practice by many councils. 32% of carers say the care and support services available to them do not meet their needs or the needs of the person they care for, and understandably 31% are reluctant to access services due to fears around the COVID-19 infection risk for themselves and the person they care for.

Twenty two months on from the beginning of the pandemic, and long after Wales emerged from the lockdown which ended in early Spring 2021, carers in Wales are still seeing widespread disruption to the services they rely on. This is forcing them to provide more care with less support at great cost to their own health and wellbeing. Only 8% of carers say that day services for the person they care for have fully reopened, with 31% reporting that while they have been able to access the service it has been on a reduced basis.

Similarly, just 8% of carers say that care homes which enable carers to have short respite breaks are fully reopened, and only 16% have found that sitting services are fully operational. Nearly three-quarters (72%) of carers in Wales reported¹⁰ that they have been unable to take any breaks at all since the pandemic began in March 2020.

While support from paid care workers was the most likely service to have reopened, only 40% of carers reported that this service had actually fully reopened. This still leaves the majority of carers having reduced or no support at all from paid care workers. Unpaid carers are facing immense additional caring burdens caused by the recruitment and retention challenges within the social care workforce, risking their ability to continue providing care to their loved ones.

Only 20% of carers report that NHS funded care has fully reopened, with 44% saying they still have reduced or significantly reduced access to this form of support. Already exhausted by the pandemic, unpaid carers desperately need local authorities and health boards to prioritize the recovery and restoration of the services carers rely on. Without this investment, the health and wellbeing of carers and the ill, disabled and elderly people they care for will deteriorate, placing further burdens on the already over-stretched health and social care systems.

Table 2: State of services and support for carers where this option or service applied to them

	This is fully re-opened	I still have reduced access to this	I have significantly reduced access to this	I have chosen not to use this service	This service has closed
Day services	8%	12%	18%	28%	33%
Care homes for short respite breaks	8%	15%	16%	48%	14%
Residential care	7%	13%	10%	64%	7%
Activities provided by local carers' organisation	8%	27%	26%	24%	16%
Activities and support provided by a local charity	11%	27%	27%	19%	15%
Support from paid care workers	40%	14%	14%	23%	4%
Sitting services	16%	12%	18%	42%	12%
Other breaks services	5%	13%	21%	39%	22%
NHS funded care	20%	19%	26%	27%	9%

10 Carers Week: Breaks or breakdown Carers Week 2021 report (2021)

Looking to the future

Carers are fearful about the future of services. 66% believe services will be further reduced, 51% are unsure what services they will be able to access in the next 12 months and only 9% are confident that local respite services will continue into the future.

The social care system in Wales is in dire need of reform if society believes that ill, disabled and elderly people deserve high quality care that consistently meets their needs and that unpaid carers shouldn't have to sacrifice their health, personal lives, careers and finances to care for loved ones.

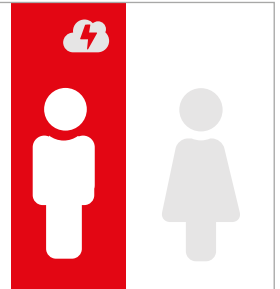
Against the backdrop of the planned UK-wide Health and Social Care levy, the Welsh Government-Plaid Cymru *Co-operation Agreement* of November 2021 has promised to work towards the creation of a National Care Service in Wales. When asked for their top three priorities for social care reform, the leading priority chosen by 66% of carers was access to better quality and more personalised care for their loved one, demonstrating the selfless nature of caring. Second, access to suitable breaks from caring was chosen by 57% of carers, and 49% of carers prioritised access to care that was tailored to their needs.

If any future fundamental reform of social care in Wales is to achieve its objectives, the needs of unpaid carers must be understood and addressed.

66% of carers
**believe services will
be reduced**
next year



51%
of carers said they are
**unsure what
services they will
be able access**



57%
of carers said they
**want suitable
access to
breaks**



Carer's assessments



The Social Services and Well-being (Wales) Act 2014 gives carers a right to have a Carer's Needs Assessment and to have their support needs met if they meet eligibility criteria. Any carer can request an assessment, and the Act also places a duty on local authorities to offer a Carer's Needs Assessment to any carer who may require support, regardless of perceived eligibility.

Despite this duty on local authorities, just 21% of carers reported having an assessment in the last 12 months. Of those who had undergone an assessment, 28% had been made to wait more than six months to have their needs assessed, risking the health and wellbeing of both the carer and the person they care for. Of those who had not requested a Carer's Needs Assessment, 37% of carers did not know what it was and 20% did not feel the process would be beneficial to them.

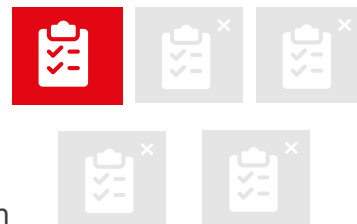
These findings strongly suggest that a core component of the 2014 Act, and the main avenue for carers to arrange support for themselves and the person they care for, is not being delivered. These findings also mirror the findings of our annual Track the Act evaluations conducted since 2016 which have found that the majority of carers in Wales have not received a Carer's Needs Assessment at all since the Act came into force in 2016¹¹.

Turning to the quality of assessments for those who have undergone them, 72% said that their assessment did not adequately consider the support they needed to look after their own physical and mental health, and 58% said their ability and willingness to provide care was not adequately addressed. This is despite the principle that carers should only provide care if they are "able and willing" being embedded throughout the Social Services and Well-being Act. Just 20% said their need to have regular breaks from caring was thoroughly considered in their assessment and reflected in the support they subsequently received.

The pandemic has demonstrated the importance of contingency planning, with many carers deeply worried about what would happen to the person they care for if they were taken ill and were unable to provide care. Regrettably, only around a quarter (27%) of carers who had undergone an assessment said that it fully considered the support that would have to be put in place for the person they care for should an emergency occur. This presents clear and potentially serious risks to the health of many people who rely on carers in Wales.

21%

of carers have had
**a carer's
assessment**
or re-assessment in
the last 12 months


37%

of carers
**did not know
what a carer's
assessment
was**


20%

of carers
**do not feel
they would
benefit from a
carer's
assessment**



¹¹ Carers Wales: Track the Act Briefing 5: Monitoring the 4th year of implementation of the Social Services and Well-being (Wales) Act 2014 (2020)

Carers' health and wellbeing



For many years there has been growing evidence that taking on unpaid caring duties has clear detrimental effects on a person's physical and mental health. Recently, the research published for Carers Week in June 2021 found that 73% of carers in Wales described themselves as exhausted and worn out as a result of caring through the pandemic, with 40% of carers saying they felt unable to manage their caring role¹².

A recent report by Public Health Wales, informed by a longitudinal cohort of carers, concluded that there is a clear association between being an unpaid carer and poor health, irrespective of deprivation levels¹³. Unpaid carers often have to perform physically demanding tasks such as operating equipment or lifting the person they care for, and frequently experience feelings of stress, worry and guilt.

¹² Carers Week: Breaks or breakdown Carers Week 2021 report (2021)

¹³ Public Health Wales: Unpaid carers in Wales: The creation of an e-cohort to understand long-term health conditions amongst unpaid carers in Wales (2021)

Physical health

When asked about their physical health in general, carers described their physical health as follows:

Table 3: Carers' reports of their physical health

	Very good	Good	Fair	Bad	Very bad
Physical health	6%	24%	43%	21%	5%

In the State of Caring survey, over 1 in 4 carers (26%) rated their physical health as bad or very bad, while over a third (36%) said their mental health was bad or very bad. Many carers have to cut back on seeing friends or family to manage their caring role, and 36% of carers in Wales say that they are often or always lonely. On a 1 to 10 scale, carers sadly rate their satisfaction with their lives at just 4 out of 10, and their anxiety levels as 6 out of 10.

Encouragingly, 68% of carers say their GP knows that they are an unpaid carer, and 42% said their GP had made them aware of the free flu jab carers can access. Less positively, only 6% of carers said their GP has discussed the possibility of flexible or double GP appointments to fit around their caring role, and just 5% of carers said their GP had signposted them to information to help them care or had given them such information. This is a missed opportunity to make sure carers are informed of where they can access support.

Mental health

When asked about their mental health in general, carers described their mental health as follows:

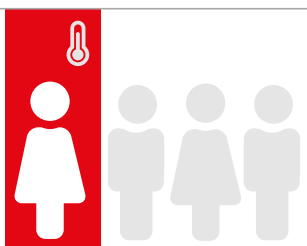
Table 4: Carers' reports of their mental health

	Very good	Good	Fair	Bad	Very bad
Mental health	7%	19%	41%	26%	8%

At a time of disrupted access to services and increased public health concerns, the large majority of carers (71%) say the condition of the person they care for has worsened over the course of the COVID-19 pandemic. Regarding their own health, 60% of carers say their physical health has deteriorated during the pandemic, 71% say their mental health has worsened and 76% say their ability to take breaks from caring has reduced, impacting their ability to have respite from the demands of caring.

26%

of carers said their
physical health
was
bad or very bad



34%

of carers said their
mental health
was
bad or very bad



Technology

Of all the available technology that could help them to manage their caring role, carers chose digital ways of keeping in touch with family/the person they care for, and remote healthcare such as online GP appointments as most likely to make their caring role easier, with 38% and 37% saying this respectively. Thinking about how their use of technology has changed and how they would like to continue to adopt these changes moving forward, 44% said they would like to continue accessing health and social care services digitally in the future.



However, the 28% of carers who disagreed suggests lingering concerns that in-person provision may not be re-established. Mixed views could be found regarding online support services such as virtual networks and activity groups, with 31% saying they would like to continue to access these digitally, while 30% disagreed, underlining the importance of both in-person and online support provision moving forward. Encouragingly, the large majority of carers were confident in their ability to access digital technology, with only 16% of carers saying they felt a lack of digital skills was holding them back, though upskilling carers in digital skills should remain a priority as proficiency with digital technology tends to vary with age.

75% of carers would like there to be data systems that flag that they are a carer on their patient and care records, and 76% said they would like data systems to record that they are a carer on the records of the person they care for. These sentiments, along with data over several years from our Track the Act series that the large majority of carers are not identified as carers and offered support, reaffirms our belief that a national register of unpaid carers would help health and social care services to identify carers they interact with and would ensure carers are offered information and support more consistently

68% said they would like to see systems that make booking appointments and talking to health and care staff easier, and 64% said they would welcome greater information sharing between services so they can avoid having to explain their situation again and again. This underlines the importance and likely efficiency benefits of good information sharing between services.

Digital access to services and records would make 66% of carers feel more in control of their own health and wellbeing, and 59% said this would help them to better manage their caring role.

76%

of carers would like to be

flagged as a carer on the care record on the person they care for's care record



Carers and Employment



Employees in every industry are balancing their jobs with unpaid caring responsibilities. Before the pandemic, it was estimated that 223,000 employees in Wales also had caring responsibilities¹⁴, a number that was estimated to have risen to 345,000 at the height of the pandemic¹⁵.

The COVID-19 pandemic has had wide-ranging impacts on the world of work, and while some changes have helped working carers to balance their employment with caring, it is clear much more needs to be done to ensure this significant proportion of the workforce can participate fully in the labour market.

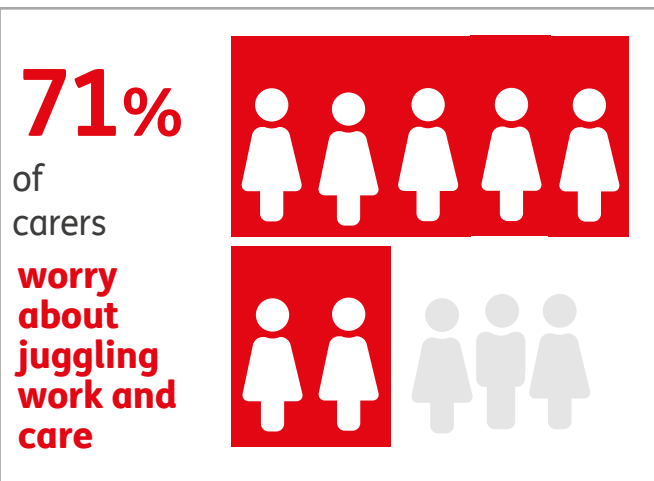
When carers in employment feel they must reduce their hours or give up work altogether, employers suffer from increased staff turnover, individuals may lose their skills and deplete their savings, while society at large bears the costs of unemployment, such as increased welfare payments.

The pandemic has had a dramatic impact on the working patterns of carers in employment. 51% are now working from home on a full or part-time basis, and 11% have had to reduce their working hours to manage caring. Three quarters (76%) of carers in employment feel tired at work because of their caring role, 7 in 10 (70%) carers feel anxious about caring while they work, and 71% worry about their ability to continue juggling work and caring. Even when carers are able to maintain employment alongside caring, many face having their career curtailed with 63% saying they have given up opportunities at work due to caring. Maintaining employment has a positive impact on the wellbeing of carers, with 64% saying that work gives them a break from their caring role.

Turning to measures that would help carers stay in employment, 21% said that without the option to work from home most or all of the time they would be at risk of reducing their hours or giving up work altogether, and 16% said they faced the same risks if they did not have the option to work from home some of the time. The UK Government have confirmed their intention to introduce a right to 5 days unpaid carers leave, but many employers already offer paid carers leave to remove a financial detriment to taking time off to care. 55% of working carers in Wales said that they need paid carers leave and 18% said they would have to consider reducing their hours or leaving their jobs altogether if this was not available.

While it is welcome that 6 in 10 carers said their employer was understanding of their caring responsibilities, 33% said they needed their employer to be understanding, suggesting many employers could do more to understand and support their employees with caring responsibilities. A fifth of working carers (22%) said their employer had introduced new measures over the course of the pandemic which had helped them to juggle work and care, but a larger proportion (33%) said their employer had not.

Employers in all sectors should commit to learn from and replicate good practice measures which help their workforce to balance work and caring, and the Welsh Government should proactively encourage and incentivise the adoption of such measures.



Recommendations

The Welsh Government should:

- Use their social partnership mechanisms to engage with the public, private and third sectors, including trade unions, to improve awareness of the challenges facing employees with caring responsibilities and promote best practice across Wales.
- Ensure that Welsh Government funding is only provided to organisations fulfilling, or working towards fulfilling, the definitions and characteristics of fair work. This must include requiring employers to adopt carer-positive practices.
- Extend the recently announced £100 winter fuel support payment to people in receipt of Carer's Allowance.
- Provide targeted funding to local authorities for the immediate full restoration of disrupted carer services with an accompanying increase in funding to meet the backlog of need created by the pandemic. The Welsh Government should also work with local authorities to mitigate further disruption to carers services that may arise due to expected restrictions in response to the Omicron variant.
- Increase flexibility in the use of direct payments and require local authorities to provide additional direct payments to carers so they can source alternative provision in light of challenges within the social care workforce.

Local Authorities should:

- Ensure any hardship funds or grant schemes they operate are accessible to carers.
- Issue local guidance that emergency contingency planning should be discussed in all Carer's Needs Assessments.
- Take steps to establish, or fully re-instate, carers services to meet the backlog in carer need created by the pandemic. Local authorities should also ensure they mitigate any further disruption to carer services and still deliver respite opportunities for unpaid carers should further restrictions be introduced in response to the Omicron variant.

Local Health Boards should:

- Review their guidance to GPs regarding support for unpaid carers.
- Investigate how a person's status as an unpaid carer can be more consistently and seamlessly recorded on their health records and those of the person they care for.



Carers Wales, part of Carers UK, is a national charity working to improve the lives of unpaid carers in Wales. We conduct research and publish reports on the experiences of unpaid carers in Wales and then campaign for policy changes. We operate the Wales hub of Employers for Carers, helping employers to support the carers in their workforce. Our Listening Support Service provides a listening ear for carers and our online Me Time sessions help carers unwind and socialize. We also produce guides and factsheets to help carers understand their rights, with content shaped by carers who volunteer with us.

Please contact Carers Wales to discuss this research or our wider work supporting carers in Wales.

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