

State of Caring in Wales 2022

A snapshot of unpaid care in Wales

November 2022



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

A record number of carers and former carers shared their experiences this year, with over 1,000 carers taking part in the survey. 1,043 of these are currently providing care. This makes this the largest State of Caring survey carried out by Carers Wales to date.

About this research

Carers UK carried out an online survey between July and September 2022. A total of 13,415 carers and former carers responded to the survey. Of the respondents to the survey:

- 84% are female, 15% are male, and 1% describe their identity in another way.
- 35% consider themselves to have a disability.
- 4% are aged 0-34, 15% are aged 35-44, 26% are aged 45-54, 35% are aged 55-64, 15% are aged 65-74 and 5% are aged 75 and over. These skew younger than the UK average.
- 4% identified as lesbian, gay or bisexual, with 2% choosing to self-describe.
- 2% described themselves as Black, Asian or from a mixed/multiple ethnic backgrounds.
- 20% also have childcare responsibilities for a non-disabled child under 18.
- 42% of current carers are in employment. Of those, 21% work full-time, 16% part-time and 5% are self-employed. 31% are looking after the home/family/dependents full-time and 19% are retired. 6% are unable to work due to sickness or disability. 1% are unemployed/looking for paid work and 1% are in education.
- 34% have been caring for 15 years or more, 15% for 10-14 years, 23% for 5-9 years, 26% for 1-4 years and 3% for less than a year.
- 46% care for 90 or more hours each week, 16% care for 50-89 hours, 26% care for 49 hours and 12% have been caring for 0-19 hours.
- 70% care for one person, 21% care for 2 people, 4% care for 3 people and 4% care for 4 or more people.

As not all respondents completed every question in the survey, a number of the figures given in this report, are based upon responses from fewer than 1,043 carers but always more than 200 carers.

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The State of Caring: context

Across Wales, hundreds of thousands of people provide unpaid care for an ill, older or disabled family member or friend. The number of unpaid carers has been increasing as the population ages and healthcare continues to improve.



We estimate that the total number of carers in Wales today is around 500,000¹, which means that nearly 1 in 4 adults are providing care². In the next few months, updated data on caring will be published as part of the Census 2021, giving us new insights into the number of carers in Wales.

Carers' support was valued at £33 million per day during the pandemic, or £112 billion a full year – exceeding the value of the NHS³. But this comes with high personal costs. Many carers find that their relationships are impacted, that they often struggle to balance work and care, and that they are facing their own health problems as a result of their caring role. There are also significant financial costs associated with caring. Carers often use their income or savings to pay for support services and care equipment.

We already know that carers face poorer health outcomes, with a high proportion of carers struggling with mental and physical health problems and experiencing low levels of well-being. However, the huge pressures placed across the NHS, resulting in delays in obtaining both primary and secondary health care appointments, together with the record levels of demand for social care services, means many carers may not be getting the support they need.

These struggles in Wales, due to the higher average population age⁴ and lower economic output⁵, are felt sooner and deeper than in other areas of the UK. This has been evidenced earlier in the year by more referrals to debt services and food banks per capita than the UK average⁶. This means carers in Wales are already closer to the point of crisis.

¹ 25 Calculated by Carers UK based on ONS Population Estimates 2020

² Carers UK (2022) Make Caring Visible, Valued and Supported (https://www.carersweek.org/media/qf0p5u4t/carers-week-2022-make-caring-visible-valued-and-supported-report_final.pdf)

³ Carers UK (2020) Unseen and undervalued (https://www.carersuk.org/images/News_and_campaigns/Unseen_and_undervalued.pdf)

⁴ Census 2021 - Population and household estimates, England and Wales: Census 2021 Census 2021 rounded population and household estimates for local authorities in England and Wales, by sex and five-year age group

⁵ <https://www.ons.gov.uk/economy/grossdomesticproductgdp/bulletins/gdpukregionsandcountries/octobertodecember2021>

⁶ Citizens Advice Cymru - Wales: Cost of living briefing

Executive summary

This report contains a snapshot of carers' experiences in 2022, capturing the impact that caring has on carers' lives and evidencing the policy recommendations that would improve this.



This year, with the cost-of-living crisis, carers have faced unprecedented pressure on their finances. A quarter of carers (26%) said they were cutting back on essentials such as food or heating, and over three-quarters (87%) said that the rising cost of living is one of the main challenges they will face over the coming year.

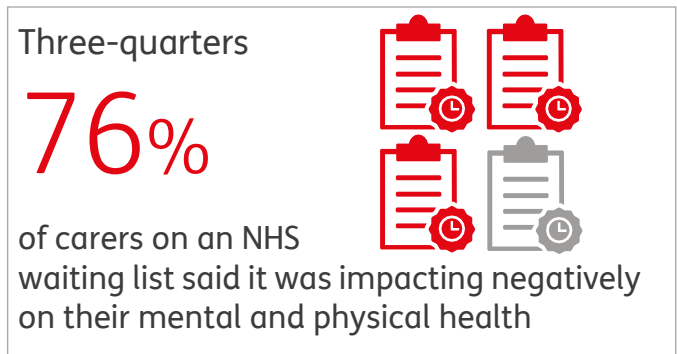
Many carers have been finding ways of saving money, but this can be difficult for those who need to use life-saving care equipment or ensure the person they care for is kept warm.



Nearly three-quarters (72%) said they were ‘extremely’ worried about managing their monthly costs. Carers with an income of under £1,000 were even more likely to be ‘extremely’ worried (87%). These financial worries have been having a negative impact on carers’ mental and physical health. 74% of carers agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health. Nearly all carers who were struggling to make ends meet (89%) agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health.

With the health and social care system under intense pressure, many carers have experienced delays in accessing healthcare appointments and services. A fifth (20%) of carers who had requested a GP appointment said they had had to wait over a month for this and two in five (41%) of carers who were waiting for specialist treatment or assessment had been waiting for over a year. This has caused additional stress and anxiety and resulted in many carers feeling isolated and forgotten about. 76% of carers waiting for specialist treatment or assessment said that waiting was having a negative impact on their mental or physical health, with 46% of those strongly agreeing. Many carers told us that they are experiencing considerable physical pain as a result of an untreated condition, making their caring role more difficult.

Many carers are struggling with poor mental and physical health. Nearly a quarter said their physical health was bad or very bad (24%) and 34% said their mental health was bad or very bad. Nearly a third of carers (32%) said they felt lonely often or always. Although carers are providing many hours of support to the person they care for, few are taking a break from caring, resulting in tiredness and, in some cases, exhaustion and burnout. 42% of carers haven’t taken a break from their caring role in the last year. Many carers would like to do more physical activity, to improve their health, but simply don’t have the time to do so. Nearly half of carers (47%) said they had been less active in the last 6 months.

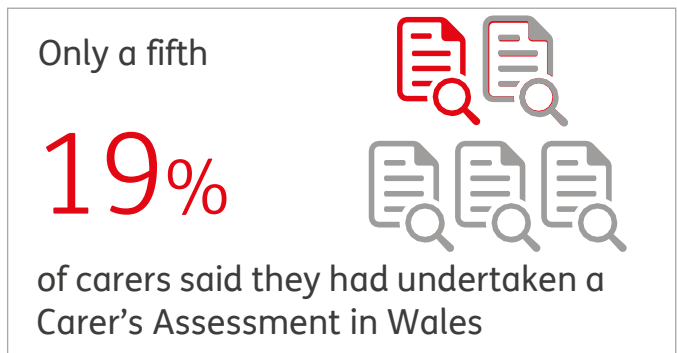
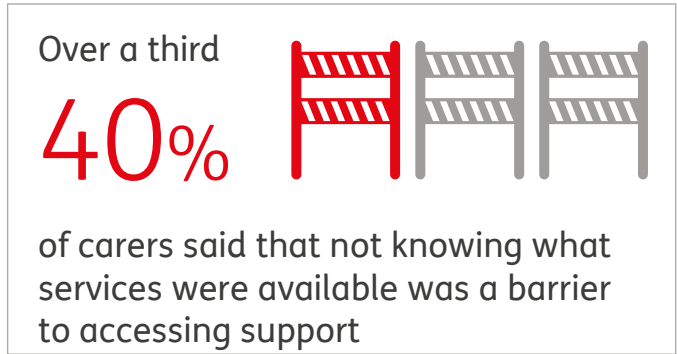


While public health measures around COVID-19 have significantly reduced, the pandemic continues to impact carers' lives, with some carers still shielding or reducing their contact with others to protect themselves or the person they care for. A fifth of carers (20%) said that concerns over catching COVID-19 were a barrier to accessing services. Although support services may have now reopened for some, carers are unaware of the available support, or reluctant to access it due to concerns that services do not meet their needs or are unaffordable. Over a third of carers (40%) said that not knowing what services were available was a barrier to accessing support. With many services being reduced or cut completely, carers are extremely worried about the future: 57% said they were uncertain about what practical support they might be able to access in the next 12 months.

This year, only a quarter (19%) of carers said they had undertaken a Carer's Needs Assessment in Wales and, of those who had, many were frustrated that the assessment has not led to any improvements in the support provided to them. 43% of carers who had not had an assessment said that a barrier was not knowing what an assessment was. Many carers do not recognise themselves as a carer, which can mean they are not getting the support they need. Half of all carers (52%) took over a year to recognise their caring role, with over a third (39%) taking over three years to recognise themselves as a carer. 47% of carers stated that seeing themselves primarily as a family member or friend was a barrier to identifying themselves as a carer.

Supporting carers to stay in, or return to, paid work, is essential to ensure that carers can live a life free from poverty in older age. While increasing numbers of employers are recognising the importance of supporting carers in the workplace, it is essential that employers maintain flexibility as they welcome employers back to the office, so that people can juggle work and care. Concerningly, 77% of carers worry about continuing to juggle work and care.

To help those with caring responsibilities to continue working, Carers Wales (as part of Carers UK) continues to advocate for better support in the workplace, including Carer's Leave. This year, Wendy Chamberlain MP introduced a Private Members Bill that would introduce a landmark new right for employees in Great Britain with caring responsibilities of up to one week of unpaid Carer's Leave each year, which we are strongly supporting.



More than half (55%) of carers say they need paid Carer's Leave to help them balance work and care, while a third (33%) say they need unpaid Carer's Leave to do so.

The Welsh Government and public authorities have taken a range of actions to provide carers with help and support, but this report shows that more must be done.

Recommendations

UK Government

- The UK Government should continue to support the Private Members Bill tabled by Wendy Chamberlain to introduce a new right to unpaid Carer's Leave in the workplace. Forward-thinking employers should adopt this provision without delay and consider joining the many employers who offer paid Carer's Leave to their employees.
- The UK Government should uprate benefits in line with inflation earlier than announced, increase the earning's limit for Carer's Allowance and provide a supplementary payment to all Carer's Allowance recipients.
- Welsh Government should ensure unpaid carers are considered as an at-risk, priority group in all Welsh Government anti-poverty and anti-fuel poverty and strategies and policies.
- Welsh Government should expedite their work exploring the creation of a Carers Register which we believe could improve identification of carers and connect carers to vital information.
- Welsh Government should support carers to stay in work by encouraging employers to co-create carers policies for the workplace with carers and their representatives, in keeping with the Welsh Government's commitment to fair work and social partnership.

Welsh Government

- Welsh Government should include unpaid carers in the planning and resourcing of the health and social care system.
- Welsh Government should prioritise additional investment in carers, social care, local government and health when allocating the £1.2 billion Barnett Consequential for Wales resulting from the UK Chancellor's Autumn Statement.
- Welsh Government should publish an update on the progress of re-opening local services for carers. A year and a half on from the last lockdown in Wales, it is unacceptable that many services are still operating at significantly reduced levels and some appear to be closed entirely.
- Welsh Government should commit to repeating the Fuel Support Scheme in early 2023 and at least twice yearly until the cost-of-living emergency passes.
- Welsh Government should explore how future payments to mitigate the cost-of-living emergency can be provided to carers who are not eligible or do not receive Carer's Allowance (including those who are above pension age or those with an underlying entitlement and who do not claim other means-tested benefits).
- Welsh Government should clarify the timescales for the recently announced rapid review of carer's needs assessments.

NHS Wales

- NHS Wales needs a strategic approach to identifying carers so carers can be identified systematically and proactively. Health Boards must review the processes by which carers are provided with information and review the information and support they offer to carers to ensure it is meeting their needs.
- NHS Wales needs to consider caring responsibilities when assessing the urgency of clinical treatment plans.

Local Authorities

- Local authorities should expand their local grants and hardship funds, proactively promote them to carers, review eligibility criteria and consider elements of discretion to remove barriers to carers applying.
- Local authorities should clarify and publish what services are currently available for unpaid carers in their area.

Financial impact of caring



Our latest survey found that carers are continuing to face financial difficulties, with over a quarter of carers struggling to make ends meet. Carers face additional costs as a result of care equipment and increased fuel costs, and the cost-of-living crisis has meant that many carers are no longer able to afford utility bills or food.

Key findings

- Just under a third (32%) of carers said they were struggling to make ends meet. Carers in receipt of Carer's Allowance were more likely to be struggling to make ends meet (39%). 16% of carers said they were unable to afford utility bills
- Carers who had been caring for longer were more likely to be struggling financially. 20% of people caring for over 5 years were in debt as a result of caring, compared to 15% of people caring for less than 5 years.
- Carers who were struggling to make ends meet were more likely to be cutting back on spending. More than a quarter of carers (26%) said they were cutting back on essentials such as food or heating, nearly twice as many compared to 13% last year. Carers receiving Carer's Allowance were even more likely to be cutting back on food and heating (36%).
- The majority of carers (72%) said they were 'extremely' worried about managing their monthly costs. 87% said that the rising cost of living was one of the main challenges they would face over the coming year. Both are 10% higher than the UK average.
- 74% of carers agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health. Nearly all carers who were struggling to make ends meet (89%) agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health.
- Three in five carers (60%) said that they need more financial support.

An overview of carers' finances

72% of carers said they were worried about living costs and whether they would be able to manage in the future. Nearly a third (32%) of carers said they were struggling to make ends meet. 16% said they were unable to afford utility bills, 21% said they were in debt as a result of caring and 22% said they were struggling to afford the cost of food. .

“ I forage or look for free food and stuff. I depend on my son's benefits to pay bills”

“ I've got clothes which would look shabby on a scarecrow, I cut my own hair, I try to be economical with toilet paper”

Carers in receipt of Carer's Allowance were more likely to be struggling to make ends meet (39%), more likely to be struggling to afford the cost of food (31%) and more likely to be unable to afford utility bills (25%).

Carers who were providing more hours of care were much more likely to be struggling financially. 34% of people caring for over 35 hours were struggling to make ends meet compared to 24% of people caring for less than 35 hours. Similarly, 17% of people caring for over 35 hours were unable to afford utility bills compared with 11% of people caring for less than 35 hours.

As the table below shows, compared to last year, carers are struggling to afford the most essentials with more than a quarter (26%) unable to afford essentials like food or heating and over a third (34%) unable to see friends and family who are most likely to be their core support networks.

Table one: How carers who are struggling financially

Measure taken	State of Caring 2022	State of Caring 2021	% increase over the last year
Cutting back on luxuries	49%	42%	17%
Cutting back on hobbies or leisure activities	44%	42%	10%
Cutting back on seeing family and friends	34%	28%	21%
Cutting back on essentials like food or heating	26%	16%	63%

Almost half of all carers (49%) said they were cutting back on luxuries, while 44% said they were cutting back on hobbies/leisure. These figures may be on the lower end as many carers said that they had already cut luxuries and hobbies out of their lives.

“ I don't do anything as I don't have the money or help for me to look after myself”

“ I am currently unable to afford to fill up fuel in my own Motability vehicle so don't use it.”

“ I can no longer plan days out or holidays for the future for my family”

“ Used to have a little holiday that I arranged, but I can't even have that now. Never again! As finances are all about survival now.

Several carers told us that the costs of care, such as buying certain foods to meet special dietary requirements, keeping the person they care for warm, and paying for life-saving caring equipment reduced their ability to make ends meet.

“ I skip meals and eat the leftovers. I cannot afford to buy the food they need as one is gluten intolerant. I wrap us all up in blankets and even though one is incontinent we shower once a day to cut down on costs we eat yellow sticker foods and never throw anything out. I feel life is not worth living but try to keep a brave face. I am so scared. I do think one of us will not survive the winter months.

I am now in despair.”

Many carers who were employed said they had had to cut back on their working hours to fulfil their caring responsibilities and were struggling to manage on a reduced income.

“ I have had to reduce my working hours significantly to care for my daughter and it is likely my fixed term contract won't be renewed... I am struggling to find any new work so my finances will be further impacted.”

Financial support

Nearly three-quarters of carers (72%) said that they need more financial support. Carers in receipt of Carer's Allowance were more likely to say they needed financial support (74%).

“ The benefits are not enough to live on now. Don't know what I will do as [the difference] keeps increasing. The only way to get the amount of money others seem to get is to be dishonest - how fair is that!!!”

We asked carers whether certain financial changes would make a difference to their experience as a carer. 84% of carers receiving Carer's Allowance said that an increase in the value of carers' benefits would be one of the main three things that would make a difference. A sixth of all carers (16%) said that a one-off payment to help with the cost of living would make a difference.

“ My energy bill was £34 last year, it's now £100. Groceries have gone up significantly. Driving is a significant element of my caring responsibilities, but we struggle to afford to put fuel into the car. Because of unexpected car trips and these increases, the £500 Welsh Government grant vanished within a month.”

26% of carers felt that widening eligibility criteria for carers' benefits so that carers in receipt of a pension can access would make a difference. 66% said that an increase in the earnings limit for Carer's Allowance would make a difference

Cost of living

Almost all carers (88%) said their energy bill had increased and that they were spending more on food and drink (85%). The majority of carers (71%) also said they were spending more on transport.

“ I am more than concerned that the increasing costs of motoring will prevent me from taking my elderly father to hospital appointments in neighbouring counties some 70miles away and the obvious costs of running and maintaining a diesel car...” so my finances will be further impacted.”

“ Just that day-to-day items are going up. I have recently had to take my old car off the road and cannot afford to purchase a new one to help when taking my mum for her hospital appointments and having to take additional time off work as we are reliant on buses or ambulances. I am finding it is eating into my annual leave.”

“ We are using our small savings more now especially due to diesel price rises getting to lots of appointments.”

Some carers were spending a significant amount of their income on energy costs: 39% of carers said that over 20% of their income went towards their gas and electricity bills.

“ If the cost of living goes up much more it will be a choice between eating or staying warm.”

“ The cost of gas and electric and diesel is already extortionate. It's really worrying that it's going to go up again when my gas and electric is already in arrears. You get no extra supplement for caring for more than one in Wales. There is no possible way of increasing our income due to caring responsibilities.”

A quarter of carers

26%

said they were cutting back on essentials like food or heating – nearly double the proportion last year



Carers who need to use life-saving care equipment or ensure the person they care for is kept warm were extremely concerned about the impact of further increases in gas and electricity.

“ *Doing online shopping is shielding so having to pay delivery fees/postage, buying more than is needed at the time so don't waste money on basket fees. Turning things off/down to save on energy bills as using more on medical equipment for my husband.”*

“ *These are costs we cannot make better. These are equipment that needs to be on and always on. It is his life on the line. He is home with a lung condition The same as being in a hdu or in intensive care.”*

We asked carers to tell us more about how the cost of living crisis had impacted on them. Some carers told us how they were taking various cost-saving measures, such as buying reduced-price items, shopping in cheaper stores or buying second-hand, wearing warmer clothes rather than putting the heating on, washing clothes by hand, sharing bath water, submitting regular meter readings to ensure their bills were accurate, growing their own food or batch cooking, and being more careful about turning lights off. However, many carers were taking more drastic measures, such as walking long distances rather than paying for a bus journey, taking cold showers, delaying dental treatment, and sitting in the dark.

“ *I can't afford to buy fruit and vegetables because they are so expensive, and I can no longer bath because of the cost of my gas bill. I have to shower. I am disabled myself and being able to bathe is one of the ways I manage my chronic back pain.”*

“ *Living in fear already cut back, and will throughout the day use as little electricity as possible, and no heating on until the children come home from school.”*

Concerningly, several carers told us that they were cutting back on food and skipping meals:

“ *Heat or eat.... soon it will be neither...”*

“ *We can't afford to live. We are just existing! We eat one meal a day as no more money for tea and breakfast, things are breaking in the house I can't replace, and mental health is worse 100% due to stress and worry.”*



Many carers said that the cost-of-living increases meant they were unable to spend any money on hobbies, days out and holidays. As a result, many felt their quality of life had reduced significantly.

“ Takes away money for leisure and seeing friends. This is essential to keep me as a carer sane.”

“ Important part of our week is getting out, this is mentally and physically essential for our well-being. We have had to stop anything that costs because we can no longer afford them. Our budget is now very tight because of the increase in prices. I am currently on a fixed-price energy plan but when that ends next year. I am really worried that we will have to start reducing our food bill to pay for energy.”

Some carers told us they had had to give up their homes, sell their car, or drop out of university due to the cost-of-living crisis.

“ I’ve sold my car to pay off the finance to free up £200 a month and car sharing.”

“ If costs continue to increase then we will have to consider selling our home and downsizing which will mean that my adult children will have to share a room. This will be a disaster for us as they will not cope with this and behaviours will escalate and I will feel even more desperate.”

Caring can have a catastrophic impact on a family’s finances because of the loss of work and the additional costs of caring. With disability and carers’ benefits falling behind in value, it’s clear that this situation is unsustainable for families throughout the UK in the short, medium and longer term. Given that there is such a clear link to mental and physical health - and that caring has been identified as a social determinant of health - this is not just a financial issue, but one of health inequalities.



Support and services



Carers often need practical support to enable them to carry out their caring role and to look after their own health and wellbeing. However, many carers are not getting the support they need, and many essential services remain unavailable to them, are inaccessible or unaffordable, or not of sufficient quality.

Key findings

- Over a fifth of carers (40%) said that not knowing what services were available was a barrier to accessing support. Many carers told us that they had never accessed certain services like sitting services and day services.
- A quarter of carers (24%) said the cost of care was too high. 29% said they needed more affordable care services for the person they care for. Over half (58%) said they were worried they won't be able to afford services or practical support in the future.
- 40% of carers said that services not meeting their needs were a barrier to accessing support.
- 57% of carers said they were uncertain about what practical support they might be able to access in the next 12 months.
- As we found last year, the biggest area of need identified by carers was more support to enable them to look after their health and wellbeing, with 66% saying they needed this support. 78% said the impact of caring on their physical and/or mental health was one of the main challenges they would face over the coming year.
- 60% of carers said that they would like better understanding and recognition of unpaid carers from the general public.

Access to services

Of those carers who believe they need and should be eligible for services, the vast majority of carers told Carers Wales that they had never had access to one or more services. Two-thirds had never had access to care homes for short respite breaks (66%) or residential care (64%).

Nearly half of carers did not get support in their caring role from paid care workers (47%) while only a third (36%) had NHS-funded care.

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

	Service has fully reopened	Services have been reduced or significantly reduced	I have chosen not to use this service	Service has been closed
Day Services	24%	31%	30%	15%
Care homes and short respite breaks	24%	21%	51%	4%
Residential care	16%	13%	70%	1%
Activities provided by local carers' organisations	25%	41%	29%	6%
Activities and support provided by a local charity	27%	42%	25%	6%
Support from paid care workers	46%	30%	21%	3%
Sitting Services	25%	28%	42%	4%
Other breaks services	16%	30%	42%	13%
NHS Funded care	28%	49%	16%	6%

The table above shows some concerning trends around carers' reluctance to use respite and breaks services with 70% choosing not to re-access residential care, 42% sitting services and 30% day services.

Carers gave a mix of reasons for why they have chosen not to access services ranging from concerns about inexperienced staff or lack of staffing, refusal from those being cared for to accept support, and worries about the cost of accessing services or the transport to attend to the lingering dangers of COVID.

“ Inexperienced care workers, leading to anxiety that my son is not an getting acceptable level of care.”

“ Less staff due to covid isolation. Less care staff generally. No back up so cancelled.”

“ My dad takes over caring for my mum on weekends which is the only break I have. My mum does not trust anyone else to help her and neither does my dad or me.”

“ My father was attending Tonna dementia day unit but it has still not opened. We were advised of another unit but the cost to travel and attend is in excess of £40 a day, which is more than we can afford.”

“ Day venue has partially reopened but my son still is not able to attend because of the limits on transport and numbers in the building.”

“ I am not interested in my family members going anywhere especially now because it is too dangerous during Covid-19 and we are still shielding.”

Even when carers are using services, many are still finding that there are limitations and restrictions on access with carers reporting that, on average, only a quarter of services are fully reopened. Alarming, this is consistent across social, private and third-sector support therefore unpaid carers are not getting the same level of support as before COVID.

Especially concerning is that carers report that less than half (46%) of care work support is fully re-established. Carers have told us about contracts being handed back, people being left without support and how they haven't been able to find private support when receiving direct payments.

Progress on re-opening services is disappointing overall. Only 24% say day services have fully reopened after Covid restrictions compared to 8% last year, sitting services just 25% (16% in 2021) and NHS funded care only 28% from 20% in 2021. This is a year of lost support for many unpaid carers.

“ My care company handed back the contract as they had no staff. I'm a physically disabled single parent of 3 children, two of whom have extensive additional needs.”

“ Day services have returned, but they have shorter hours meaning more hours for me. Respite care is simply not being delivered even though it is in the care plan, and I have begged for it to be delivered.”

“ Respite stopped a month before the first lockdown (2 years ago) and has yet to be made available to me even though I have requested a few months ago for some sort of respite to be reinstated I have heard nothing and it is available.”

Barriers to accessing support

We asked carers whether there were any barriers in accessing support. Over a third of carers (40%) said that not knowing what services were available was a barrier.

Nearly a quarter of carers (24%) said the cost of care was too high and 29% said they needed more affordable care services for the person they care for. 19% of all carers said that a reduction in charges to care would be one of the main financial changes that would make the most difference to them.

“ All my time & money goes on making sure my cared for accesses day services.”

“ The cost of day services and transport has increased, and it is taking a significant percentage daughter's benefit money.”

“ I have had to cut my hours as a registered nurse. It is not only the financial impact but the impact to my mental well-being. I love my daughter dearly, but to be reminded in all review meetings she is 2 to 1. But consistently being left to care for her on my own and having to keep us both safe is severely taking its toll. I fear for the future.”

22% of carers said that services not meeting their needs was a barrier to accessing support, a decrease from 32% last year. People who were caring for someone with a mental health condition were more likely to say that services not meeting their needs was a barrier (20%).

A fifth of carers (20%) said that concerns over catching COVID-19 was a barrier to accessing services, indicating that the pandemic is still affecting carers' ability to access support. Some carers told us that they were still shielding or restricting their activities.

We asked carers whether any other barriers were preventing them from accessing support. Barriers highlighted by carers included the increase in the cost of fuel preventing them from travelling to access support and struggling to access services during working hours. Many carers told us that the person they cared for did not want them to access any support, often because they did not accept that they needed any help. Several people caring for someone with a mental health problem said that the complex needs of the person being cared for meant they did not want any support:

“ We have an autistic non-verbal 8-year-old who is frustrated and violent towards his carers, we get very little practical support from social services.”

“ My mental health and own well-being needs are overridden by the wish of the person I care for not wanting services to the point that I now feel unable to care for them and unhappy in my own home.”

Carers who were not receiving support told us that they felt abandoned, exhausted and stressed:

“ I have access to no services now. I am at my wit's end. I am tired, No exhausted. Constant sleepless nights through care giving and no respite to enable me to do anything.”

Support in the future

When asked about the future, 57% of carers said they were uncertain about what practical support they might be able to access in the next 12 months. 57% said they were concerned that services would be reduced and 40% said they were worried they might lose access to voluntary sector services due to funding constraints. Only 9% said they were confident that they would have the practical support they need in the next 12 months.

Over half of carers (62%) told us that they were worried they won't be able to afford services or practical support in the future. Carers receiving Carer's Allowance were more likely to say they were worried they won't be able to afford services or practical support in the future (66%).

Table three: Carers' current needs

Carers needs	%
More support to be able to look after my own health and wellbeing	66%
More financial support	62%
Better understanding and recognition of unpaid carers from the general public	60%
Better recognition from the local council of my needs as a carer	60%
More support from the social security system (eg a rise in Carer's Allowance/Carer's Element)	51%
More breaks or time off from my caring role	47%
Better recognition from the NHS of my needs as a carer	46%
More support from the NHS or health care professionals	46%
Increased choice in which services I can access	40%
Support to prevent/reduce my loneliness/social isolation	40%
Better quality care services for the person I care for	37%
More information and advice about caring	34%
More affordable care services for the person I care for	30%
More support so I can maintain/build my relationships with others	28%
More support from family and friends	26%
More learning and training opportunities about caring	25%
Better support to return to or maintain paid work	18%
A more supportive employer to help me stay in paid work	11%

Carers struggling to make ends meet were even more likely to say they were worried they won't be able to afford services or practical support in the future (71%).

Carers' needs

We asked carers to tell us more about their current needs as a carer. The biggest area of need identified was more support to enable carers to look after their health and wellbeing, with 66% saying they needed this support. People caring for over 35 hours a week were more likely to say they needed more support with their health and wellbeing than people caring for less than 35 hours (70% vs 52%). Many carers told us that they had disabilities, health issues or mobility issues which made their caring role more difficult, while some felt that the demands of their caring role meant they were unable to look after their own health.

60% of carers said that they would like better understanding and recognition of unpaid carers from the general public, and over half of carers (60%) said that they would like better recognition from the local council of their needs.

Many carers told us that they felt their expertise was not acknowledged by services, while others were concerned that their hard work was unrewarded and unrecognised.

“ I think there is a whole army of carers out there working and caring for family members who are totally forgotten about and ignored completely. My main worry is getting ill....as my brother will see no one apart from the carers he sees 4 times a day.”

“ I’m now disabled myself as a result of caring for two without safe housing or equipment.”

“ Fractured my hip and my son spent two weeks in respite care as not enough carers to manage three visits per day.”

“ Trying to care for two 92 yr olds. One with dementia and one with incurable cancer. Very stressful and exhausting. I’m in my 70s so get very tired.”

Current challenges

One of the main challenges that carers said they faced in the coming year was the impact of caring on their physical and/or mental health, with 77% saying this would be challenging. People caring for over 35 hours a week were more likely to say that maintaining their health and wellbeing would be challenging than people caring for less than 35 hours a week (80% vs 71%).

Many carers who were employed said that returning to the office would be challenging and would impact their caring role. Other challenges identified by carers included coping with the person they care for moving into a care home, arranging end-of-life care and coping with bereavement.



Access to NHS services



Many carers are struggling with their own physical and mental health issues, yet too often are not getting the support they need. Long waiting times within the NHS and concerns about the quality of health and social care services are causing carers additional stress, negatively impacting their health and wellbeing, and impacting their ability to work.

Key findings

- 59% of carers disagreed that NHS services are well-coordinated, and that information is shared effectively. 52% disagreed that NHS staff provide them with the information, advice and support they need to be able to care well and safely.
- 20% of carers who had requested a GP appointment said they had had to wait over a month for this. 16% said the person they cared for had had to wait over a month.
- 41% of carers who were waiting for specialist treatment or assessment had been waiting for over a year. 43% said the person they care for had been waiting for over a year.
- 76% of carers waiting for specialist treatment or health assessment said that waiting was having a negative impact on their mental or physical health, with nearly half 47% of those strongly agreeing.
- 29% of carers who said that the person they cared for had been admitted to hospital in an emergency said that the admission could have been prevented through higher quality and more reliable care and support.
- 48% of carers who had experienced hospital discharge for the person they care for disagreed that they had been involved in the decisions about the discharge from hospital and the care and treatment needed, with nearly a third (30%) strongly disagreeing. 63% disagreed that they had been asked about their ability and willingness to provide care.
- Over a quarter of carers said it was unlikely or very unlikely they would complain about a health service (30%) or social care service (31%). 50% of carers said the main barrier was feeling like complaining would make little difference.

Carers' views on NHS services

We asked carers about their experiences of NHS services. 59% of carers disagreed that NHS services are well-coordinated, and that information is shared effectively, while 52% disagreed that NHS staff provide them with the information, advice and support they need to be able to care well and safely.

46% of carers disagreed that NHS staff recognised their knowledge and treated them like a partner in care.

Primary health care

We asked carers about their experiences of getting primary care appointments. Of those who had requested a GP appointment, 47% had waited less than a week and 52% said the person they care for had waited less than a week. However, 20% of carers said they had had to wait over a month for their appointment, while 16% said the person they cared for had had to wait over a month. Wait times were longer for dental appointments, where two-thirds (67%) of carers who had requested an appointment had waited over a month.

We asked carers to tell us more about any challenges in making or attending primary health appointments. Many carers told us that it was very difficult to contact GP surgeries to request an appointment, with calls going unanswered or put on hold. Several carers said that their GP surgery operated a first-come-first-serve appointments system, but because of the needs of the person being cared for, they were unable to call early in the morning. Some carers told us that telephone calls from GPs were often made at times that weren't convenient when they were busy with their caring role or when they were in a public place and unable to talk openly about their symptoms.

One in three

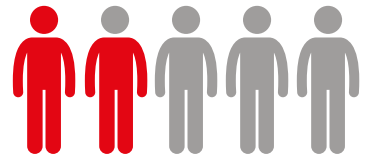
32%



unpaid carers said the emergency admission to hospital of the person they cared for could have been prevented with more care and support work

One in five

20%



of carers said they had had to wait over a month for a GP appointment

“I did not get a face-to-face appointment, only a telephone call. For my mum, myself, sister and neighbour had to keep trying to get hold of the GP, calling every half hour for four days, eventually got through and offered an in-surgery appointment only. Complete refusal of a home visit. Mum fell trying to get into a taxi to the appointment and went to hospital. Took a further 3 weeks of trying to contact the GP before they came for a home visit. Mum fell again the next day and went back to hospital. Hospital then advised us not to bother with the GP and to ring the ward if we have concerns over the next few months.”

“They only have same-day appointments now but that means you have to wait in a 20min phone queue early in the morning to get an appointment- if something goes wrong later in the day there's nothing”

More than half

52%

of unpaid carers felt that NHS staff didn't provide them with the information, advice and support they need to be able to care well and safely



“ Ask My GP service is only available for a few minutes every day at my GP surgery - typically between 8 am and 8.15am, sometimes as short as 1 minute! Having to await a return call at any time during the morning makes it difficult to secure privacy to discuss health concerns with the GP”

“ Unable to see the Dr at all, still doing phone consultation which does not work when dealing with a profoundly deaf person”

“ We have to book before 9.30 am to get an appointment, which usually isn't practical”

Several carers said that GP facilities were not sufficiently accessible to disabled people. Others told us that they or the person they care for would prefer a face-to-face appointment rather than a telephone appointment, particularly those who were deaf or hard of hearing or who had learning disabilities, but that these were not always available. Some carers also told us that they found it difficult to take the person they care for to appointments because they were anxious or distressed or reluctant to leave the house.

As a result of these difficulties in obtaining appointments, many carers are feeling stressed and anxious.

“ Have to phone 8:30, but by the time I get through all appointments are gone”

“ The challenge was making the appointment - it took an hour on hold”

In some cases, health problems have worsened because carers, or the person they care for, have not received the support they need, leaving them in pain, and unable to carry out their caring role or their day-to-day activities.

“ For myself, you can only access using Ask My GP. I've complained as this has taken over 3 weeks to be completed. My health is affecting my life.”

Due to frustrating experiences in trying to get appointments, some carers have decided not to seek help, which means they are not getting the treatment they need.

“ I find the biggest barrier and stress is getting passed the receptionist, who asks so many questions and can be very belittling. They seem to decide if you are needing an appointment but they are only getting very basic information. One time I called needing an appointment for myself. Husband and son. All completely different non-related issues. I was told I could only pick 2 of the three for appointment as they have lots needing this service. So I went without. It's also been challenging having telephonic appointments. It's not so personal. Trying to send photos of things to be assessed has been incredibly difficult”

Secondary health care

We asked carers whether they or the person they care for, were currently waiting for specialist treatment or assessment by a hospital doctor. The maximum waiting time for non-urgent, consultant-led treatments is 18 weeks from the day an appointment is booked when the hospital or service receives the referral letter. However, it is clear that many carers have been waiting much longer than this. Of those who were waiting for an appointment for themselves, 26% had been waiting less than 18 weeks. However, 41% had been waiting for over a year. Of those who said the person they care for was waiting for an appointment, 26% said they had been waiting less than 18 weeks and 43% said they had been waiting for an appointment for over a year.

76% of carers said that waiting for specialist treatment or assessment was having a negative impact on their mental or physical health, with 47% of those strongly agreeing. 60% said that waiting for specialist treatment or assessment was having a negative impact on the mental or physical health of the person they care for.

“ I have run out of energy to chase up my own postponed specialist assessments and treatment and can't face the barriers and battle to ask my GP for help.”

“ I dread going to bed as we have had to call the ambulance four times through the night. We are still waiting for my husband to receive a priority referral for suspected seizures. The last episode resulted in significant memory loss”

“ The person I care for has been on the waiting list for over 5 years for psychological help, he is a high suicide risk; it is a nightmare”

Some carers had decided to pay for private health care as a result of long wait times in the NHS, often using their savings to pay for this.

“ We have had to go private. This is the first time I’ve ever paid for private healthcare”

Emergency care

We asked carers whether the person they care for had experienced an emergency admission or unplanned visit to hospital since April 2021. Of those who had, 54% said this was because the health of the person they care for had deteriorated and 54% said this was due to an accident or unplanned emergency. 2% said this was because the impact of caring on their health meant they were unable to continue caring, and 1% said that health and social services had broken down, making it unsafe for the person they care for.

We asked carers whether the emergency admission was a result of any other reasons. Some carers told us that the person they care for had attempted suicide or expressed suicidal thoughts. Others said that the hospital admission was related to COVID-19.

We also asked carers whether anything could have prevented the emergency admission. Half of carers (50%) felt it could not have been prevented. However, 29% said that it could have been prevented through higher quality and more reliable care and support, and 21% said it could have been prevented by having more health services at home.

Hospital discharge

We asked carers whether they had experienced hospital discharge for the person they care for since April 2021 and, if so, what their experience had been like. Although 27% agreed that they were involved in the decisions about the discharge from hospital and the care and treatment needed, nearly half (48%) disagreed that they had been involved, of which over a quarter (30%) strongly disagreed.

65% of carers disagreed that they had been asked about their ability and willingness to provide care, and 63% disagreed that they felt listened to about this.

Several carers told us that waiting for treatment or assessment made them feel isolated.

“ No, I don’t feel it was managed well at all. As the next of kin, I was completely ignored and received no telephone calls about my father’s care or discharge.”

“ They said if I took him home, I would receive a full package of care ...they did not turn up and social services said they knew nothing about it”

“ Pressured to leave but no care plan was in place. Information from hospital differed from local services such as district nurse.”

“ Discharged from England to Wales. No care package. It was more like a leap of faith and hope that I would manage mum’s care”

“ Distressing to describe the impact as 'cared-for' was extremely poorly (Palliative care) when discharged home. Did not feel enough information and guidance was provided in regards to care and support plan - it felt 'done to us”



Many carers also told us that they felt the person they care for had been discharged too soon, often resulting in them going back into hospital because their condition had worsened.

“Discharged and readmitted within 14 hrs after I told them he was not ready to come home. I was so scared he was going to die I got no sleep at all that night.”

“They tried repeatedly to kill themselves and tried again when they were discharged, and almost succeeded. No one listened.”

Complaints

We asked carers whether they had made a complaint or expressed concerns about a health or social care service in the last year. Just over a quarter (26%) said they had complained about a health service and 18% had complained about a social care service.

We asked carers whether they felt they would make a complaint or raise concerns if they were unsatisfied with a service. While over half of carers felt that it was likely or very likely that they would complain about a health service (55%), or social care service (53%), over a quarter said it was unlikely or very unlikely they would complain about a health service (30%) or social care service (31%).

We asked carers what might prevent them from making a complaint or raising concerns if they were unhappy with a service. Carers felt the main barrier was feeling that complaining would make little difference, with 50% of carers saying this would prevent them from complaining or raising concerns about a health service and 45% saying this would prevent them from complaining or raising concerns about a social care service.

“I can complain easily enough. I have no confidence that it would make a difference. Our experience is the result is not worth the time outlay. We are disregarded and treated as problems. Our name was blackened by professionals.”

“The system is so unresponsive and inefficient that complaining is pointless”

“We have made a complaint. Everyone agreed it was justified and nothing was done, no one is accountable. I can't stress myself like this again when there is no accountability and no interest in correcting things. It's desperate that we are the only ones to suffer from their mistakes”

Nearly a third of carers said they would be worried about the consequences of making a complaint about a health service (34%) or social care service (31%).

“Possible recriminations against those I care for while not in my or any other family members' presence.”

“After making a complaint about social services decided to punish me by finding excuses to harass my daughter and then took my grandchildren into care. They make it very clear that complaints will cause consequences.”



Carers' health and wellbeing



Carers' health can be impacted by their caring role. This could be due to the physical demands of caring, limited opportunities to take a break, or the stress and anxiety of making ends meet. Many carers have poor physical and mental health, but are not always receiving the support they need. Carers' life satisfaction is also significantly lower than the national average. There is increasing evidence that caring should be considered a social determinant of health.⁷

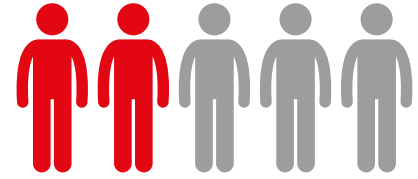
Key findings

- 24% of carers said their physical health was 'bad' or 'very bad' and 34% said their mental health was 'bad' or 'very bad'.
- Carers receiving Carer's Allowance were more likely to report 'bad' or 'very bad' physical health (31%) and mental health (48%).
- 42% of carers haven't taken a break in the last year. Of those, 26% of carers haven't tried to take a break because they felt it was too difficult.
- 29% of carers said they felt lonely often or always.
- 52% of carers said that being able to take a break would help them feel less lonely.
- Carers have lower levels of well-being compared with the general population

⁷ Public Health England (2021) Caring as a social determinant of health (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/971115/Caring_as_a_social_determinant_report.pdf)

42%

of carers haven't taken a break in the last year. A quarter of carers (26%) haven't tried to take a break because they felt it was too difficult.



Carers' physical and mental health

Just over a fifth of carers (21%) said their physical health was 'bad' or 'very bad'. Carers rated their mental health as worse than their physical health, with 30% saying their mental health was 'bad' or 'very bad' (no change from 2021).

People who were caring for over 50 hours a week were more likely to report 'bad' or 'very bad' physical health than people caring for less than 50 hours a week (25% vs 16%), as well as 'bad' or 'very bad' mental health (32% vs 25%).

“ This last year I have become very aware of how I am no longer coping as well as I used to: migraines, hormones, brain fogs daily, etc.”

“ Responsibility of my son is massive. No one can appreciate the impact this has on my mental health.”

Just over a fifth of carers (24%) said their physical health was 'bad' or 'very bad'. Yet carers rated their mental health as worse than their physical health, with 34% saying their mental health was 'bad' or 'very bad'.

People who were caring for over 50 hours a week were more likely to report 'bad' or 'very bad' physical health than people caring for less than 50 hours a week (32% vs 18%), as well as 'bad' or 'very bad' mental health (42% vs 28%).

Carers receiving Carer's Allowance were more likely to report 'bad' or 'very bad' physical health (31%) and mental health (48%).

Carers who were employed were more likely to report 'good' or 'very good' physical health (33%) and mental health (36%).

Carers' health concerns

We asked carers which three aspects of their health and well-being they were most worried about. Carers were most worried about feeling stressed or anxious (54%), followed by not having time to prioritise their physical and mental health (35%), being unable to take a break (32%) and getting enough sleep (28%).

Carers in employment were more likely to worry about not having the time to prioritise their physical and mental health (45%) compared to those who were looking after family or dependents full-time or unable to work (38%).

Breaks

We asked carers whether they had tried to take a break in the last 12 months. 42% said they had taken a break. However, 42% said they had not taken a break. Of those, 10% said they had tried to take a break but hadn't been able to, 6% felt they didn't need a break, and 26% hadn't tried to take a break because they felt it was too difficult. 17% said they had taken a break but this hadn't been enough for them to look after their mental or physical health.

Table four: Carers' self-reported physical and mental health

	Very good	Good	Fair	Bad	Very bad
Physical health	5%	24%	47%	20%	4%
Mental Health	4%	20%	41%	26%	8%

“ My daughter goes out twice a week with day support for 2 hours a time, it is a service we need for her and myself. It's only 2 hours but it's greatly received. She enjoys going out with them and I have got 2 hours free time to go do something quick, not long enough for me to go anywhere has sometimes they are late.”

Of those carers who had been able to take a break, most had done so when a friend or family member provided care. Few carers mentioned using respite or sitting services. Some carers told us that taking a short break was not enough to allow them to look after their physical and mental health.

“ 1 day a week my husband goes to St David's Foundation hospice this is not enough for me as I am up every night seeing to him.”

Loneliness

We asked carers how often they felt lonely. 29% of We asked carers how often they felt lonely. 32% of carers said they felt lonely often or always, while 48% said they sometimes felt lonely and 13% said they hardly ever felt lonely. Only 8% said they never felt lonely. 40% of carers said they needed more support to prevent or reduce their loneliness, while over a quarter (28%) said they needed more support so they can maintain and build their relationships with others.

Carers who had been caring for longer were more likely to feel lonely. 31% of people caring for over 5 years said they felt lonely often or always, compared with 23% of people caring for less than 5 years.

We asked carers what might help them to feel less lonely. The majority of carers (52%) said that being able to take a break would help them feel less lonely. This was followed by more understanding and recognition from society about the role of carers (48%), being able to take part in physical and leisure activities (33%) and having access to emotional support services (32%).

Wellbeing

We asked carers to rate different aspects of their wellbeing on a scale of 0-10, where 0 was 'not at all' and 10 was 'completely'. These indicators of national wellbeing are used by the Office for National Statistics (ONS) to explore how people in the UK are doing across different aspects of their lives. By asking carers the same questions we can compare their experiences to the general public.

Carers in Wales rated their life satisfaction at an average of 4.5, 0.2 below the UK average for carers and significantly lower than the UK average of 7.5. Carers rated their happiness at an average of 4.5, 0.3 below the UK average for carers and much lower than the UK average of 7.4. When asked to rate the extent to which they felt the things they do in their lives are worthwhile, carers rated this as 5.1, 0.4 below the UK average for carers and much lower than the UK average of 7.8. When asked how anxious they were, carers rated this as 5.2, 0.1 higher than the UK average for carers and far higher than the UK average of 3.2.

Nearly a third

31%



of carers caring for over 5 years said they felt lonely often or always

Physical activity

The UK Chief Medical Officer recommends that each week adults take part in at least 150 minutes (or 2.5 hours) of moderate-intensity cardiovascular activity (an activity that raises the heart rate, makes breathing faster and a person feel warmer, such as a brisk walk, dancing, a light cycle, or climbing

upstairs), or 75 minutes of vigorous-intensity activity (an activity that takes hard physical effort and makes you breathe much harder than normal, such as heavy lifting, running, gym work, fast cycling or aerobics).



Many carers want to be more active and recognise that physical activity can improve physical and mental health, but face barriers to being active, including lack of time, resources, or energy.

Key findings

- 68% of carers said they had not undertaken any vigorous activity in the last week, and 40% had not undertaken any moderate activity.
- Carers with poor physical and mental health were less likely to be active. Just over half (53%) of carers who said they had bad or very bad physical health had done no moderate physical activity in the last week.
- Nearly half of carers (47%) said they had been less active in the last 6 months.
- Only 14% of carers said that they use leisure facilities sometimes or often. The main barrier to using facilities was carers feeling that they did not have the time (71%).

Levels and type of physical activity

We asked carers how many days in the last week they had done light, moderate and vigorous physical activity for 10 minutes or more. 68% of carers said they had not undertaken any vigorous activity, and 40% had not undertaken any moderate activity. Most carers had done some light physical activity, with only 14% saying they had not undertaken any light physical activity.

Only 2% of carers had undertaken vigorous activity every day in the last week, and 10% had undertaken moderate activity every day in the last week, only just over a third (34%) of carers said they had done light physical activity every day in the last week.

Carers with bad or very bad physical health are unsurprisingly less active, and this may be due to the strain of carrying out a caring role or a long-term health condition. Just over half (51%) of carers who said they had bad or very bad physical health had done no moderate physical activity in the last week, compared with a quarter (29%) of those with good or very good physical health.

Carers who were caring for over 50 hours a week were more likely to be inactive. The time constraints on carers are such that being able to carve out time and energy to be active can be challenging, and not being able to take a break means there is limited opportunity for carers to consider their own health. A higher number of carers caring for over 50 hours a week are doing no vigorous (69%) or moderate (38%) activity per week, compared with 60% and 31% of carers caring for less than 50 hours a week.

44% of carers have cut back on hobbies and activities as a result of the cost-of-living crisis, which may have impacted on physical activity. The majority of carers report not having the time or energy to take part in physical activity. Other barriers include guilt, anxiety, tiredness, injury or illness. There is also a lack of awareness about how much and which types of physical activity to do to maintain health and well-being.

Over one-fifth of carers (21%) said that worrying about getting enough exercise was one of their main concerns about their health and well-being.

“ Doing activities are great but as a working carer with a family there is no time to do anything”

“ When I am unable to travel, leisure facilities might as well be on the Moon for all I can access them, rather than somewhere I drive past every day.”

Changes to physical activity levels

We asked carers whether there had been any change to the amount of physical activity they had done over the last 6 months. Nearly half of carers (47%) said they had been less active in the last 6 months, and only 13% said they had been more active. 40% said there had been no change to their physical activity levels.

Carers who were struggling to make ends meet were more likely to say they had been less active over the last 6 months (62%). This may be due to carers having to juggle caring responsibilities alongside the stress of the rising cost of living, resulting in carers feeling anxious or less motivated.

Use of local leisure facilities

As part of Carers UK's Carers Active project, we are keen to explore how carers are able to access opportunities to be physically active so that we can identify any barriers. Leisure facility sites, such as swimming pools, sports halls, gyms, aerobics studios, leisure centres and saunas, provide a wide range of activities and ways to be physically active.

Significantly, three-quarters of carers (75%) never use any local leisure facilities. Only 14% say that they use them sometimes or often.

Carers who said they feel lonely often or always were even less likely to use local leisure facilities, with 86% saying they never used these. This suggests that carers who feel lonely may feel detached from these types of facilities.

We asked carers whether there were any barriers to them accessing local leisure facilities. The main barrier identified was carers feeling that they did not have the time to use facilities (71%).

The other main barrier identified was the cost of leisure facilities being too expensive (45%), which is likely to worsen with the current cost of living crisis. Over a quarter of carers (29%) said they were worried about catching Covid-19, demonstrating that the pandemic is still impacting on carers' lives.

“ Shielding but also can't leave husband on his own.”

“ Concerned about bringing covid into the home.”

Carer's needs assessments

In Wales, the Social Services and Wellbeing (Wales) Act 2014 gives anyone who is looking after someone who is disabled, ill or elderly the right to a carer's needs assessment.

These assessments are carried out by local authorities and should cover topics such as carers' mental and physical health, their ability and willingness to care, and their relationships with others.



However, too many carers still face barriers to receiving an assessment, and many of those who are assessed feel that the assessment does not sufficiently consider their needs or lead to meaningful support. Many carers also face long waiting times for assessment.

Key findings

- 19% of carers surveyed reported having a carer's assessment or re-assessment in the last 12 months in Wales.
- 39% of carers who had not had a carer's assessment said that a barrier to having an assessment was not knowing what an assessment was. Nearly a fifth of carers (19%) said that they had not requested a carer's assessment as they didn't think it would be beneficial to them.
- A third of carers (33%) who had received an assessment felt that the need to take regular breaks from caring was not properly considered in their assessment or the support they receive.

Assessment take-up

We asked carers whether they had a carer’s assessment, review or reassessment in the last 12 months. 19% of carers surveyed reported having a carer’s assessment or re-assessment in the last 12 months in Wales.

While the majority of these carers (70%) waited less than six months for a carer’s assessment, 30% of carers were still left waiting for over 6 months to have their needs assessed by their local council.

The older a carer is, the more likely they will have an assessment. Carers aged 65+ are more likely to have an assessment (28%) than carers aged 18-64 (17%).

Only 18% of carers in receipt of Carer’s Allowance have had an assessment.

Barriers to having an assessment

We asked carers who had not had an assessment whether various barriers had prevented them from doing so. The main barrier was not knowing what an assessment was, with 43% of carers saying this was a barrier.

Nearly a fifth of carers (19%) said that they had not requested a carer’s assessment as they didn’t think it would be beneficial to them.

We asked carers whether there were any other barriers to them having an assessment. Some carers told us that they were afraid the process would be too upsetting.

“ Talking to anyone about everything that has happened in the last year would be too distressing and I am afraid I would cry during the assessment.”

Other barriers identified included the COVID-19 pandemic, being too busy with caring, feeling judged and not having the energy to go through the process. Some carers also said that the person they care for did not want an assessment.

Carers’ views on the assessment process

We asked carers who had undergone a carer’s assessment whether they felt the assessment process had considered various areas.

A third of carers (33%) felt that the need to take regular breaks from caring was not properly considered in their assessment or the support they receive. Just under a third (32%) said that their ability to maintain relationships with friends and family was not properly considered in their assessment or the support they receive. 31% said their ability to have time to themselves was not considered, and another 31% said there had been no consideration of what needs to be put in place in case of an emergency.

In general, many carers felt the assessment process was not helpful.

“ I had one carer’s assessment. This is about 5 years ago. I have asked for another since, but I have been refused as I already had one a few years back..”

Some carers felt that although things had been considered in the assessment, insufficient support had been provided.

“ They initially didn't consider one of my cared for at all even though I'm full-time for both of them.”



Employment and skills



Hundreds of thousands of people across Wales juggle their unpaid caring responsibilities with paid employment. For many, balancing work and care can be a real struggle – as a result, carers tell us they are tired, stressed and struggling to manage their own physical and mental health

Carers urgently need more support to ensure they can remain in work, including through better access to affordable and accessible social care services. People also need to have the ability to work flexibly and take Carer's Leave to manage their combined responsibilities more easily. Without more support, many more people will have to give up work or reduce their hours to care.

Key findings

- 77% of respondents worry about continuing to juggle work and care.
- 7% of respondents have given up opportunities at work because of caring.
- Over a quarter (26%) of respondents said they needed better support to return to or maintain paid work.
- More than half (54%) of respondents say they need paid Carer's Leave to help them balance work and care, while a third (32%) say they need unpaid Carer's Leave to do so.
- Half (50%) of respondents said they needed affordable and accessible alternative care at work.
- A further 24% said they were at risk of reducing their hours at work or of giving up work completely without access to it.
- 55% of respondents said they had already reduced their hours at work, while a further 24% felt they needed to help manage their caring responsibilities.
- 58% of respondents agreed (25%) or strongly agreed (33%) that not being able to work from home would make them consider leaving their employment.
- 43% of respondents said that their employer has introduced new measures since COVID-19 which really helps them juggle work and care.
- 1 in 8 (11%) respondents said they needed a more supportive employer to stay in work.

The impact of juggling work and care

We asked carers about the impact that juggling work and care had on them, and the extent to which they agreed or disagreed with several different statements. 57% of respondents agreed (21%) or strongly agreed (36%) that they have given up opportunities at work because of caring.

68% of respondents agreed (40%) or strongly agreed (28%) that work gives them a break from their caring role. However, 69% of respondents agreed (50%) or strongly agreed (19%) that they feel anxious about caring while they are working, while three quarters (76%) of respondents agreed (86%) or strongly agreed (28%) that they feel tired at work because of their caring role.

The support carers need to juggle work and care

Many carers have had to reduce their hours at work, or quit their job entirely because they do not get enough support in work, or with their caring responsibilities, to be able to juggle both successfully. 77% of respondents agreed (40%) or strongly agreed (37%) that they worry about continuing to juggle work and care.

One in four (26%) said they needed better support to return to or maintain paid work.

Flexible working

Positively, over two-thirds (67%) of respondents said they already have flexible working arrangements at work. However, one in five (19%) respondents say they need flexible working arrangements. Concerningly, a significant number did not have access to flexible working, meaning 5% of respondents said they are at risk of reducing their working hours, while 9% said they are at risk of giving up work altogether.

“ *It's very difficult to expect your employer to understand your circumstances fully and I would never take advantage, but I am allowed to take time off whilst I take my mother to medical appointments. This is unpaid leave again which is understandable. I don't really know what the answer is.”*

“ *My employer was aware of my caring responsibilities at the time of employment, but this is not covered in the flexible working policy. I work 2 hours a week from home but am now in the office on my other working days.”*

Carer's Leave

Having access to paid or unpaid Carer's Leave is an important way for carers to balance their working and caring responsibilities. Nearly a third (32%) of respondents already can take paid Carer's Leave. However, more than half (54%) of respondents say they need paid Carer's Leave to help them balance work and care; 8% say they are at risk of reducing their working hours, and 5% say they are at risk of giving up work completely without paid Carer's Leave.

When looking at unpaid Carer's Leave – again, it is positive that half (53%) of respondents already can take unpaid Carer's Leave. Less encouragingly, a third (32%) say they need unpaid Carer's Leave to balance work and care; 8% said they are at risk of reducing their working hours, and 6% say they are at risk of giving up work completely, without unpaid Carer's Leave.

An understanding line manager

Encouragingly, over three-fifths (63%) of respondents said they already had an understanding line manager or employer which helped them to balance work and care. However, a quarter (28%) said they needed an understanding line manager or employer to help them juggle their responsibilities, while 1 in 8 (11%) of respondents said they needed a more supportive employer to stay in work.

“*Employers do not understand the impact of caring. My job role as a teacher comes with a considerable expectation that I can work many extra hours and when I cannot do this I am pulled up for not being able to do the job as 'all teachers have to work at home and extra hours - you knew this when you took the job.'*”

“*My main Managers do not understand how difficult it is for me being a main carer, they only care about getting the work done, as it's based on getting the figures in time. I do have one support manager who understands what I'm going through as a relative of theirs was recently a carer for a family member*”

“*I have had a very positive experience with this, with a supportive employer, line manager and colleagues at Hywel Dda University Health Board. I can work flexibly around my care needs.*”

Affordable and accessible care

Having access to affordable and accessible care services which carers can rely on while they go to work is essential for many people juggling work and care. Half (50%) of carers in employment said they needed affordable and accessible alternative care at work. A further 19% said they were at risk of reducing their hours at work and 17% said they were at risk of giving up work completely without access to it. Not having access to affordable and accessible care was the primary reason that people said they would have to either reduce their hours or give up work completely – and combined was selected by 1 in 3 (36%) of respondents.

Reduced hours at work

One way in which respondents said they were better able to juggle work and care was by reducing the number of hours they worked. 55% of respondents said they had already done this, while a further 24% felt they needed to. This means that potentially three-quarters of the caring workforce in Wales have already or are considering reducing their working hours to care.

Working from home

58% of respondents agreed (25%) or strongly agreed (33%) that working from home has enabled them to balance work and care more effectively. Encouragingly, the vast majority of respondents said they already had the ability to work from home some, most, or all of the time. Over a third (38%) said they had access to home working most or all of the time, while two-fifths (41%) said they could work from home some of the time.

However, a significant number of respondents said they needed access to home working to help them balance their work and care. 39% of respondents agreed (17%) or strongly agreed (22%) that not being able to work from home would make them consider leaving their employment. One in 10 respondents said they were either at risk of reducing their hours (6%) or giving up work completely (4%) if they couldn't work from home most or all of the time.

When asked about having to return to the office if they had been working from home during the pandemic, 57% of respondents agreed (21%) or strongly agreed (36%) that returning to the office will make caring more challenging.

“ *The increasing demand on my time for my carer’s role even makes working at home very difficult especially as my relative is unable to recognise work time as being a distinct activity. Though being in the office would be even more difficult and possibly disastrous.* **”**

Changes since the COVID-19 pandemic

43% of respondents agreed (23%) or strongly agreed (20%) that their employer has introduced new measures since COVID-19 which really help them juggle work and care – and 29% of respondents agreed (16%) or strongly agreed (13%) that their employer has become much more understanding about caring since the pandemic.

Carers and employment status

We asked carers about their employment situation. 1 in 5 (21%) said they were a full-time employee, 16% said they were a part-time employee, and 5% were self-employed. 19% were retired.

We found that there was a correlation between those providing fewer hours of care and the likelihood that they were in full or part-time employment, including a significant difference between those providing more or less than 35 hours of care a week.

Table six: Skills gained through caring

Skill	%
Empathy (eg the ability to understand and share the feelings of another person)	72%
Advocacy (eg the ability to communicate another person’s concerns and act on their behalf)	71%
Resilience (eg the ability to cope under pressure)	70%
Risk management (eg the ability to identify and manage potential risks and challenges)	63%
Communication skills (eg the ability to communicate effectively with a range of people)	60%
Time management (eg the ability to juggle different commitments)	57%
Financial management (eg the ability to budget effectively and/or identify and apply for financial support)	36%
Partnership working (eg the ability to work in partnership with support services)	29%



“ *I have been made to feel as though I am overreacting about how Covid-19 may affect my vulnerable family members.* **”**

Those providing under 9 hours of care a week were the most likely to be full-time employees

Skills gained from caring

We asked carers which skills they felt they had gained from their caring role. The skills prioritised by most carers are listed in the table below.

Most of the skills listed, including empathy, resilience, advocacy, risk management, communication skills, and time management were all selected by over half of all respondents – demonstrating the wide range of skills that people gain from providing unpaid care.

Carer identification



One of the main barriers to carers getting support with their caring role is identification. This includes people self-identifying as a carer, and GPs and other health professionals identifying people as carers. Many carers view their relationships with the person they care for as a family relationship or friendship and don't necessarily see themselves as a 'carer' who may need more support.

Key findings

- Half of all carers (52%) took over a year to recognise their caring role, with over a third (36%) taking over three years to recognise themselves as a carer
- 77% of carers stated that seeing themselves primarily as a family member or friend was a barrier to identifying themselves as a carer.

Identification

Many carers do not recognise their caring role until some time after they start undertaking caring responsibilities. Half of all carers (52%) took over a year to recognise their caring role, with over a third (36%) taking over three years to recognise themselves as a carer. Only a third (32%) recognised their caring role immediately.

“ I cared for my mother when a child then my father before my husband. There was no mention of carers, benefits and support. You were simply a member of the family and it was your duty”

The relationship to the person being cared for can also have an impact. People caring for a partner or ex-partner were marginally more likely to recognise their caring role immediately (35%) compared to people caring for a parent or parent-in-law (27%) or a child or child-in-law (28%). Conversely, people caring for parents take longer (9%) and children (6%) are more likely to take over 16 years to recognise their caring role than people caring for a partner/ex-partner (4%).

One in three carers who live in the same house as the person they care for report recognising their caring role immediately (32%), compared to just over one in four (25%) carers who live away from the person they care for.

38% of carers with a monthly household income of under £1500 recognised their caring role immediately, compared to 27% of carer households earning over £1500 per month.

Carers in any form of employment were considerably less likely to immediately recognise their caring role (27%) than carers not in work (34%). Only a quarter (25%) of older carers, aged over 65, recognised their caring role immediately as opposed to 34% of carers under 65.

Barriers to recognition

We asked carers whether various barriers might prevent them from identifying as a carer. For carers who didn't immediately recognise themselves as a carer, over three quarters (77%) stated that they saw themselves primarily as a family member or friend. This was the main barrier identified by carers and was a particular issue for people caring for a parent/parent-in-law or a child/child-in-law. 85% of carers caring for a parent or parent-in-law stated that they didn't recognise themselves as a carer because they primarily saw themselves as a family member or friend, compared to only 74% of people caring for a child or child-in-law and 71% of people caring for a partner, or ex-partner

“ My Mum saw it as part of her role as a wife - as her 'duty'.”

“ I care for my husband. It was a relative who pointed out to me that I am a carer.”

Carers in receipt of Carer's Allowance were more likely (78%) to state that they saw themselves primarily as a family member or friend compared to 77% of all carers.

Carers in employment were significantly more likely to state that they did not recognise themselves as a carer as they saw themselves as being a family member or friend (79%) compared to carers not in employment (76%).

More than half of carers (55%) stated that their caring role developed gradually so it took time to realise they were a carer. Carers in receipt of Carer's Allowance were less likely (39%) to state that their caring role developed gradually so they didn't recognise themselves as being a carer.

“ I was young and male so people/professionals didn't see me as a carer”

We asked carers whether there were any other barriers to identifying themselves as a carer. Some carers said they were uncomfortable with the idea of being 'labelled' as a carer:

“ As I am an at-a-distance carer, I didn't feel like a carer in the same way as mum”

Conclusion

The State of Caring in Wales 2022 report demonstrates the daily challenges that carers are facing. With the rise in the cost of living, carers' finances are under more pressure than ever before, causing additional stress and anxiety and leaving carers to face unprecedented financial hardship this winter.



These issues are being felt more acutely in Wales compared to the rest of the UK with more carers suggesting they are at the point of crisis than anywhere else.

Issues around accessing healthcare appointments and social care services mean that many carers are feeling lonely, isolated, undervalued and unrecognised, and many are not getting the support they need. Several carers have told us that their physical health is poor and that they are waiting for specialist treatment. As a result of health conditions being untreated, many carers are in pain, and unable to carry out their caring role.

Concerningly, some carers have been forced to pay for private healthcare, often by using their savings, which has impacted on their ability to make ends meet.

While many services have reopened in the last year, 1 in 5 carers are still reluctant to access support due to concerns over COVID-19. Several carers are still shielding or reducing activities to protect themselves and the person they care for. As we found last year, not knowing what services are available is the main barrier to accessing support, with many carers unaware of what help is available locally.



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