

Make caring Visible, Valued and Supported

Carers Week 2022 report

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Introduction and summary

Caring can happen to any of us at any time, when we might provide unpaid care to a relative, close friend or neighbour because of chronic illness, including mental ill-health, dementia, disability, or older age. Caring can be overnight with an accident or sudden medical emergency or gradually as a condition develops over time. Millions of people providing unpaid care help their family, friends and neighbours live longer in the community. The value of their care is staggering and has been estimated at £530 million per day during the pandemic, or the equivalent of £193 billion a year.¹

The impacts of caring, however, can be profound and significant. It can affect health and wellbeing, ability to be in paid work, relationships, income and finances. It is something that most of us will experience at some point in our lives, but few of us are prepared for it and it's impossible to predict when we might have to provide care.

During the pandemic things have been especially tough for unpaid carers, with services shutting down, carers being left to cope often alone and the added worry and risk of COVID and keeping their relative safe. Whilst many people may feel that the world is 'opening up' and that they are 'living with Covid', for carers, the legacy of the pandemic is profound, and they feel they continue to face significant challenges. The added pressure of increased costs of living is making life harder for carers.

This Carers Week 2022, the charity supporters are coming together to make caring Visible, Valued and Supported.

Visible: To carers, this means the public understanding about caring and being recognised and identified as a carer.

Valued: To carers, this means the public, services, other family members, community and the government of their country valuing what they do.

Supported: To carers, this means that they get the information, advice, support and recognition to protect their health and wellbeing, support relationships, get breaks when they need them, continue working and be able to manage financially.

As the Carers Week charities, we believe that everyone has a role to play in making sure that caring is Visible, Valued and Supported.

^{1 &}lt;u>Unseen and Undervalued – the value of unpaid carers' support during the pandemic, Carers UK, November 2020</u>

Research key findings

Carers Week carried out polling of the general public, which includes people who are currently caring. We found:

Carers are not sufficiently Visible, Valued or Supported.

- Numbers of carers are still higher than pre-pandemic although have fallen since the height of the pandemic. There are now an estimated 10.58 million carers across the UK, one in five adults.²
- Caring has intensified since autumn 2020

 carers are providing significantly more unpaid care despite society 'opening up'.
 The proportion of unpaid carers providing significant care ie over 20 hours per week, has increased by 42% since October 2020.
- Carers' worries have intensified and increased around the negative impact of caring on physical and mental health which is now the top concern compared with five years ago. 4.87 million carers are worrying about the impact of caring on their physical and mental health.3

10.58m
people in the UK
are estimated to be
unpaid carers



42%
increase in unpaid carers
providing significant care
ie more than 20 hours
per week since October 2020



4.87m
unpaid carers are
worrying about the
impact of caring on their
physical and mental health

² Calculated by Carers UK based on ONS Population Estimates 2020

³ Calculated by Carers UK based on ONS Population Estimates 2020

- 2.86 million carers are worrying about the impact of not getting a break.⁴
- The proportion of carers worrying financially has increased since the height of the pandemic. 2.2 million carers are worrying about their ability to cope financially because they are caring.⁵
- Carers working part-time are particularly worried about reducing hours of work or leaving altogether.
- Nearly 7 out of 10 (69%) of the general public feel that the role of unpaid carers is not well valued by the general public. This feeling has increased since early in the pandemic.
- Three quarters of carers (75%) caring before the pandemic think that the role they do is not valued.
- 84% of general public agree that the government in their country should provide additional support for unpaid carers.



2.2m
unpaid carers are
worrying about their
ability to cope financially
because they are caring



⁴ Calculated by Carers UK based on ONS Population Estimates 2020

⁵ Calculated by Carers UK based on ONS Population Estimates 2020

Every year, around 2.3 million people start caring for the first time and are potentially new to caring.⁶ We therefore also looked at whether adults who were not currently caring thought they would be carers in the future, what their concerns would be and where they would turn to get help. We found:

- Their key worry would be the impact on their health and wellbeing, which has become the top concern (55%).
- They are now more likely than five years ago to turn to a GP or to their local council for support – even though health and care services are facing huge demand and access challenges. This runs the risk that these services will fall short for people new to caring.







Key recommendations

- A Recovery and Respite Plan in all nations.
- Given the negative impact of the pandemic on carers and the people they care for, the governments in Wales, Scotland, Northern Ireland and the UK should bring forward a 12-month Recovery and Respite Plan to support carers, with longer term objectives.

This would look to ensure that there is immediate and sustained support for carers to:

- Protect their physical health with specific and targeted investment, including £1.5 billion for carers' breaks in England with similar investment in Wales, Scotland and Northern Ireland.
- Improve and sustain their mental health with specific and targeted investment in carer-focused wellbeing support, and specialist support to help carers better understand their caring role.
- Planning before next winter to ensure that targeted packages of support are in place for carers including practical support, any infection control measures eg PPE and free testing and making carers a vaccination priority.
- Put in place active measures to support their ability to juggle work and care, including making a right to Carer's Leave a legislative priority.
- Protect carers from the cost of living crisis, helping them with energy costs and the ability to pay bills and by introducing or increasing carer payments, including to those on the lowest incomes to ensure that they are most able to manage financially. Specifically in England and Northern Ireland payments to carers should match those in Scotland, ie around £250 every six months, which has been doubled during the pandemic.

- Measures to increase the identification of carers and awareness.
- Embed transparent, measurable and long-lasting commitments to better value and invest in care, and carers, within relevant performance frameworks to drive transformative policy and spending action.

84%

of the general public agree that in general the government in their country should provide additional support to unpaid carers



A series of measurements by governments in the UK, Wales, Scotland and Northern Ireland that value and support carers, and recognise the importance of their role in our economy and society. These measures will:

- Invest in social care significantly in the short term with sustained investment over the longer term.
- Deliver a supportive healthcare system capitalising on measures in all four nations, with targeted programmes to identify and support carers.
- End carers' financial hardship and recognise their role including: a review of Carer's Allowance with a view to increasing substantially carers' benefits, including means tested benefits for the longer term.
- Increase carers' ability to stay in or return to paid work.

Visibility of caring – hidden in plain sight

How many carers are there?

One in five adults (20%) is currently caring across the UK. This is 10.58 million people.⁷

16% of adults in the UK have been caring since before the pandemic, and 4% of adults in the UK started caring since the pandemic started.

Table 1: Prevalence of caring. % of the population aged 18+ who are providing unpaid care, by parts of the UK.

	% people who are currently carers (May 2022)
England	20%
Northern Ireland	20%
Scotland	20%
Wales	23%

The overall rate of caring peaked at 26% during the lockdown in May 2020, and by the second wave in October 2020 22% of the UK population were carers. However, the current rate of caring is still 3% higher than the prepandemic level when 17% of the population were providing care.8

Table 2: Prevalence of caring. % of the UK population aged 18+ who are providing unpaid care, by date.

DATE	% people who are currently carers
Feb 2019	17%
May 2020	26%
Oct 2020	22%

At the time this research was undertaken, in May 2022, women are much more likely to be caring (23%) with 19% caring since before the pandemic and 4% since the pandemic started. Men were less likely to be caring (18%) with 14% caring before the pandemic started and 4% since the outbreak.

The peak age of caring is 55-64 with 29% of adults providing care and 22% of people aged over 65 were providing unpaid care. 14% of younger adults aged 18 to 24 were providing unpaid care.

⁷ Calculated by Carers UK based on ONS Population Estimates 2020

⁸ Unseen and Undervalued, the value of carers' support during the pandemic, Carers UK November 2020

30% of the general public were not currently caring in May 2022 but had given care in the past. Around four in ten of the general public (41%) had no experience of caring at all. 40% of older people aged over 65 were not currently caring but had done so in the past and only 32% had no experience of caring at all and were more likely to have experience of caring.

18% of all workers said they were providing unpaid care. Part-time workers were most likely to be providing care – nearly one in four (24%) and were more likely to have done so since the start of the pandemic (6%). Nearly one in five carers (24%) described themselves as retired, 15% as a student and 29% were not working/other.

How much care is being provided?

Even though society has opened up for many under the 'Living with Covid plans', carers are providing significantly more care than earlier in the pandemic during lockdowns and tighter Covid restrictions.

Whilst the overall number of carers has gone down since the start of the pandemic, the intensity of care has increased significantly in all amounts above 10 hours per week. The proportion of unpaid carers providing significant care ie over 20 hours per week, has increased by 42% since October 2020. This is important as there were still restrictions in October 2020 and a large percentage of services had still not returned. This of great concern as we already know that providing more care is linked to poor health and wellbeing, reduced ability to work, and low income, often due to a lack of support for carers, and that this will have been exacerbated by the pandemic.



Table 3: Hours of care provided per week – all adults aged 18+ currently providing unpaid support.

HOURS PER WEEK	October 2020	May 2022	% growth / reduction
Up to 9	67%	50%	- 25%
10-19	14%	20%	+43%
20-49	9%	14%	+56%
50+	10%	13%	+ 30%
Don't know	n/a ⁹	3%	

This could be due to several different factors:

- Services still not returning to full capacity in Autumn 2021, only 14% of carers had full use of day services that they had before. 55% of carers no longer had access to the same level of day service as before or at all, including one in five carers who had seen day services close completely.¹⁰
- Increased needs of the person being cared for during the pandemic. 81% of carers said they were providing more care and for three quarters of them this was due to the needs of the person being cared for increasing.¹¹
- Continued shielding of people who are concerned about engaging with the community and services due to COVID-19 infection rates. One third of carers who used to use day services were still not doing so in the autumn of 2021 because of fear of infection.¹²

- The overall shortage of social care and delays in accessing assessments and care. A survey of councils conducted by the Association of Directors of Adult Social Services in 2022 found that over half a million people are waiting for an adult social care assessment, for care, or a direct payment to begin or for a review of their care. 13
- Challenges accessing health services, particularly primary health services.
 Analysis by the Nuffield Trust found that the waiting list for people waiting over two years for consultant led treatment grew to 23,778 – more than eight times the number in April 2021.¹⁴

^{9 &#}x27;Don't know' was not a response option in October 2020

¹⁰ State of Caring 2021, Carers UK, November 2021

¹¹ Caring Behind Closed Doors: the impact of the pandemic on unpaid carers - six months on, Carers UK, November 2020

¹² State of Caring 2021, Carers UK, November 2021, sample of over 8,000 carers

¹³ Adass, 2022. Waiting for Care ADASS Report

¹⁴ Nuffield Trust, 2022. NHS Performance Summary Jan-Feb 2022

Carers providing more care are on lower incomes

Carers with lower household incomes were much more likely to be providing significant amounts of care ie over 20 hours per week. Providing more care also increases the likelihood of experiencing financial hardship and poverty as carers are less likely to be able to juggle work and care.

- 34% of carers with a gross annual household income of £19,999 or less said they are caring for over 20 hours a week.
- Compared with 24% of carers with a gross annual household income of more than £19,999.

Carers from the C2DE (lower socioeconomic) groups were more likely to be providing 20 or more hours of care than those from the ABC1 (higher socioeconomic) groups – 34% vs 22%.

Longer term carers provide more care

Longer term carers are far more likely to provide higher hours of care.

There was a sudden increase in carers at the peak of the pandemic, when numbers reached 13.6 million in May 2020 and 4.5 million people started caring almost overnight. These newer carers tended to be providing fewer hours per week.

This finding can also be explained by the fact that care can intensify over time when caring for a condition that deteriorates over time such as Lewy body dementia or motor neurone disease, or an older person with increasing frailty.

Table 4: Hours of care provided per week – all adults aged 18+ currently providing unpaid support.

Hours per week	All carers 2022	Currently caring but started before the pandemic	Currently caring but started some time since the pandemic
Up to 9	50%	49%	55%
10-19	20%	18%	27%
20-49	14%	15%	10%
50+	13%	15%	5%
Don't know	3%	4%	2%

Jacqui's story



When Jacqui Darlington's second child was diagnosed with Down's syndrome, she found herself in a brand new role with no idea just what it would involve.

Many of you will have read the story/poem or seen the film 'Welcome to Holland' and that was exactly how I felt when I gave birth to my son, Joshua, and was told he had Down's syndrome. I had planned everything down to the smallest detail as this was my second child... except for what to do or how to feel if things did not turn out as expected. No one gave me a job description.

Once I had dealt with the shock, with having to tell family and friends and the number of visits to the doctors and hospitals, etc., I eventually got into a routine – even to the point that I was going to go back to work. However, things changed when Joshua started school and I had to deal with a whole new set of rules for this game. No one gave me a job description.

Eventually I went back to work part-time, which was great as I was around to take both my boys to school and could pick them back up again, and life went on normally (if that is what you call it). At the back of my mind, I believed that things would get easier the older Joshua got: Joshua would become more independent, speak and do exactly what his peers did when they did them.

How wrong could I have been! No one had given me a job description.

"I had to deal with a whole new set of rules for this game"

Joshua started college full time – but full time was not what I expected and not like school. He attended three days a week, with 'progress weeks' off every term. I struggled to maintain a home, be a mum, be a carer and have a career for just over six months before admitting that this situation was not working. I had become ill with the stress of it all. No one had given me a job description.



Reluctantly I gave up working to become a full-time carer but, with that, I had to give up our home as I could not afford to keep it with no income coming in. This broke me in ways I never thought it would. It still brings tears to my eyes. No one gave me a job description. (I have since returned to part-time work).

"Joshua is and always will be my beautiful handsome son"

Joshua no longer attends college but does various things on various days but I feel that I am more of a chauffeur/companion/nurse/interpreter than his mum. Even though Joshua has PAs, the allotted funding does not equate to the needs he has.

I have so many happy memories of Joshua growing up, including him walking at two years old when I was told he would not walk until he was five, and, more recently, him 'telling me' he was going Tesco for batteries only to spend £20 getting cheese and sausage rolls. I could go on and on...

Joshua is and always will be my beautiful handsome son who I will continue to love, cherish and adore... even though I never got a job description. But then again, this is no ordinary job.

Rasila's story



I'm a carer for my younger sister who has an advanced stage of dementia. She's at the end of life now and is under the care of a palliative team.

I had to give up my full-time job working for American Express to take on board caring for my sister. Prior to this, I was also a carer for my elderly parents. Caring for my parents was manageable alongside my full-time job, but with my sister, her condition deteriorated so rapidly that it wasn't possible to carry on with my job.

This completely changed my world. I suddenly didn't have the money coming in. I was not even a pensionable age at the time, so I had to dig into my savings to pay for my mortgage.

It's changed me as a person too. As a career minded person, I was very strong, tough. I now still have to be assertive, but in a different way. I have to be a calmer person. I remember meeting my friends from my old workplace and they just said, "everything in you has changed."



My sister needs a hoist now as she cannot stand. Finally, after nearly two years of waiting we got trained, but my sister's condition has deteriorated so much that we have now been instructed against hoisting her. As she is now in a very high-risk category it has added on additional burden and stress on myself.

The pandemic has greatly affected us because, at one point, we had to stop all of the carers coming in. We also had issues with PPE. We always had the aprons and gloves, but we didn't have masks. When we tried to order them, they were hard to find. We tried social services, everybody. Nobody had them.

Sometimes I just want my own space to think. But I don't have that. I can't even think about going out for dinner or lunch, or meeting with friends. Because I know that something will come up and I'll have to cancel it.

There's nothing that makes things better. It's constant. If you get a call, you've got to deal with it. Visits to the GP surgery, hospital stays. There's no time for me.

I used to love reading and used to love going to the library, going for walks. It's all gone.

I have no life of my own. My sister is constantly in my mind. I need more support from the system to have some sort of my life back.

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Valuing carers

Are carers valued?

Seven out of ten adults in the UK (69%) do not think that the role of unpaid carers is valued by the general public. This has increased since May 2020 when 65% of the general public thought carers were undervalued.¹⁵

Carers who have been providing care since before the pandemic are more likely to feel that the role of carers is not valued compared to those who have started caring since the pandemic (75% vs 53%). 71% of people who had never provided unpaid care thought that unpaid carers were not valued and 69% of former carers thought carers were undervalued.

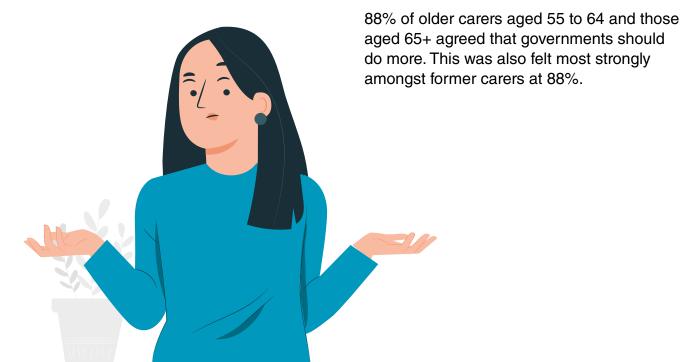
Being valued by society was a key priority for carers.¹⁶

What does the general public think the different governments across the UK should do?

There is strong support from the general public for governments to do more to support carers.

84% of the general public think that the government in their country should provide additional support to unpaid carers eg increased financial support, invest in care and support services so unpaid carers can have a break, invest in social services, etc. Only 3% disagreed.

This was much more marked for women, with 87% of women agreeing that governments should do more compared with 82% of men. 62% of women strongly agreed compared with 54% of men strongly agreeing.



¹⁵ Carers Week research report, the rise in the number of unpaid carers during the pandemic, published June 2020, fieldwork May 2020

¹⁶ State of Caring 2021, Carers UK, November 2021

Heather's story



My partner Chris was diagnosed with early onset Lewy body dementia at the age of 60.

Chris is a very active campaigner, gives lots of talks and is an ambassador for several charities, including The Lewy Body Society. I want to support her to do these things and live her life as she wants to, but the support she requires has significantly increased during the COVID-19 pandemic.

Chris has gone from being a person being able to travel to meetings on her own and giving talks, to now needing much more support to do this. She needs someone to accompany her and needs reassurance.



Chris was classed as clinically vulnerable and wasn't allowed to leave the house for significant periods of time, not even to have a walk. Due to this her mood and symptoms have declined, and she has lost confidence. This directly impacts on the time I have to look after my own well-being.

Her medication used to be put into dosette boxes by the pharmacy which ensured the right tablets were in order and labelled for morning, evening and night-time. Due to Covid this was withdrawn and has never been reinstated. This meant I had to purchase our own boxes and still have to take on the extra responsibility for sorting out all the medication into correct time zones. She is on about 30 different tablets per day and I have to prompt her to take the tablets.

I get less of a break as I am far more worried about leaving Chris for longer periods now. Not only does she forget to take medication, but she struggles to prepare food and eat meals without reminders.

I have little to no confidence in getting the support we will need in the future from official sources and expect to be heavily reliant on support from charities supporting those living with dementia and carers groups. We will probably have to use all our savings to pay for care, and I fear we will live out our last years in poverty. I don't understand why dementia is classed as a social care problem. As a terminal, life-limiting brain illness it should come fully under health care. We urgently need the government to do something about this.

Supporting current carers

For people currently caring, the most common worries were health, stress, impact on relationships and not getting a break. However, financial worries were a concern for nearly one in five carers (21%), a substantial proportion of carers who are already under pressure.

The results below show that the pandemic has taken its toll on all areas of carers' lives, particularly on their health. Stress and the responsibility of caring has increased since the lockdowns in the May 2020. People who were caring before the pandemic are showing far stronger signs of stress and impact. For example, 50% carers who have been caring since before the pandemic are concerned about the impact of caring on their physical and mental health, compared with 32% of carers who have started caring since the pandemic.

46% of carers were concerned about the impact on their physical and mental health, 42% were worried about the stress of caring, 29% about the negative impact of unpaid caring on their relationship with family and friends and 27% were worried about the ability to get time away from caring, ie a break from caring.

This means that across the UK:

- 4.87 million carers are worrying about the impact of caring on their physical and mental health¹⁷
- 2.86 million carers are worrying about the impact of not getting a break from caring.¹⁸

Carers' top worries have changed significantly since we asked the question in May 2020:¹⁹

- Managing the stress and responsibility of caring 37%
- The negative impact on physical and mental health - 36%
- The negative impact on relationships -24%
- Not having the skills or experience to provide care - 22%
- Not being able to cope financially 16%.



¹⁷ Carers UK calculated this based on ONS 2020 population estimates

¹⁸ Carers UK calculated this based on ONS 2020 population estimates

¹⁹ Carers Week research, op cit

Table 5: Top worries for all carers and by length of caring.

Area of worry	All carers	Currently caring but started before the pandemic	Currently caring but started some time since March 2020
Being able to cope financially (eg being able to afford the care services or equipment required etc)	21%	21%	19%
Having the skills or experience to provide care	20%	20%	19%
Managing the stress and/or responsibility of being a carer	42%	44%	35%
The impact on my own physical and mental health	46%	50%	32%
Having to reduce my paid working hours, leave work or stop studying	16%	16%	15%
Not knowing or understanding what help is available to me as a carer	22%	22%	22%
The negative impact it has on my personal relationships (eg with family, friends, partners etc)	29%	30%	22%
Not being able to take time away ie a break from my caring role	27%	28%	22%
Not having anyone to talk to about the challenges of caring	23%	23%	23%
Other	4%	4%	2%
None of these	22%	21%	22%
Don't know	2%	2%	2%

Cost of living and finances

A staggering one in five people, 21% of adults currently caring say that a key worry was managing financially as an unpaid carer. Taking this as a proportion of the caring population, this means that 2.2 million carers were worrying about the impact of caring on their finances.²⁰

The results below show that this is disproportionately felt by carers with lower incomes, and by people who are providing more care, who are also in a lower socio-economic group.

Household income

Carers with much lower household incomes were much more likely to report worries about caring on their finances, their physical and mental ill-health and not knowing or understanding what help was available.

- 29% of carers with a gross annual household income of £19,999 or less said that they are worried about being able to cope financially compared with 18% of carers with a gross annual household income of £19,999 or more.
- 51% of carers with a gross annual household income of £19,999 or less said that they are worried about the impact of caring on their physical and mental health, compared with 44% of carers with a gross annual household income of £19,999 or more.
- 28% of carers with a gross annual household income of £19,999 or less said that they are worried about not knowing or understanding what help is available to them as a carer compared with 19% of carers with a gross annual household income of £19,999 or more.

Working carers

Carers working part-time were significantly more likely to be worried about leaving work, reducing paid working hours, and stopping studying (27%) compared with 16% of all working carers or carers working full-time.

Gender impacts

Women are much more likely to be worried about the impact of on their caring on different aspects of their lives. Women who are caring are much more worried than men who are caring about the impact on their physical and mental health, the stress of caring, the impact on relationships. Not being able to take a break was nearly twice as likely to be cited as a key worry for women who are currently caring compared with men (32% compared with 19%).

Table 6: Carers worries about the impact of caring, by gender.

Area of worry	All carers	Men	Women
Being able to cope financially (eg being able to afford the care services or equipment required etc)	21%	21%	21%
Having the skills or experience to provide care	20%	19%	20%
Managing the stress and/or responsibility of being a carer	42%	30%	51%
The impact on my own physical and mental health	46%	36%	53%
Having to reduce my paid working hours, leave work or stop studying	16%	13%	17%
Not knowing or understanding what help is available to me as a carer	22%	22%	23%
The negative impact it has on my personal relationships (eg with family, friends, partners etc)	29%	24%	32%
Not being able to take time away ie a break from my caring role	27%	19%	32%
Not having anyone to talk to about the challenges of caring	23%	20%	25%
Other	4%	2%	5%
None of these	22%	25%	19%
Don't know	2%	3%	1%

Ethnicity

Carers from an ethnic minority background were more likely than carers from a white British background to worry about not having anyone to talk to about the challenges of caring (32% vs 22%).²¹ Carers from an ethnic minority background were less likely to worry about managing stress (44% vs 34%) and not being able to take a break (28% vs 21%).

Sexual orientation

Carers who reported their sexual orientation as lesbian, gay, bisexual or other were more likely than heterosexual carers to be worried about being able to cope financially (29% vs 20%), having skills and experience (24% vs 19%), physical and mental health (52% vs 42%), relationships (40% vs 26%), and reducing hours (28% vs 14%).

²¹ This includes anyone who selected a category other than white British

Supporting future carers

Every day around 6,000 people become carers and it is something that people often feel unprepared for. In carrying out this polling, we looked at whether people expected to become a carer, but also what their main concerns were and where they would turn to for support.

Despite the pandemic bringing caring of all kinds to the fore, the general public's perception of whether they will provide care in the future if they have not already done so is still low.

The general public's main worry if they were to become an unpaid carer would be the impact on their physical and mental health which has come top for the first time. They would also be more likely to turn to a GP for support since we first polled in 2017, either their own or of the person they care for, and to local council social care services. This would be at a time when health and care services are under extreme pressure and people new to caring run the risk of not getting the support they need.

Recognition of likelihood of caring

We asked the general public who had no experience of being a carer whether they thought it was likely that they'd become a carer in the future. 53% of adults thought it was unlikely and 20% didn't know. This is despite a 2 in 3 chance of providing care within a lifetime. Women have a 50:50 chance of providing care by the time they are 46 and men by the age of 57, 11 years later.²²

Five years ago, in 2017, half of the UK public who were not carers (50%) thought it unlikely that they would care in the future.

The likelihood is affected by both gender and age. In our survey this year, we found that women were more likely to think that they would care – with only half thinking it would be unlikely (50%) compared with men (56%). Unsurprisingly 63% of younger people aged 18-24 thought it unlikely they would provide care compared with 44% of people aged 45 to 54.



A carer's story



Rethink Mental Illness have made me feel validated for all of the care and support I provide to my son.

Because of the wonderful support I've received from Carers Oxfordshire I felt like I had to send you this letter.

You see, this December, before I spoke to the service, I was a really frustrated dad. My clever, beautiful son, had been diagnosed with a borderline personality disorder and I was really struggling to understand his condition and work alongside him to give him the help he needed.

The support I was offered to change this stressful situation was literally non-existent. All I saw before me was a big black hole of support. Like many carers, I guess, all I could do was hit Google with my burning questions: 'What is a personality disorder?', 'What are the warning signs of a crisis?', 'How do I support someone with a mental health problem?'

The answers I got back were helpful to a degree. But what I really needed was some expert support and advice. Someone I could talk to who fully understood what I was going through and what my son was going through too.

Thankfully (and I always will be thankful), a friend mentioned the Rethink Mental Illness' Carers Support Service to me. After hanging onto the number for a few days, I gave them a call and straightaway my life started to change for the better.

What the person who answered that call offered in that hour was literally a revelation to me. She helped me understand my son's condition much better. And she just listened to my worries and stresses, which meant a great deal.

Being able to benefit from this incredible level and breadth of support for free has been a real eye opener to me. It's made me realise not only how special Rethink Mental Illness is but also how fantastic the people are who make their services possible.

After that first call, I felt in a much, much better place. And, I guess, excited to put what I'd learnt into practice.

Susan (59 years old) carer for 28-year-old son who has been diagnosed with schizophrenia.

"Caring for someone you love is a real privilege fraught with sorrow and laughter, I often feel alone, isolated and frustrated with the lack of understanding from others who do not understand the emotional and physical impact this has on me and my relationships. I wish I could have a mother and son relationship that is not impacted by his mental illness. I would like more recognition and validation for all the care and support I provide for my son."

Worries about becoming a carer

We asked the general public not currently caring what their worries would be if they became an unpaid carer. The top three worries were:

- impact on physical and mental health -55%
- being able to cope financially 49%
- not having the skills and experience to provide care - 44%.

The impact on carers' physical and mental ill-health has taken over as the top worry for people not currently caring and is now 53% higher than 2017.

In 2017 when the same question was asked, not being able to cope financially was the top worry at 46% followed by not being able to cope with the stress of being at carer at 43%.

Even though impact on physical and mental health has taken over as the top worry for people not currently caring if they became a carer, not being able to cope financially is still higher than it was five years ago.

Table 7: Key worries about caring of UK adults aged 18+ with no experience of caring.

Area of worry if they became a carer	People not currently caring
Being able to cope financially (eg being able to afford the care services or equipment required etc)	49%
Having the skills or experience to provide care	44%
Managing the stress and/or responsibility of being a carer	36%
The impact on my own physical and mental health	55%
Having to reduce my paid working hours, leave work or stop studying	34%
Not knowing or understanding what help is available to me as a carer	38%
The negative impact it has on my personal relationships (eg with family, friends, partners etc)	31%
Not being able to take time away ie a break from my caring role	38%
Not having anyone to talk to about the challenges of caring	21%
Other	2%
None of these	3%
Don't know	8%

The general public not currently caring was asked to imagine if they became a carer where they would be most likely to turn to for support, using up to three choices.

The top choices were:

- Friends and family 50%
- Local council services eg social care - 44%
- GP 41%
- Charity or support group 28%.

Table 8: Where adults without caring experience would turn to for support (% of respondents).

	% of adults not currently caring
Local council services (eg social care)*	44%
Care services you pay for/ the person you care for would pay for	23%
The benefits system	21%
Your own GP or the GP of the person you care for	41%
Technology (ie internet, online forums, telecare, health monitoring devices, smartphone apps, etc)	20%
A charity/support group	28%
Family/friends	50%
Support from my workplace (eg flexible working hours)	19%
Support for school/university (eg flexible study hours, extended deadlines)	4%
Somewhere else	2%
Don't know	9%

^{*}As this was a UK-wide survey, we asked people about local council services, rather than Health and Social Care Trusts

This pattern has changed significantly in the last five years when this question was last asked. Although support from family and friends was the most frequent choice at 47%, only 39% would have turned to their local council and 36% to their GP.

Given the pressure on social care and on primary health services, there is a significant risk that people taking on caring responsibilities will not get the support they needed.

Nearly one in three people working (29%) and not currently caring would turn to their employer for support. This increased to 31% of full-time workers but only 21% of part-time workers.

Younger people aged 18 to 24 are less likely to turn to their GP as one of their key sources of support compared with older people aged 65+ (30% vs 50%) but they are more likely to choose technology as one of their top three sources of support compared with people aged 55+ (24% compared with 15%).

Similarly, only 26% of 18- to 24-year-olds put local council support eg social care as a top choice of where they would turn to for support compared to 57% of people aged 65+.

Older people aged 65+ are most likely to turn to a charity or support group for help compared with the 18- to 24-year-olds (32% versus 23%) if they became a carer.

People from an ethnic minority background were less likely than those from a white British background to say they would seek support from their local council service (38% vs 45%), GP (36% vs 42%), or a charity/ support group (23% vs 29%). However, people from an ethnic minority background were more likely to say they would seek support from their workplace (27% vs 18%).

People from a white British background were more likely than those from an ethnic minority background to worry about the impact on their physical or mental health (56% vs 46%).

Those who reported their sexual orientation as gay, lesbian, bisexual or other were more likely than those who said they were heterosexual to be worried about being able to cope financially (55% vs 48%), having skills and experience (49% vs 43%), managing stress (45% vs 35%), physical and mental health (61% vs 54%), reducing hours (47% vs 32%), relationships (40% vs 29%) and having a break (43% vs 38%).

James' story



James Parkinson is 20 years old and studies at the Royal College of Music. He plays trombone, tuba and guitar. He is one of four siblings and a young adult carer to his brother and his youngest sister.

When he's at home he supports his brother, George (18), who is autistic and has obsessive-compulsive disorder (OCD) and epilepsy. James listens for his brother during the night in case he might be having a seizure, aids him in his drumming and bass guitar and keeps him safe when they go walking. James also supports his youngest sister, Stella (17), who has Diamond-Blackfan anaemia, by helping her with her music and anything else she physically struggles with. Stella has other physical disabilities, but despite having joint issues and minus a finger on each hand, she is very adept at piano.

Over lockdown James was at home, and spent more time helping his parents care for George and Stella. The family stayed in to shield and protect Stella. George had been used to going out for daily walks, so James set up activities to so he could be busy with his art, worksheets, drumming and bass guitar lessons.

Respite opportunities reduced drastically during the pandemic, with so many outdoor things closed. James' local Carers Trust Network Partners suggested he could do some respite at home, safely, to comply with all the restrictions. James applied for a small grant for a microphone which meant he could record music, and collaborate with others. James said:



Over the lockdown, the mic grant motivated me to keep making music. It's been therapeutic. It's allowed me to record high quality music, to collaborate with others online and be creative. Being able to make my own music has given me quality time for myself.

When I was younger, my other able sister Daisy and I would come straight home from school and help care for George and Stella. Not because we weren't allowed to go out, but because we would be concerned about being away from George and Stella for the long school day. The time we spent at home all together was always so lovely. Being a carer from a young age has given me an ability to understand and respond appropriately to certain situations, especially living with someone with autism, OCD and epilepsy.

"We all enjoy music, and my parents have been incredibly encouraging. From buying my instruments, to taking me to youth orchestra rehearsals, and paying for lessons. I wouldn't be where I am now if I didn't have that. They never let me being a young carer hinder my musical journey.

Samantha's story



Casey was diagnosed with motor neurone disease (MND) in 2018, not long after we first got together. Casey was 19, I was 20. We had everything planned, we had our whole lives ahead of us.

Before COVID-19, I was working full-time as a dental nurse and my mum and dad looked after Casey. At that point, Casey could still stand, walk and feed himself. Once everything went into lockdown, my mum, dad and little brother were all in the high-risk category so we couldn't see them. Casey and I were shielding, so I couldn't go to work, and I couldn't work from home because of my caring responsibilities.

I couldn't go and have a coffee with one of my friends or go to my mum and dad's and see my little brother or play with their dog. We were trapped. This all impacted on Casey's mental health, which had a knock-on effect on his physical deterioration and his speech. It was really tough. I honestly didn't think we were going to get through it.

Because of Casey's health and how high risk the dental profession is, I've not gone back to work, I'm caring full-time. Casey's movement is now very restricted and he communicates by using eye movements and making noises. We now have care workers in every day, in the morning and afternoon – I'm only able to share my story with you now because they're here. They get him out of bed, shower him and take him to the toilet. I have to do everything else on my own. I feed him, give him medication, do pressure relief, and put him to bed.

I compromise the amount of sleep I get just to help myself mentally. I get up at 7:30am just to have five minutes to get up and brush my teeth and wash my face. It's 6am if I want to go to the to the gym, just so I can have a bit of a break. I've only been away two or three times since we came out of lockdown.



We had to try and navigate ourselves through the first year, knowing what to do, when to do it, who to speak to. It was the MND Association helpline who told me what benefits I could get, who I needed to speak to, and how to get a note on my medical record defining me as a carer.

Going to university this September is a massive change in mine and Casey's lives. We've got funding for care workers through Continuing Healthcare (CHC) now, so we finally have the right amount of support. I feel more confident knowing that, even though things are going to get worse, we've got a really good team around us, and the carers are exceptional. There are some lovely local charities that focus on carers, thanks to them I get a break for holistic therapies and get my nails done.

Conclusion and recommendations

The pandemic has had a significant impact on unpaid carers despite society opening up, many carers are still struggling to get the support they need and are waiting for services to fully return. Significant numbers are now providing even more hours of care now than they did during the height of the pandemic.

Carers' main concern about their physical and mental health is a clear manifestation of the pressure that they've been under; the shortage of breaks, the lack of appropriate, accessible and affordable care services, increased needs that must be supported, uncertainty about paid work and financial pressures.

The outlook for people who may take on caring responsibilities in the near future is worrying, given that health and care services are under intense pressure and don't have sufficient resource to support people currently caring, let alone new carers coming into the system.

The need for dedicated Recovery and Respite Plans for unpaid carers in Wales, Scotland, Northern Ireland and the UK that meet their needs is clear to prevent further issues from developing further. The Scottish Government has already committed to a Covid recovery plan and is in the process of producing it. Carers Scotland urges the government to publish the strategy as soon as possible and ensure that sufficient resources are dedicated to it to meet the ongoing challenges facing carers as the country learns to live with Covid.

As well as this short term focused intensive support, measures are also needed to support carers in the longer term.

We believe any Recovery and Respite Plan needs to have the following areas of focus:

- Measures to identify carers to ensure that targeted preventative support can be delivered rapidly in place before next winter and ongoing to maximise the benefits.
- Planning before next winter to ensure that targeted packages of support are in place for carers.
- Measures to support carers physical and mental health, with specific targeted investment.
- A focus on carers' ability to juggle work and care over the short term.
- Investment in support that helps deal with carers' worries around relationships.
- Financial support for carers.

We believe that this Recovery and Respite Plan should aim for a period of 12 months to tackle the pandemic's legacy for carers looking at support for immediate and sustained support for carers to:

- Protect their physical health with specific and targeted investment, including £1.5 billon for carers' breaks in England with similar investment in Wales, Scotland and Northern Ireland.
- Improve and sustain carers' mental health with specific and targeted investment. This might include investing in organisations that provide carers with focused emotional and wellbeing support, either 1:1 or in a peer support group, and/ or specialist support helping carers better understand their caring role.
- Consider targeted packages of support for carers including practical support, any infection control measures eg PPE and free testing and making carers a vaccination priority.
- Put in place active measures to support their ability to juggle work and care, including making a right to Carer's Leave a legislative priority and encouraging carer friendly employment practices.
- Protect carers from the cost of living crisis, by boosting carers' incomes, helping them helping them with energy costs and the ability to pay for essentials, and by introducing or increasing carer payments and other social security measures to ensure that carers do not experience financial hardship as a result of providing care. Specifically in England and Northern Ireland payments to carers should match those in Scotland, ie around £250 every six months, which has been doubled during the pandemic.

- Focus on local integrated plans to increase carer identification, particularly within health services, ensuring that this is systematically recorded on care records.
- Embed transparent, measurable and long-lasting commitments to better value and invest in care, and carers, within relevant performance frameworks to drive transformative policy and spending action.

Governments in the UK, Wales, Scotland and Northern Ireland also need to adopt a series of measures that:

- Invests in social care significantly in the short term with sustained investment over the longer term.
- Delivers a supportive health care system capitalising on measures in all England, Wales, Scotland and Northern Ireland, with targeted programmes to identify and support carers.
- Ends carers' financial hardship and recognises their role including: a review of Carer's Allowance with a view to increasing substantially carers' benefits, including means-tested benefits for the longer term.
- Increases carers' ability to stay in or return to paid work, protects their health and wellbeing.
- Ensure that caring is visible, valued and supported.

Caring in Northern Ireland



Visible

20% of the general public aged 18 and over are currently caring. This means that there are currently an estimated 290,880 carers in Northern Ireland currently providing unpaid care.²³

Like England, Scotland and Wales, the number of carers within Northern Ireland has dropped since the height of the pandemic in May 2020, but rates remain higher than prepandemic.

Across the UK, there has been a rise in the intensity of care provided by carers compared with Autumn 2020 when there were more carers and lockdown was in place.

17% of adults aged 18+ in Northern Ireland currently caring were doing so before the pandemic and 3% adults started caring since the pandemic. 30% of people not currently caring have experience of doing so and 44% have no experience of caring.



Valued

68% of people in Northern Ireland don't think that unpaid carers are valued by the general public, with only 22% thinking carers are valued.

Supported

89% of the public in Northern Ireland thought that the government should provide additional support for unpaid carers such as increase financial support, invest in care and support services so unpaid carers can take a break, invest in social services etc. This was the highest compared with England, Scotland and Wales. 65% strongly agreed compared with 58% strongly agreeing across the UK.

Preparing for caring in the future

Only 47% of people not currently caring think it's unlikely that they will care in the future. 23% thought it was likely but a much bigger proportion than the rest of the UK didn't know (29%).

The three top areas that people not currently caring would worry about most if they became a carer were:

- Being able to cope financially 52%
- Impact on physical and mental health 49%
- Not having the skills and experience to provide care 46%.

Table 1 - Northern Ireland:

What adults aged 18+ not currently caring would worry about if they became a carer by % of respondents.

Area of worry if they became a carer	People not currently caring UK	People not currently caring Northern Ireland
Being able to cope financially (eg being able to afford the care services or equipment required etc)	49%	52%
Having the skills or experience to provide care	44%	46%
Managing the stress and/or responsibility of being a carer	36%	35%
The impact on my own physical and mental health	55%	49%
Having to reduce my paid working hours, leave work or stop studying	34%	30%
Not knowing or understanding what help is available to me as a carer	38%	38%
The negative impact it has on my personal relationships (eg with family, friends, partners etc)	31%	29%
Not being able to take time away ie a break from my caring role	38%	30%
Not having anyone to talk to about the challenges of caring	21%	18%
Other	2%	3%
None of these	3%	2%
Don't know	8%	3%

The top three areas people without caring experience would turn to if they became a carer were:

- Local council services eg social care –
 39% the only nation to have this first
- Family or friends 54%
- GP or the GP of the person you care for – 50%.

Table 2 - Northern Ireland:

Where adults aged 18+ who are not currently caring would turn to for support – using up to three choices by % of respondents.

	% of people not currently providing unpaid care - UK	% of people not currently providing unpaid care - Northern Ireland
Local council services (eg social care)	44%	39%
Care services you pay for/ the person you care for would pay for	23%	20%
The benefits system	21%	35%
Your own GP or the GP of the person you care for	41%	50%
Technology (ie internet, online forums, telecare, health monitoring devices, smartphone apps, etc)	20%	17%
A charity/support group	28%	36%
Family/friends	50%	54%
Support from my workplace (eg flexible working hours)	19%	19%
Support for school/university (eg flexible study hours, extended deadlines)	4%	2%
Somewhere else	2%	-
Don't know	9%	4%

Additional recommendations for the Northern Ireland Assembly and Executive

- The Department of Health should work with each Health and Social Care Trust and other providers to ensure the full re-opening of day centres and similar services as a matter of urgent priority.
- The Department for Communities should introduce a Carers Allowance Supplement in Northern Ireland, paid at the same value as in Scotland.
- The Department for Communities should establish a fuel poverty taskforce – with representation from carers and the organisations that support them – to design short, medium and long-term solutions to fuel poverty in Northern Ireland.
- The Department of Health should prioritise the carer-related proposals in the reform of adult social care – appointing a Carer Champion and beginning work on a new Carer Strategy within the first year of the new Assembly mandate.
- The Department for the Economy should bring forward legislation to introduce paid carers leave in Northern Ireland.

Roisin's story



My name is Roisin McMackin.

I am a full-time unpaid carer and mum to four daughters with autism and co-morbid conditions.

As one of the quarter of a million carers in Northern Ireland I find that support is practically non-existent and hours get longer as the demands increase. It's impossible to get any free time or go back to work due to the financial and physical demands of the responsibilities for my daughters. Covid has made the situation worse.

Carers are the forgotten backbone of society, an undervalued commodity who suffer at the expense of the health.

For things to change, carers need to be placed at the heart of any government reforms, including a properly funded model of social care. In my view, Carer's Allowance needs to be raised to match other European models. Raising the level of Carer's Allowance would lessen the current financial hardship experienced by carers. The forgotten carers need to be recognised as partners in care and reimbursed accordingly.



Caring in Scotland



Visible

20% of the general public aged 18 and over are currently caring. This means that there are currently an estimated 887,815 carers in Scotland.²⁴

Like other nations across the UK, the number of carers within Scotland has dropped since the height of the pandemic in May 2020, but rates remain higher than prepandemic.

14% of adults aged 18+ in Scotland currently caring were doing so before the pandemic and 6% of adults aged 18+ started caring since the start of the pandemic. 33% of people not currently caring have experience of doing so and 40% have no experience of caring at all.

Across the UK, there has been a rise in the intensity of care provided by carers compared with Autumn 2020 when there were more carers and lockdown was in place.

20% of adults in Scotland are estimated to be unpaid carers

Table 1 Scotland:

Hours of care provided per week -% of all adults aged 18+ currently caring.

Hours per week	Carers in Scotland
Up to 9	42%
10-19	22%
20-49	14%
50+	14%
Don't know	8%

Valued

69% of people in Scotland don't think that the role of being an unpaid carer is valued – with just over one in five people, 21%, thinking carers are valued. 10% weren't sure whether carers are valued by the general public.

Supported

87% of the public in Scotland agreed that, in general, the government in their country should provide additional support to unpaid carer such as to increase financial support, invest in care and support services so unpaid carers can take a break, invest in social services etc. 61% strongly agreed.

Preparing for caring in the future

53% of people not currently caring think it's unlikely that they will care in the future. 29% think it's likely and 18% don't know.

The three top areas that people not currently caring would worry about most if they became a carer were:

- Impact on physical and mental health 55%
- Not being able to cope financially 47%
- Not having the skills and experience to provide care – 44%.

Table 2 - Scotland:

What adults aged 18+ not currently caring would worry about if they became a carer by % of respondents.

Area of worry if they became a carer	People not currently caring UK	People not currently caring Scotland
Being able to cope financially (eg being able to afford the care services or equipment required etc)	49%	47%
Having the skills or experience to provide care	44%	44%
Managing the stress and/or responsibility of being a carer	36%	36%
The impact on my own physical and mental health	55%	55%
Having to reduce my paid working hours, leave work or stop studying	34%	34%
Not knowing or understanding what help is available to me as a carer	38%	40%
The negative impact it has on my personal relationships (eg with family, friends, partners etc)	31%	34%
Not being able to take time away ie a break from my caring role	38%	38%
Not having anyone to talk to about the challenges of caring	21%	18%
Other	2%	1%
None of these	3%	4%
Don't know	8%	12%

The top three areas people without caring experience would turn to if they became a carer were:

- Family/friends 56%
- Their GP or the GP of the person they care for – 45%
- Local council services eg social care – 42%.

Table 3 - Scotland

Where adults aged 18+ who are not currently caring would turn to for support – using up to three choices by % of respondents.

	% of people not currently caring - UK	% of people not currently caring Scotland
Local council services (eg social care)	44%	42%
Care services you pay for/ the person you care for would pay for	23%	20%
The benefits system	21%	18%
Your own GP or the GP of the person you care for	41%	45%
Technology (ie internet, online forums, telecare, health monitoring devices, smartphone apps, etc)	20%	17%
A charity/support group	28%	23%
Family/friends	50%	56%
Support from my workplace (eg flexible working hours)	19%	16%
Support for school/university (eg flexible study hours, extended deadlines)	4%	4%
Somewhere else	2%	2%
Don't know	9%	11%

Additional recommendations for the Scottish government

- The Scottish government should seek to implement the Covid recovery actions in the upcoming Carers Strategy urgently. The Strategy must have significant investment to support carers' lives and enable them to recover from impact of the pandemic, as well as live with Covid as the country moves forward.
- The Scottish government should work with local councils and HSCPs to reopen day centres and similar services. This is a matter of urgent priority to support carers, many of whom have been caring without support for more than two years.
- The Scottish government should seek to increase carers' incomes including by continuing to provide the Carer's Allowance Supplement at a double rate to compensate for the additional and disproportionate costs faced by carers.
- The Scottish government should develop plans to reduce some of the costs carers and those they care for face such as care charging, travel and health costs. An urgent priority is to work with the Convention of Scottish Local Authorities (COSLA) to make progress on removing care charging. At a minimum this should involve reducing care charging this year by requiring all local councils to include heating and other additional costs of living for disabled and older people within Disability Related Expenditure.
- The Scottish government and partners should develop a dedicated Carer Poverty Strategy to look at all aspects of poverty amongst carers and identify measures within devolved powers, locally and nationally to reduce this. This should sit alongside a new Disability Poverty Strategy.

Jim's story



I started in a caring role with my wife, when my father-in-law came to live with us, as he was beginning to have difficulties coping on his own following the death of his wife.

We were able to get some support after my wife spoke to the manager of the care home in which she worked. This led to day care and minor adaptations to the house.

The caring role only started to become difficult after he had a fall and lost all his confidence. He finally became incapacitated prior to his passing away. The support we received from the local health practice was excellent all the time during this period.

Subsequent to that we then had to look after my youngest son who suffers from phases of severe depression. This resulted in him and our grandson coming to stay with us as he was incapable of looking after the grandson properly. The treatment he has received by the mental health team has been effectively zero. This is due to the waiting times due to the lack of staff.

He is now being helped by a local third sector organisation but even they had problems during the pandemic. This did not help with my son's recovery as he effectively reverted to where he was prior to the start of the pandemic.

Mental health requires more investment to ensure that waiting times are kept to a minimum to prevent an escalation in the person's illness that consequently requires greater investment and time spent on the patient by health professionals.



There also requires more finance available to ensure that carers can access short breaks more easily.

Caring in Wales



Visible

23% of the general public aged 18 and over are currently caring – the highest proportion across the UK. This means that there are currently an estimated 584,134 carers in Wales.²⁵

The number of carers within Wales has seen the smallest drop compared with other nations across the UK since the height of the pandemic in May 2020, but rates remain higher than pre-pandemic.

Across the UK, there has been a rise in the intensity of care provided by carers compared with Autumn 2020 when there were more carers and lockdown was in place.

20% of adults aged 18+ in Wales currently caring were doing so before the pandemic and 3% of adults in Wales started since the pandemic. 35% of people not currently caring have experience of doing so, the highest across the UK and only 35% have no experience of caring. 7% were unsure or did not respond.



Valued

73% of people in Wales think that the role of unpaid carers is not valued by the general public – the highest in the UK with only one in five people, 22% thinking carers are valued. 5% of people weren't sure whether carers are valued by the general public.

Supported

86% of the public in Wales agree that in general the government in their country should provide additional support for unpaid carers such as increase financial support, invest in care and support services so unpaid carers can take a break, invest in social services etc. 59% strongly agreed.

Preparing for caring in the future

52% of people not currently caring think it's unlikely that they will care in the future. 29% think it's likely and 19% don't know.

The three top areas that people not currently caring would worry about most if they became a carer were:

- Impact on physical and mental health 56%
- Not being able to cope financially 45%
- Not having the skills and experience to provide care/not knowing or understanding what help would be available to me as a carer – 42%.

Table 1 - Wales: What adults aged 18+ not currently caring would worry

about if they became a carer by % of respondents.

People not People not currently caring Area of worry if they became a carer currently caring UK Wales Being able to cope financially (eg being able to afford the 49% 45% care services or equipment required etc) Having the skills or experience 44% 42% to provide care Managing the stress and/or 36% 32% responsibility of being a carer The impact on my own physical 55% 56% and mental health Having to reduce my paid working hours, 34% 29% leave work or stop studying Not knowing or understanding 38% 42% what help is available to me as a carer The negative impact it has on my personal relationships 31% 27% (eg with family, friends, partners etc) Not being able to take time away 38% 34% ie a break from my caring role Not having anyone to talk to 21% 16% about the challenges of caring Other 2% 1% None of these 3% 2% Don't know 8% 8%

The top three areas people without caring experience would turn to if they became a carer were:

- Local council services eg social care 53% – the only nation to have this as the most frequently selected source of support
- Family or friends 52%
- GP or the GP of the person you care for – 40%.

Table 2 - Wales:

Where adults aged 18+ who are not currently caring would turn to for support – using up to three choices by % of respondents.

	% of people not currently caring - UK	% of people not currently caring Wales
Local council services (eg social care)	44%	53%
Care services you pay for/ the person you care for would pay for	23%	23%
The benefits system	21%	26%
Your own GP or the GP of the person you care for	41%	40%
Technology (ie internet, online forums, telecare, health monitoring devices, smartphone apps, etc)	20%	21%
A charity/support group	28%	24%
Family/friends	50%	52%
Support from my workplace (eg flexible working hours)	19%	12%
Support for school/university (eg flexible study hours, extended deadlines)	4%	2%
Somewhere else	2%	1%
Don't know	9%	8%

Additional recommendations for the Welsh government

- Issue an additional recognition payment to unpaid carers, in line with the second payment previously made to social care workers in Wales. An additional payment should include those with an underlying entitlement to Carer's Allowance who found themselves excluded from the first payment.
- Explore issuing regular payments to unpaid carers to alleviate their heightened exposure to cost of living pressures.
- Encourage and support local authorities to fully re-open services for carers and those receiving care, in light of the Deputy Minister's welcome statement in the Senedd on 22 March that she would be "redoubling [her] efforts to try and encourage local authorities to open those services".

Melanie's story



My name is Melanie Davies, I live in North Wales. I have cared for my husband Mal for the last 33 years; he has physical disabilities as well as having had two mini strokes.



I also have helped care for my daughter, for the last 25 years, who has mental health issues, heart problems and diabetes.

I used to help care for my Dad when I was young, who he had heart problems, as well as for my Mum who had Alzheimer's.

Covid-19 placed yet another massive, almost unbearable, insurmountable pressure on caring. The limitations were endless; I had problems trying to help my daughter recognise these limitations. Both of us felt isolated as we could not visit, and she missed a lot of support services that were suspended – and are still not back in place completely. My husband faced the same situation with the cancellation of appointments, which placed more stress on both of us

Covid has meant that people could not travel around – so for me, a break was as conceivable as a walk on the moon. There was even a point when exercise could only be 'local', to the extent that we were not even allowed to sit on a bench and rest.

I am hopeful that future support will be delivered, and that services and government will continue to recognise the 24/7 nature of the 'job' for carers - we don't go 'home' from work, we don't go on 'annual leave'.

I do hope things improve for carers, and I feel very strongly that government and services, and especially Local Authorities, would hugely benefit from hearing carer experiences. They need to see us as people who need to be listened to, and if unpaid carer's applied for a job, their list of skills would be quite extensive.

I have lots of interests which are very varied I just never seem to have the time to follow them.
Sometimes, it would be lovely to be 'just me'.

About this survey

- All figures, unless otherwise stated, are from YouGov Plc.
- Total sample size was 4,317 adults.
- Fieldwork was undertaken between 29 April 4 May 2022.
- The survey was carried out online.
- The figures have been weighted and are representative of all UK adults (aged 18+).

References

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About Carers Week

Carers Week is an annual awareness campaign to recognise the vital contribution made by unpaid carers across the UK.

In 2022, Carers Week is made possible through Carers UK working together with six other major charities: Age UK, Carers Trust, Motor Neurone Disease Association, Oxfam GB, Rethink Mental Illness and The Lewy Body Society.

Find out more and get involved at carersweek.org





