

General Election 2024

A manifesto for unpaid carers

















Contents

About this manifesto	07
What carers want to see from the next Government	06
A snapshot of unpaid care in 2024	05
Introduction	03



Supporting carers' health and wellbeing



Preventing financial hardship



Better identification and recognition 14



Improving care and support



Support to juggle work and care



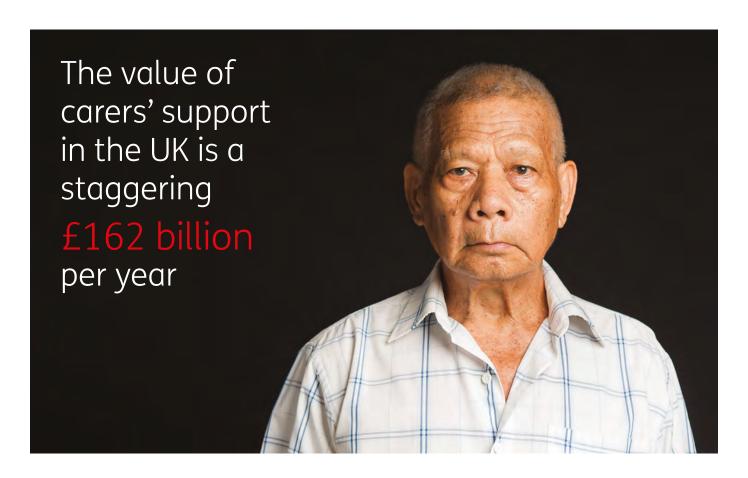
Equality for carers

22

A new National Carers Strategy	24
Annex: Carers UK's policy calls	25
Endnotes	30

It's time for a new social contract to transform the lives of unpaid carers

Across the UK, millions of people provide unpaid care for a family member, friend or neighbour who is affected by long-term illness, disability, or older age. Thousands of us take on new caring responsibilities every day – it can happen unexpectedly, or gradually, but almost all of us will experience care at some point in our lives.



Since 2011, the number of hours of unpaid care being provided has increased significantly, with 1.5 million people in England and Wales now caring for over 50 hours every week. As a result, the value of carers support is now worth a staggering £162 billion a year – equivalent to spending on the NHS, without which our health and care systems would simply collapse.

The unpaid care people provide daily has a profound and positive impact on the individuals they care for, society, and our wider economy.

Yet, despite their huge contribution, far too many carers do not feel recognised or supported. And too often caring comes at a significant personal cost, drastically affecting people's finances, health, ability to work and to live full and social lives. The widespread lack of formal support from health and social care services has left many carers extremely concerned about the future and how they will cope.

To ensure their huge contribution to society is properly recognised, over the next 5 years and beyond, the next Government must do much more to ensure that every carer has the financial, practical and workplace support they need.

Supporting carers to continue providing care and to participate in everyday life through work, education and leisure is cost-effective and in everyone's best interest.

There is a compelling economic case for providing carers with the support they need. Ensuring carers, especially those over 50 can stay in, or return to, paid employment is vital, with independent analysis suggesting the value to the economy of carers being able to work is £5.3 billion a year.³ The lack of accessible and affordable social care services also affects carers' ability to juggle work and care. With unprecedented numbers of unpaid carers out of the workforce, there is a double imperative to invest in social care and ensure carers can look after their own health and wellbeing.

Ahead of the upcoming General Election, Carers UK is calling on all political parties to commit to a new social contract for carers, one fit for the 21st Century and which recognises the enormous contribution millions of people make each day by providing the unpaid care that their families and friends need.

Our call builds on previous work undertaken by Carers UK and the University of Leeds.⁴ Such a contract is long overdue and much needed – to give carers greater control over their lives, to reduce the penalties carers face as a result of the care they provide, to mitigate the unprecedented pressures currently being felt by our health and social care systems, and more broadly to sustain our economy.

While many elements of society need to adapt and change to realise our vision of a society where all carers are recognised, valued and fully supported, Government has a central role to play in providing the structures, mechanisms and legislative basis for change.

There is no time to waste. If we do not transform our approach to supporting carers, ever more people reaching breaking point, with huge implications for themselves and the people they care for, as well as the NHS, the adult social care system, and society as a whole.



A snapshot of unpaid care in 2024



- Every year, 4.3 million people become unpaid carers – 12,000 people a day.6
- 59% of carers are women.7
- Women have a 50:50 chance of providing care by the time they are 46; men have the same chance by age 57 – 11 years later.8
- 3 in 5 carers are worried about living costs and how they will manage in future.⁹
- 27% of unpaid carers have bad or very bad mental health; 79% feel stressed or anxious, 50% feel depressed and/or lonely.¹⁰

- Nearly 3 million carers are juggling paid work and unpaid care across the UK – 9% of everyone in employment.¹¹
- 51% of carers take over a year to recognise their caring role, with 36% taking over three years to do so meaning they often miss out on vital support when they need it most.¹²
- 61% of carers are uncertain about what practical support they can access.¹³
- 57% of carers say they do not have a life outside of caring and are unable to remain connected to the people who matter to them.¹⁴

What carers want to see from the next Government



When asked about their priorities for the future in our State of Caring 2023 survey, carers told us they wanted to see:

- **83%**: Reform of Carer's Allowance and other social security payments.
- 80%: Investment in social care services.
- 80%: The introduction of two weeks of paid Carer's Leave a year for working carers.
- 73%: All carers to be supported to take a break.

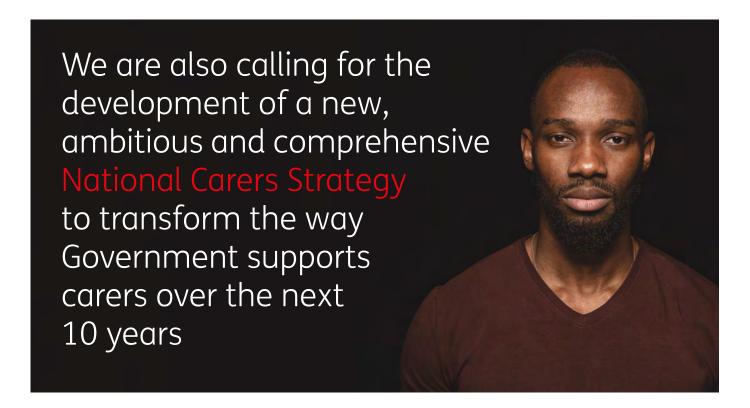
- 72%: New NHS legislation to ensure carers are regularly identified and supported.
- 70%: Improvements to carers' health and wellbeing.
- 66%: Caring to be made the 10th protected characteristic under the Equality Act.
- **61%**: Better identification and awareness of unpaid carers.

About this manifesto

Through our engagement with thousands of unpaid carers and our wider research and policy work, Carers UK has identified six themes where we want to see all political parties commit to significant and meaningful policies to transform the lives of millions of carers, ahead of the General Election later this year.

These themes are:

- 1 Supporting carers' health and wellbeing
- 2 Preventing financial hardship
- 3 Better identification and recognition
- 4 Improving care and support
- 5 Support to juggle work and care
- 6 Equality for carers



Please see a full table of our detailed policy calls in the Annex.

Supporting carers' health and wellbeing

A widespread lack of support and recognition from health and care services is severely damaging unpaid carers' mental and physical health. People caring round the clock for older, disabled or seriously ill relatives do not have adequate support from statutory services that are meant to help them – leaving many steeped in thoughts of hopelessness, fear, dread, and urgently in need of more support.



Our evidence shows carers' mental and physical health is getting worse, and for some it is now at rock bottom. A staggering proportion of unpaid carers are putting off health treatment and not seeking help for health issues. Many are worn out, exhausted and feeling stressed, depressed and lonely. A significant proportion of carers are not seeking support with health conditions due to the demands of their caring role, and many are unable to take a break from caring to do the things that might improve their wellbeing.

Concerningly, 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 are not getting the support they need.

It is clear that unpaid carers desperately need more support to help them look after their own health and wellbeing. Carers' experiences suggest that there are systemic and systematic failures within the NHS to identify and support carers, and a distinct lack of

understanding of caring being a social determinant of health.

Working with local authorities and the NHS, the next Government must urgently drive a programme of quicker and more targeted interventions to prevent poor mental and physical health amongst carers. The NHS also needs a strategic approach to identifying carers across all its structures and delivery mechanisms, so that it is identifying carers systematically and proactively. This must include an approach that treats carers as partners in care, ensuring they have a choice about caring, as well as having the information, advice and support to care safely and well.

66 I have mental health difficulties of my own that need treatment and support but due [to] my caring responsibilities I don't have the time or energy to get the support I need, so I am getting worse."

- An unpaid carer

Key stats from State of Caring 2023¹⁵

- 82% of carers say the impact of caring on their physical and mental health is a challenge.
- 27% say their mental health is bad or very bad.
- Over three quarters (79%) of carers feel stressed or anxious, half (49%) feel depressed, and half (50%) feel lonely.
- 69% of carers said they found it difficult to get a good night's sleep.
- **54%** of carers said their physical health had suffered, and **22%** said that they had injured themselves while caring.
- 61% of carers worry they will not be able to take any breaks in the coming year.
- 53% of carers find it challenging to maintain relationships with their family and friends.
- 42% of carers need more support from the NHS or healthcare professionals.
- 28% of carers had waited for more than an hour for an ambulance to arrive.

66 I have cancelled a hospital appointment twice as I had no one to assist me after an anaesthetic. I am back on antidepressants and anxiety tablets after trying to control my own mental health to no avail." – An unpaid carer

"I didn't know what to expect and I was very alone."

When Sherene's husband Lee experienced a life-changing traumatic brain injury, she became a carer overnight, but it took years for her to find support.

Lee's injury affected his speech, his movement and resulted in post-traumatic amnesia, leading to confusion disorientation and memory loss.

The pandemic made circumstances especially challenging, and after just 16 days in hospital Lee returned home for rehabilitation and recuperation supported almost entirely by Sherene. She reflects,

Conce we were out of the hospital doors, that was it. I didn't even have his discharge notes or medication. He needed 17 different medications a day which I had to wean him off gradually with the help of a GP over the phone... it was very disorganised. No-one checks in, we were just left. I didn't know what to expect and I was very alone."

After the accident Lee could not work, which hit the family financially. Juggling work, care

and looking after two children gave Sherene no time to seek support for herself.

It took two and a half years for a care pathway plan to be put into place for Lee.



- **66** It took a long time for me to receive support because I relied on professionals to give it to me. I was too much in the zone with the caring element of things."
- Last February I had a breakdown due to exhaustion. I felt like I had a massive rock tied to me. I was sinking and sinking, as though the water was coming into my lungs. I was drowning, but I felt numb with it. It was at that point that I finally received some support. The NHS need to look at their policies and follow their NICE guidelines, to put theory into practice and follow through."

The next Government must:

- 1 Transform the way the NHS interacts with unpaid carers to make it the most carerfriendly health service in the world by:
 - » Offering all carers an annual health check.
 - » Developing a nationally funded public health programme for carers.
 - » Providing Carer's Allowance recipients with free prescriptions.
 - » Introducing mandatory carer-awareness training for professionals.
 - » Systematically capturing people's caring responsibilities through the use of electronic medical records and the NHS app.
 - » Upholding carers' rights at hospital discharge.
 - » Amending and improving references to carers within the NHS Constitution.
- 2 Legislate to place a new statutory duty on the NHS to have regard to carers and support their wellbeing, to ensure systematic identification of carers in all NHS settings.
- 3 Invest an additional £1.5 billion in breaks and respite services in England (with consequential funding for Devolved Nations), and legislate so all carers have a statutory right to regular and meaningful breaks.
- 4 Invest in a programme of activities to improve carers' mental health and address other factors which affect carers' mental health such as poverty, discrimination, housing and other related issues.

- 5 Recognise that caring is a social determinant of health.
- 6 Ask the Equalities and Human Rights
 Commission to undertake an inquiry into the
 accessibility of healthcare services for unpaid
 carers.



"

I have cancer but could not have an operation as I cannot care for myself or my wife. I am having radiotherapy and chemo instead. I am worried this will affect us both."

- An unpaid carer

For more information, click here to see our <u>State of Caring 2023 report on carers' health</u> <u>and wellbeing</u>.

Preventing financial hardship

Hundreds of thousands of unpaid carers are now facing extremely precarious financial positions due to a lack of financial support with their caring role. Joseph Rowntree Foundation estimate that 44% of working age adults who provide more than 35 hours of unpaid care a week are living in poverty.¹⁶



Providing unpaid care limits many carers' ability to earn a full income, with many having to reduce their working hours or give up work completely as a result. Caring also adds extra costs that they would not otherwise have. This is particularly true of carers who care for more than 35 hours a week and those who care for longer periods of time.¹⁷

The current cost of living crisis has had a profound impact on unpaid carers across the UK. Many are now unable to afford food, petrol or their utility bills, all of which have rapidly risen in price over the last 18 months. ¹⁸ It is extremely concerning that many anticipate that things will only get worse in the coming months.

The additional costs carers face are not being met by existing social security payments that are available. Carer's Allowance is the lowest benefit of its kind at only £81.90 per week (2024/25 rates) for providing a minimum of 35 hours of care. And an inflexible and strict earnings limit for the benefit hinders carers' ability to work extra hours to make ends meet, and can also result in devastating cases of overpayments.

Carers who are struggling financially often have to make extremely tough decisions about spending.

Many carers are turning to unsustainable solutions to cope with these challenges, such as falling into debt or cutting back on activities that improve their health and wellbeing.

The financial difficulties carers face can have a significant impact on their physical and mental health, increasing stress, anxiety and feelings of inadequacy. This often increases their own need for treatment and support in order to cope.

It is unacceptable that so many unpaid carers are struggling with their finances and worrying about the future. Urgent action is required to ensure no carers have to live in poverty due to a lack of financial support.

66 Couldn't afford my internet bill, explained I need it to get medication, food, heating and light, contacting in emergency and they cut me off, I was literally crying on the phone to them, telling them it is my lifeline, they didn't care..."

- A carer in receipt of Carer's Allowance

Key stats

- Unpaid carers experience an average 'pay penalty' of nearly £5,000 per year.¹⁹
- The rate of poverty for carers in receipt of Carer's Allowance more than doubled over 10 years, from 16% in 2010/11 to 34% in 2020/21.²⁰
- 60% of carers are worried about the impact of caring on their finances.²¹
- 65% of carers say the increase in the cost of living had had a negative impact on their physical and/ or mental health. ²²
- 68% of carers are worried about their ability to save and plan for the future.²³
- 45% of carers receiving Carer's Allowance are struggling to make ends meet.²⁴
- 1 in 3 carers have had to cut back on essentials like food and heating.²⁵

"Becoming a carer affected my financial situation immensely"

In 2017, Gary's wife Natasha was diagnosed with a spinal cord tumour meaning he had to become her full-time carer, providing more than 60 hours of care each week.

Before Natasha's diagnosis, both she and Gary worked full-time, but their household income quickly fell to zero.

While Natasha was declared unfit for work, Gary had to quit his job to care for her. With no safeguards in place to cover existing loans, he had to reach out to debt management services, was forced to borrow money from friends and family to cover bills, and had to rely on food banks. He also had to support his three teenage children who were living at home. Gary explains,

I've worked since the age of thirteen; I've never been out of work. I didn't know what to do or where to go for help."

Gary receives Carer's Allowance, alongside the carer's element of Universal Credit. However, this is not always enough to get by – particularly due to the cost-of-living crisis.

66 It's very difficult to cut down on heating and electricity bills."

To cope with these additional financial pressures, Gary has taken out a loan and started part-time work – even though this means leaving Natasha home alone.



It is a bit easier having those extra pounds, but I cannot earn too much, or it will affect my benefits... We are just about getting by, but there have been times when we were really struggling."

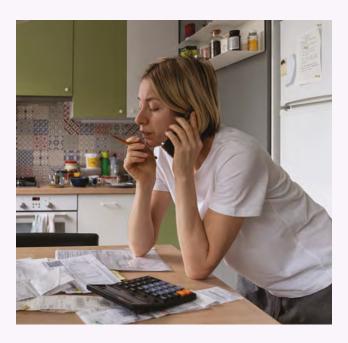
Gary wants the next Government to review the level of Carer's Allowance and increase the limit on what carers can earn while claiming the benefit.

66 Even looking at carers and mentioning them in government budgets would help. We save the country a lot of money... without being mentioned, you feel forgotten about."

The next Government must

- 1 Raise the level of Carer's Allowance and associated premia by at least £11.10 a week in England and Wales (with this also mirrored in Northern Ireland), to match the effective rate in Scotland.
- Increase the earnings limit for Carer's Allowance to the value of 21 hours work a week at the National Living Wage rate and define this link in law so carers' ability to earn is not eroded over time.
- 3 Reform the eligibility rules for Carer's Allowance giving access to a lower rate of the benefit for those caring between 20 and 35 hours a week, enabling more than one person to receive the benefit if multiple people are caring for the same person, and extending the run on of payments for bereaved carers from 8 to 12 weeks.
- 4 Carry out a full review of the links between caring and poverty across the UK and commission an independent inquiry to explore longer-term solutions to bringing more unpaid carers out of poverty.
- 5 Provide additional financial support to carers of State Pension age, including a new nonmeans-tested payment. There should also be a review of pension rules for carers, with implementation of initiatives to get carers up to similar pension levels as non-carers.

6 Modernise and digitise the delivery of Carer's Allowance to make it less complicated for claimants, protect carers from overpayments, and to allow for much faster adjustments to recipients' payments.



"

Life is on hold. Our quality of life is awful due to lack of funds. Food is scarce and basic due to no funds. We have no extra to pay off bills which cause extra stress as in debt."

- An unpaid carer

For more information, see our detailed **State of Caring report into carers' finances**.

Carers UK leads the Carer Poverty Coalition, over 130 organisations who are campaigning to reduce financial hardship and poverty for unpaid carers. Find out more about the <u>Carer Poverty Coalition</u>.

Better identification and recognition

Millions of people in the UK are providing unpaid care, yet a considerable proportion do not identify as, or call themselves, a carer. It takes two years on average for someone to identify themselves as a carer; ²⁶ many people consider caring as part of family life and see themselves primarily as a partner, wife, son, sibling, cousin, parent or a close friend. As a result, they can miss out on vital support.



Everyone has a role to play in helping carers to identify themselves, whether it is Government, family and friends, health and social care, community organisations or employers. It is also critical that there are sound systems in place to help carers to identify themselves, keeping the right records as well as linking carers to further support so they do not miss out on support they are entitled to.

The identification of carers is essential to ensure that local health and care systems can support carers with their physical, mental and wellbeing needs. A new legal duty needs to be placed on the NHS to ensure there is systematic and routine identification of carers, and all staff throughout the NHS should be Carer Aware so they understand who carers are and how to support them. Social care has a similar role to play from first contact with any services or local authority support, ensuring that any shared care records clearly identify carers.

Where employers are understanding and supportive, with good systems in place to help and encourage carers to identify themselves in the workplace, there are positive outcomes for carers and the organisations they work for – improving the health

and wellbeing of their staff, retaining colleagues for longer and improving productivity. More employers need to adopt carer-friendly and inclusive workplace cultures.

Caring has been identified as a social determinant of health by Public Health England and needs to be considered by national and local governments, by employers, by the third sector and all service providers.

The next Government also needs to develop a new National Carers Strategy which clearly sets out Government's future commitments to supporting carers and identifies specific actions that focus on delivering tangible progress and additional support for carers, their families, and those they care for.

66 It is relentless and exhausting, but we carry on regardless because of our loved ones. Unpaid carers in the UK are saving the UK Government billions but you do not consider us worthy of more than a couple of pounds per hour."

- An unpaid carer

Key stats from State of Caring 2022²⁷

- 51% of carers take over a year to recognise their caring role, with over a third (36%) taking over three years to do so. Only a third (31%) recognise their caring role immediately.
- 71% of carers primarily see themselves as a family member or friend, which they say was a barrier to identifying themselves as a carer.
- 32% of carers who did not immediately recognise their caring role were never told that they were a carer.
- 53% of carers say their caring role developed gradually, so it took time to realise they were a carer.

66 Failing to properly recognise and support unpaid carers is organisational neglect by omission and commission. Neglect of carers' health and wellbeing and that of the people they care for. Loving someone does not mean you can do it alone."

- An unpaid carer

The next Government must

- 1 Develop a new public awareness programme to raise the profile of unpaid carers and the vital care and support they provide.
- 2 Legislate to place a new statutory duty on the NHS to have regard to carers and support their wellbeing, to ensure systematic identification of carers in all NHS settings.
- 3 Amend the Equality Act 2010 to include caring as the 10th protected characteristic.
- 4 Encourage and fund the widespread adoption of Carers Passports, helping carers to be better identified, recognised and supported as part of the day-to-day life of an organisation or community.
- 5 Develop a new National Carers Strategy which clearly sets out the Government's future commitments to supporting carers, including through better identification and increased recognition of caring throughout society, demonstrating to carers and the wider public that they are on the side of unpaid carers.
- 6 Support awareness campaigns like Carers Week, Carers Rights Day and other initiatives that aim to reduce the time it takes for carers to identify themselves and seek support.



The Government gets away with not paying for a huge caring service that is being provided for free, often by women. We urgently need to increase public awareness and education so that it is not an expectation of women to take on caring roles." - An unpaid carer

For more information, please see our online information about carer identification.

Improving care and support

Adult social care relies heavily on the care and support provided to family members, friends and neighbours by unpaid carers. In England, the number of unpaid carers, mostly women, outnumber the paid health and care workforce by at least two to one. Indeed, unpaid carers provide the bulk of all care.



Despite this, millions of carers have to bear the negative effects of social care workforce shortages and a lack of funding for social care. Many face unrelenting demands and too often feel isolated, unsupported and undervalued while providing care for a family member.

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 are entitled to under the Care Act 2014, and many essential services remain unavailable to them, are inaccessible or unaffordable, or not of sufficient quality.

Too often carers tell us they have to 'fight' to get the care and support they need. It is also increasingly difficult for carers to get respite care, with 41% of carers saying they have not taken a break in the last year.²⁸

A lack of formal social care also affects unpaid carers' ability to juggle work and care with many giving up work to do so. With a tight labour market and with unprecedented numbers of unpaid carers out of the workforce, there is a double imperative to invest in care and to support families, including disabled people, to stay in work.

The Government's vision for adult social care in England included statements which they would like unpaid carers to be able to say in the future. Concerningly, Carers UK found that a majority of carers felt that these statements did not match their lived experiences of caring.

66 Very little support or suitable care is available for ageing carers. I am now 80 years old, and no consideration is given to my reducing speed, strength and stamina. I don't know how I will be able to cope."

- An unpaid carer

Key stats from State of Caring 2022²⁹

- A quarter of carers (25%) think the cost of care is too high.
- 31% of carers need more affordable care services for the person they care for.
- 58% of carers are worried they will not be able to afford services or practical support in the future.
- 23% of carers say care services are not meeting their needs.
- 36% of carers say they do not know what services are available to support them.
- 17% of carers with 'bad' or 'very bad' mental health said they did not know where to go to access help or support.

66 Social care within councils does not have the same safeguards and range of 'checks and balances' that NHS clinical and corporate governance does. Supporting families and carers will enable a reduction in pressure in other services, including health services. Ensure co-production is mandated and that councils are held to account." – An unpaid carer

"If the Government doesn't make sufficient changes, unpaid carers will need carers themselves."

Christie, 40, has been caring for her mother, Maria, since she was a child, and around twenty years ago she gave up work to care for her full-time. "One of my earliest memories as a child was calling 999, because my mum had passed out. I was about four at the time".

Maria has numerous complex conditions, including Epilepsy, Type 2 Diabetes, mixed dementia, kidney and heart failure, and depression. Christie does almost everything for her mother, from household chores and finances, to handling medications and hospital appointments.

She constantly monitors Maria's oxygen levels and heart rate and administers daily finger-prick tests.

I'm not a trained nurse...but it's almost like I've got Mum's life in my hands. It's really stressful and I'm always on high alert. I can't rest because I'm worried something is going to happen."

Christie struggles with insomnia, as well as anxiety and panic attacks. She's unable to take a break from her caring role, even when her own chronic health conditions are causing her pain.



66 I get flare-ups every day, but I have to push through the pain, or mum won't get her food or medication."

The stresses Christie faces on a daily basis mean her mental health has worsened, and she often feels isolated and depressed, going months at a time without leaving the house, except for medical appointments. People think that if you're with someone every day, then you're with them, but I don't have any quality time with her as a daughter... there are times when I need my mum, and I can't rely on her in that way."

Christie would like to see more support and funding for carers in her local area.

There needs to be a lot more carer day centres. We could meet with other carers and have a coffee and a chat; they could do day trips and help me find care cover."

Christie wants the next Government to provide more funding for health and social care, and to be more understanding of carers' needs.

- I know funding is tight, but if community nurses were more involved and able to stay with patients for longer it would help [me] to feel better supported as a carer."
- Becoming a carer for a loved one could happen to anyone, even politicians. They should think about how that would affect their lives, and the support they would want and need. If the next Government does not make sufficient changes, unpaid carers will need carers themselves. That will cost them more money in the long run."

The next Government must

- Develop a clear plan for social care reform and provide long-term, sustainable funding to ensure all carers and those they support can access high-quality social care services when they need them.
- 2 Ensure that Local Authorities have sufficient and sustainable funding to enable them to fulfil their duties to carers under the Care Act 2014.
- 3 Develop a social care workforce strategy to ensure that there are enough skilled social care staff to provide social care, lessening the amount of unpaid care that family and friends are currently providing.
- 4 Invest an additional £1.5 billion in carers' breaks so that carers are able to access the breaks they need and improve their mental and physical health and wellbeing.
- 5 Develop a new National Carers Strategy, backed by significant investment, which sets out future commitments to supporting unpaid carers and identifies specific actions that focus on delivering tangible progress and additional support for carers, their families, and those they care for.

6 Develop a new narrative which recognises the economic impact of social care which can be fundamental for carers' ability to stay in and return to work.



For more information, please see our **State of Caring 2022 report**.

Support to juggle work and care

The number of people who are juggling paid employment with their unpaid caring responsibilities is significant and is set to increase as our society ages. Much more needs to be done to support carers to remain in work where they wish to do so.



The UK lags behind other countries when it comes to workplace rights for carers and it is time workplaces reflect the reality of carers' lives. Many countries have some form of paid Carer's Leave in place, including Japan, Canada, the US, Germany, Ireland, France, Belgium, Sweden. Our analysis of other countries' policies estimated that providing working carers in the UK with paid Carer's Leave of at least five days per year could save the UK economy around £3.5 billion a year.³⁰

Too often, the challenges and stresses people face currently when caring, combined with a lack of support from the health and care system, and not enough understanding or support from their employer, means that they have to give up work to care.

Over half a million people a year are having to take this extremely difficult decision – with devastating consequences for their careers, their finances, their sense of self, and also their health and wellbeing.³¹ And many of those who are still balancing work and care are extremely concerned about how they will continue to do so given the pressures they face, while many have had to forego opportunities at work.

Many working carers say they are exhausted, stressed, and struggling to take a break.

We want to ensure that all unpaid carers can remain in work when they want and are able to do so. There is not only a strong moral imperative to support unpaid carers, but also a strong economic imperative too. The UK economy and the productivity of business and employers, including the public and voluntary sectors, depends on retaining their skilled and knowledgeable staff. Crucially, that increasingly includes employees juggling work with caring.

As a society we must adapt in order to support our growing and changing population of unpaid carers. The next Government must recognise the importance of supporting carers to participate in the labour market, build on the Carer's Leave Act 2023, and take further steps to support and encourage them to do so.

66 I needed time off for appointments due to my caring role but was not supported in this making it impossible to work. I was not allowed to work part time and needed to attend appointments and make calls at work." – An unpaid carer

Key stats

- **2.6 million** people have had to give up work to care, and a further **2 million** working carers have reduced their hours at work.³²
- 9% of people in employment in the UK are also unpaid carers.³³
- 1.9 million employees become unpaid carers each year over 5,000 people a day.34

66 Since I was made redundant, I have been unable to get work due to my caring responsibilities; this has had a huge impact on our household. It is impossible to budget as things are going up so much. It is very, very worrying." – An unpaid carer

"I don't want to give up hope, the thought of not working again is soul-destroying..."

Jane cares for her daughter, Alex, who is autistic and has Ehlers-Danlos syndrome, auto-immunity, and mental health difficulties.

Caring responsibilities for Alex began at the time of her birth and became more complex as she grew older, influencing career decisions for Jane early on.

I was training to become a teacher, but Alex's school would often call me asking 'can you come and get your daughter?' I revised my plans to work for my local authority, which I hoped would be more flexible. I completely switched jobs and degree to accommodate that."

When Alex had a spinal stroke, her physical and mental health deteriorated.

When she had the spinal stroke, I went parttime, but there were at least three medical appointments in the diary each week. Every time I went to work, I felt guilty that I should have been doing something for Alex."

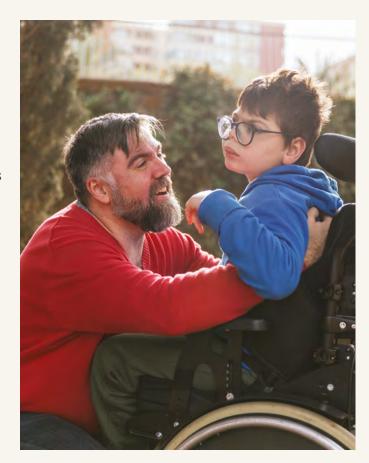
After a second spinal stroke Jane gave up work completely to become Alex's full-time carer. Jane and Alex live together, and household finances are a huge challenge. Although Jane receives Carer's Allowance and Alex receives disability benefits, there is little money left over after paying the bills.



- I don't want to give up hope, but the thought of not working again is soul-destroying, I've always had that work ethic and that's always been my social outlet I lost all my friends when I left work, because I haven't got money to go out, even to spend on fuel sometimes. I would like to receive support so that I could find a way to employment."
- Carers are saving the government so much money to do what I do. It is a fraction compared to what they would have to pay out to support carers."

The next Government must

- 1 Build on the Carer's Leave Act 2023 and give working carers a statutory right to two weeks of paid Carer's Leave a year.
- 2 Provide employees with the right to take a longer period of unpaid Carer's Leave of up to 6 months, and further enhance peoples' rights to work flexibly.
- 3 Review and implement changes to the social security system to better support carers to remain in work, removing any aspects that act as a disincentive to work.
- 4 Invest in adult social care to better enable carers to remain in work.
- 5 Provide dedicated funding to support carers to get back to work after time out to care.
- 6 Increase employers' awareness of carers in their workforce.



For more information, please see our <u>State of Caring 2023 report on carers and employment</u>.

Equality for carers

Since Carers UK was first established 59 years ago, securing rights and equality for carers has been at the heart of what we do. Carers' voices and experiences shape and evidence our campaigns, and once new rights have been gained for carers, we work with a range of partners to ensure the best delivery of those rights in practice to ensure they become a reality.



Concrete rights and entitlements matter to carers in terms of making sure that carers are valued and recognised for what they do, and so they get the vital support they need in key areas; from their finances, to receiving care and support, protections in the workplace, as well as freedom from discrimination. People also need to be able to make real choices about the unpaid care they wish to provide.

While there are robust social care rights frameworks for unpaid carers across the UK through the Care Act 2014 and similar legislation in other UK nations, the underfunding of adult social care means that these rights are too often not delivered in reality.

Carers also need new rights and legal protections. These include a right to a meaningful break, greater rights when interacting with the NHS, and carers' benefits also need to be significantly improved. Rights in the workplace need to continue to evolve and improve building on the important steps secured through the Carer's Leave Act 2023, starting with paid Carer's Leave.

However, carers continue to face many inequalities and are not fully recognised as a protected characteristic under the Equality Act, and public bodies do not have a specific responsibility in England, Scotland and Wales to promote equality of opportunity.

66 I have mental health difficulties of my own that need treatment and support but due [to] my caring responsibilities I don't have the time or energy to get the support I need, so I am getting worse."

- An unpaid carer

The next Government must

- 1 Amend the Equality Act 2010 and Section 75 of the Northern Ireland Act 1998 to include caring as the 10th protected characteristic. When applying for jobs, equality monitoring forms do not ask whether someone has unpaid caring responsibilities. There is no direct requirement for simple reasonable adjustments for carers in the workplace. Carers say that this would make a difference.
- Ensure that carers existing rights under the Care Act 2014 are always fulfilled by Local Authorities.
- 3 Provide all unpaid carers with a statutory right to a break from their caring responsibilities and provide funding to ensure that all carers can access the breaks they need when they need them.
- 4 Legislate to place a new statutory duty on the NHS to have regard to carers and support their wellbeing, to ensure systematic identification of carers in all NHS settings.
- 5 Give all carers in employment the statutory right to take two weeks of paid Carer's Leave, building on the right to unpaid Carer's Leave recently secured through the Carer's Leave Act 2023.

6 Enhance carers' rights to work flexibly, building on the new rights recently secured through the Employment Relations (Flexible Working) Act 2023.



For more information, please see our **State of Caring 2022 report.**

A new National Carers Strategy



Carers UK have long called for the UK Government to develop and publish a comprehensive and funded National Carers Strategy.

The first National Carers Strategy was published in 1999,³⁵ while the last Carers Strategy was published back in 2008, over 16 years ago,³⁶ and there has not been a dedicated cross-Government approach to supporting carers since the Carers Action Plan 2018-20 ended in 2020.³⁷

Any future National Carers Strategy should clearly set out Government's future commitments to supporting carers and identify specific actions that focus on delivering tangible progress and additional support for carers, their families, and those they care for. We want it to be led by the Prime Minister and with buy in across Government, as was the case with previous Carers Strategies. It should take account and learn from existing strategies that exist in the devolved nations, and in other countries.

Having a new National Carers Strategy would:

- Set a clear and ambitious direction of travel at the highest level of Government, regarding the need to support carers.
- Allow for coordinated interaction of different policies and shared Government ambitions across different Departments, ensuring that carers' needs are understood and being responded to.
- Improve Ministerial oversight of key policy objectives regarding unpaid carers.
- Signal strongly to the carers and the wider public that they are on the side of unpaid carers.

The All-Party Parliamentary Group on Carers recently surveyed current and former carers, as well as organisations who represent them, to gather views on what a future National Carers Strategy should focus on.³⁸ Over 5,000 people responded, with 95% strongly agreeing that a new Carers Strategy should be developed as soon as possible.

Annex: Carers UK's policy calls ahead of the 2024 General Election

Theme	Core policy calls	Detail	Nations
	Raise the level of Carer's Allowance	• The level of Carer's Allowance and associated premia should increase by at least £11.10 a week in England and Wales (and mirrored in Northern Ireland), to match the effective rate in Scotland (due to payment of Carers Allowance Supplement).	England Wales
	Increase the earning's limit for Carer's Allowance	 The earnings limit for Carer's Allowance should be raised to the value of 21 hours work a week at the National Living Wage (NLW) rate (£218.82 at 23/24 rates). The link to the NLW should also be defined in law, so the number of hours a carer can work whilst claiming Carer's Allowance, does not reduce year on year. 	England Wales
6	Reform the eligibility rules for Carer's Allowance	 A lower rate of Carer's Allowance should be introduced to give access to the benefit for those caring between 20 hours a week and 35 hours a week. More than one person should be entitled to receive Carer's Allowance, when multiple people are providing care for the same person. The run on of Carer's Allowance payments following the death of the person being cared for should be extended to 12 weeks. 	England Wales
Financial impact of caring	Commission a review to analyse the risks of carers' poverty	 UK Government should carry out a full review of the links between caring and poverty across the UK. It should also commission an independent inquiry into the relationship between carers and poverty, to explore longer-term solutions to bringing more unpaid carers out of poverty, including food poverty. 	UK wide
Financi	 UK Government should introduce an additional non-meanstested payment for older carers in recognition of the impact their caring responsibilities have on their finances in later life. There should be a review of pension rules for unpaid carers witimplementation of new initiatives to get carers up to similar pension levels as non-carers. This should include: Ensuring that the state pension age does not increase further, as this would significantly disadvantage carers. Creating a new mechanism by which carers are able to receive their state pension up to five years early. Creating auto-enrolment payments for carers in receipt of Carer's Allowance to ensure that they continue to contribute additional pensions. 	UK wide	
The delivery of Carer's Allowance should be modernised	 Carer's Allowance operations should be digitised to enable the next Government to make much faster adjustments to payments and to introduce different rates of the benefit. The current system is overly complex and difficult to navigate, leaving people unsure about what support they are entitled to, and can lead to devastating cases of overpayments. The application process for claiming Carer's Allowance should be modernised to better support people, especially older carers. 	England Wales	

Theme	Core policy calls	Detail	Nations
	Paid Carer's Leave	Government should introduce a statutory entitlement to two weeks of paid Carer's Leave for all carers in employment. This would build on the Carer's Leave Act 2023, and ensure all working carers can take advantage of Carer's Leave without losing out financially.	GB
	Enhance flexible working rights	Government should legislate to enhance carers' rights to work flexibly, building on the provisions in the Employment Relations (Flexible Working) Act 2023.	GB
	6 months of unpaid Carer's Leave	 Alongside the introduction of two weeks paid Carer's Leave, working carers should have a new statutory entitlement to enable them to take up to 6 months of unpaid Carer's Leave a year. 	GB
Juggling work and care	Review and implement changes to the social security system to better support carers to juggle work and care	 Government should undertake a review to understand where particular aspects of the social security system are currently acting as a disincentive to work – e.g., the earnings limit for Carer's Allowance means that many carers have to cap the number of hours of work they do to ensure they do not lose access to the benefit. 	England Wales
	Greater investment in adult social care to better enable carers to remain in work	Government needs to increase the level of funding available to Local Authorities to deliver adult social care to ensure all carers are able to access the social care support they need when they need it. This funding needs to be provided on a sustainable and long-term basis. Having access to reliable, affordable and quality social care services are a prerequisite to enabling many carers to participate in the labour market.	UK wide
	Dedicated funding and workstream to support carers get back to work	 Government needs to invest in structural support to enable carers to return to work following a period of absence related to their caring responsibilities. Government should invest in a new national network of carers' partnership managers, to coordinate and review carers' pathways back into work. 	GB
	Increase employers' awareness of carers in their workforce	 Government should have a rolling awareness campaign regarding the need for working carers to be supported by their employers. Encourage more employers to become Carer Confident. 	England Wales

Theme	Core policy calls	Detail	Nations
Health and wellbeing	Transform the way the NHS interacts with unpaid carers to make it the most carer-friendly health service in the world	 Develop a nationally funded public health-oriented programme to support carers throughout the NHS. Enable all carers providing substantial care to receive an annual health check. Provide carers in receipt of Carer's Allowance (or other social security benefits) with free prescriptions. Reduce waiting times for treatments for unpaid carers and the people that they care for. Amend and improve references to carers within the NHS Constitution, which should be used proactively to improve outcomes for carers. Mandatory training for frontline professionals to ensure they are able to identify, signpost and support carers when they encounter them, particularly in relation to carers' health and wellbeing. Ensure carers' rights to be involved and consulted at point of hospital discharge are upheld and are a reality for all. Patients' electronic medical records should clearly capture people's caring responsibilities. Carers should be able to access these records and self-certify as a carer through the NHS App. 	England
	Ensure all carers are able to take a break	 Invest an additional £1.5 billion in carers' breaks so that carers are able to access the breaks they need and improve their mental and physical health and wellbeing. 	England
	Implement a programme of activities to improve carers' mental health	 Instigate a rapid review of carers' mental health and wellbeing. The Government, NHS bodies and local authorities should ensure that carers are a specific group as part of programmes to combat health inequalities, with more targeted work recognising that caring is a social determinant of health. This should include targeted mental health support. The Government, NHS bodies and local health and social care services must drive a programme of quicker and more targeted interventions, working with Integrated Care Systems (ICS), to prevent poor mental health of carers. Carers should be a targeted group within Integrated Care Systems, which should have an overarching objective to support carers. The Government must also address other factors which affect carers' mental health such as poverty, discrimination, housing and other related issues. 	England

Theme	Core policy calls	Detail	Nations
Health and wellbeing	Systematic identification of carers in all NHS settings	 A new statutory duty should be placed on the NHS to have regard to carers and support their wellbeing. This duty would require the NHS to collect more systematic data on unpaid carers, including in relation to their health and wellbeing, their experiences of care, and experiences of hospital discharge. Create incentives for secondary and primary care to identify unpaid carers, including through the GP contract. On identification, there should be mechanisms to provide carers with information, self-care and digital resources to support them. 	England
Health an	Inquiry into the accessibility of healthcare services for unpaid carers	The Equality and Human Rights Commission should conduct an inquiry into the accessibility of healthcare services for unpaid carers.	England Wales
	Promote carers access to physical activity	 Continue with the Carers Active programme to increase carers' health and wellbeing and reduce loneliness through physical activity. 	England
	Make caring the 10th Protected Characteristic	 Government should amend the Equality Act 2010 and Section 75 of the Northern Ireland Act 1998 to include caring as the 10th protected characteristic. 	UK
	Right to a break from caring	• All unpaid carers should have a statutory right to take a break from their caring responsibilities.	England
Rights and equality	New Duty on the NHS to identify and support carers	 Introduce a new duty on the NHS to have regard to carers and support their wellbeing. This would mean that carers are systematically identified across all healthcare settings. 	England
	Paid Carer's Leave	 Government should introduce a statutory entitlement to two weeks of paid Carer's Leave for all carers in employment. This would build on the Carer's Leave Act 2023, and ensure all working carers can take advantage of Carer's Leave without losing out financially. 	GB
	Enhanced rights to flexible working	 Government should legislate to enhance carers' rights to work flexibly, building on the provisions in the Employment Relations (Flexible Working) Act 2023. 	GB
	Inquiry into the accessibility of healthcare services for unpaid carers	 The Equality and Human Rights Commission should conduct an inquiry into the accessibility of healthcare services for unpaid carers. 	England

Theme	Core policy calls	Detail	Nations
cognition	Develop a new public awareness programme re. unpaid carers	Government should develop an awareness campaign regarding unpaid carers to help people to identify as carers so they access support that is available, and to better recognise and value the unpaid care that people provide.	UK
	Develop a new National Carers Strategy	 Develop a new National Carers Strategy, backed by significant investment, which sets out future commitments to supporting unpaid carers and specific actions that focus on delivering tangible progress and additional support for carers, their families, and those they care for. Any such strategy must be complimentary and work in tandem with existing Carers Strategies in the Devolved Nations. 	England
Identification and recognition	New Duty on the NHS to identify and support carers	 Introduce a new duty on the NHS to have regard to carers and support their wellbeing. This would mean that carers are systematically identified across all healthcare settings. 	England
Identif	Make caring the 10th Protected Characteristic	• Government should amend the Equality Act 2010 and Section 75 of the Northern Ireland Act 1998 to include caring as the 10th protected characteristic.	GB
	Widespread adoption of Carers Passports	 The rollout of Carers Passports should be backed by investment from UK Government. Carers Passports should be established across health and social care services as well as in communities. More employers should be encouraged to develop their own Carers Passports. 	England
	Social care reform to support carers	 Develop a clear plan for social care reform and ensure there is adequate funding for all carers and those they support to access high-quality social care services when they need them. 	England
	Fulfilment of Care Act 2014 duties to unpaid carers	 Ensure that that Local Authorities have sufficient funding to enable them to fulfil their statutory duties to carers under the Care Act 2014. 	England
Care and support	Develop a new social care workforce strategy	 A social care workforce strategy should be introduced to ensure that there are enough skilled social care staff to provide social care, lessening the amount of unpaid care that family and friends are currently providing. 	England
	Develop a new National Carers Strategy	 Develop a new National Carers Strategy, backed by significant investment, which sets out future commitments to supporting unpaid carers and identifies specific actions that focus on delivering tangible progress and additional support for carers, their families, and those they care for. Any such strategy must be complimentary and work in tandem with existing Carers Strategies in the Devolved Nations. 	England
	Ensure all carers are able to take a break	 Invest an additional £1.5 billion in carers' breaks so that carers are able to access the breaks they need and improve their mental and physical health and wellbeing. All unpaid carers should have a statutory right to take a break from their caring responsibilities. 	England

Endnotes

- 1 Census 2021
- 2 Carers UK and Centre for Care at the University of Sheffield (2023) Valuing Carers 2021 in England and Wales
- 3 Carers UK (2013) Supporting Working Carers: The Benefits to Families, Business and the Economy
- 4 Carers UK and University of Leeds (2007) Carers, Employment and Services: time for a new social contract?
- 5 Census 2021
- 6 Carers UK and Centre for Care at the University of Sheffield (2022) Cycles of caring: transitions in and out of unpaid care
- 7 Census 2021
- 8 Carers UK, University of Sheffield, University of Birmingham (2019) Will I Care? The likelihood of being a carer in adult life
- 9 Carers UK (2023) State of Caring: Impact on finances
- 10 Carers UK (2023) State of Caring: Impact on health
- 11 Census 2021 (England, Wales, Northern Ireland), Census 2011 (Scotland)
- 12 Carers UK (2022) State of Caring 2022
- 13 Ibid
- 14 Ibid
- 15 Carers UK (2023) State of Caring: Impact on health
- 16 Joseph Rowntree Foundation (2022) UK Poverty 2022
- 17 Carers UK (2023) State of Caring: Impact on finances
- 18 Ibid
- 19 Joseph Rowntree Foundation (2023) The caring penalty
- 20 Joseph Rowntree Foundation (2023) The essential quide to understanding poverty in the UK
- 21 Carers UK (2023) State of Caring: Impact on finances
- 22 Ibid
- 23 Ibid
- 24 Ibid
- 25 Ibid
- 26 Carers Week (2023) I Care: Carers Week report on unpaid carer identification
- 27 Carers UK (2022) State of Caring 2022
- 28 Ibid
- 29 Ibid
- 30 Carers UK (2019) Juggling work and care: A growing issue

- 31 Ibid
- 32 Ibid
- 33 Census 2021
- 34 Carers UK and Centre for Care at the University of Sheffield (2022) Cycles of caring: transitions in and out of unpaid care
- 35 UK Government (1999) Caring about carers: a national strategy for carers
- 36 UK Government (2008) Carers at the heart of 21st century families and communities
- 37 Department of Health and Social Care (2018) Carers Action Plan 2018 to 2020: Supporting carers today
- 38 All-Party Parliamentary Group on Carers (2024) Our call for a new National Carers Strategy



Across the UK today 5.7 million people are carers – supporting a loved one who is older, disabled or seriously ill.

Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

We're here to make life better for carers.

Carers UK 20 Great Dover Street, London, SE1 4LX

T 020 7378 4999 | E info@carersuk.org











Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London SE1 4LX.