

State of Caring 2024

“I want to see a future
for carers where...”

January 2025



About this research

Carers UK carried out an online survey with unpaid carers between June and August 2024.

A total of 12,500 carers and former carers responded to the survey. This report summarises their responses. As not all respondents completed every question in the survey, some figures are based on responses from less than 12,500 people.

The survey was promoted extensively amongst both carers and organisations supporting carers. It was shared on the Carers UK website, on Carers UK social media channels, and with Carers UK members, volunteers, previous survey respondents, campaigners, affiliates, Employers for Carers members, and other organisations.

Of the respondents to the survey:

- 92% are currently providing care. Of those, 63% are in England, 15% are in Scotland, 11% are in Wales, and 11% in Northern Ireland.
- 8% have cared in the past but are no longer caring. Of those, 62% are in England, 20% are in Scotland, 12% in Northern Ireland and 6% in Wales.

- Of those currently caring, 14% are caring for 19 hours or less, 26% are caring for 20-49 hours, and 61% are caring for 50 or more hours a week.
- 68% of respondents were aged 18-64 years and 31% were aged 65 and over. The biggest proportion of respondents were in the 55-64 year category (35%).
- 81% of respondents were female; 18% were male. 1% said their gender was not the same as the one assigned at birth.
- 89% of respondents were White British, 7% were from another White background, and 3% were from a Mixed/Multiple, Black/Black British, Asian/Asian British or other ethnic background.
- 91% of respondents were heterosexual/straight, 5% were Lesbian, Gay or Bisexual, or preferred to self-describe their sexual orientation.
- 29% of respondents had a disability.

Thank you

Carers UK would like to thank every carer who took the time to complete this survey, as well as the carers who helped us test the survey. Your responses will be used in all our policy and campaigning work over the next year.



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Foreword

I'm delighted to introduce our '***I want to see a future for carers where...***' report in this our 60th anniversary year. Whilst of course we must be proud of all that we have achieved in the 60 years since our inception what is most important is to look forward and recognise how much more needs to be done.



When the Reverend Mary Webster gave up her job to care for her elderly parents and subsequently created the carers movement that is Carers UK today, she wanted equality particularly in terms of gender. In honour of this we have chosen 'Equality: today and tomorrow' as our theme for 2025 and we've asked carers themselves what that means for them.

Equality, support and recognition are the three pillars of Carers UK's current strategy and clearly these three areas are what carers want to see improved. As you will see from the report carers are desperate for a break, for better health and social care provision, financial support and equality in the workplace. We have a duty as a society to provide a future for them where these are addressed.

2025 will be a year where we will be shouting from the rooftops about unpaid carers. We have a new government and we will be working harder than ever to influence and campaign on behalf of unpaid carers. Alongside this we'll be putting on a programme of events across the year in all four nations to showcase carers and the extraordinary work that they do and to underline everywhere we can the importance of achieving equality today and tomorrow for unpaid carers. And we will be telling everyone we meet, politicians, celebrities, health and social care workers, carers and those who have the power to make change – '*I want to see a future for carers where...*' and asking them to help make it happen.

I pledge that carers, as always, will be at the heart of everything that we do and that we will make it our mission, this anniversary year, to realise our vision to make life better for carers.

Helen Walker
Chief Executive, Carers UK

Executive summary

Since Carers UK was established 60 years ago, securing equality for carers has been at the heart of what we do. Millions of people across the UK are providing unpaid care for a friend or family member, contributing over £184 billion to the economy each year. Yet carers often feel undervalued and unrecognised for what they do, and caring can have a significant impact on people's lives, from their finances to their employment and health and wellbeing. Without sufficient support from social care services, many unpaid carers feel they have no choice but to care.



For 60 years, Carers UK has been campaigning for carers rights and entitlements in relation to finances, health and care, employment and discrimination. We have successfully campaigned for every single one of the carers' rights that exists today, including the first ever financial support for unpaid carers, the first ever right to a Carer's Assessment, and the first rights in employment. Further changes have been made recently by the Government, such as a right to unpaid Carer's Leave in the workplace, and an increase in the earnings limit on Carer's Allowance. However, carers' evidence shows that much more still needs to be done.

Carers should have the right to a break, better recognition and support from the NHS, and improved financial benefits. Carers should also be able to live a life free from discrimination, and making caring a protected characteristic was a fundamental part of Carers UK's Vision 2025.

The theme for our 60th anniversary year is 'Equality: today and tomorrow.'

Because although there have been advances for carers during this time, the reality for many is extremely tough.

And that's why we need everyone to join us to push for change, and help our drive for greater equality, recognition and support for all carers.



What support carers would like in the future

As part of Carers UK's 60th anniversary year, we asked carers what support they would like to see in the future, to help us shape our campaigning priorities in the years to come and ensure these are driven by the changes carers want to see. In the State of Caring 2024 survey, we asked carers to complete the following sentence: **"I want to see a future for carers where..."**

Thousands of carers responded to this question, and we are grateful to every single carer who shared their views. It is clear that carers want to see more progress across several areas, including:

- **more recognition within society of carers' vital contributions** in preventing health and social care systems from collapsing
- **more financial support for carers** from the UK Government to support people who have had to give up work to care, and to prevent carers from falling into poverty
- **more opportunities to take a break from caring**, with increased funding for social care services so that carers have a choice in how much care they provide
- **more support for carers' own health and wellbeing**, with quicker and easier access to NHS healthcare, and more funding for programmes that aim to improve carers' wellbeing
- **more information and advice for carers** which is easily accessible and tailored to carers' individual needs
- **more practical support with caring**, with Carer's Assessments leading to specific support that is tailored to carers' individual needs, rather than just signposting alone
- **more support to enable carers to combine caring with paid employment**, including increased flexible working opportunities, paid carer's leave and a greater understanding of caring amongst employers
- **more recognition that caring is an equalities issue**. A higher proportion of women are providing unpaid care than men, and carers are more likely to have a disability than those without caring responsibilities. Research has found that caring should be considered a social determinant of health because of the significant impact it can have on both physical and mental health. Caring can also impact on finances, employment, wellbeing, and access to health services.

"I want to see a future for carers where..."



Equality for unpaid carers in the future

As the theme for Carers UK's 60th anniversary year is Equality: today and tomorrow, we were keen for carers to tell us what equality means to them.

We received responses from thousands of carers, who shared a wide range of reflections on equality and caring. The breadth of perspectives shared demonstrates how equality can mean different things to different carers.

The following themes were highlighted:

Equality amongst carers

- **More gender equality in the provision of unpaid care** so that women are not disproportionately impacted by the negative impact caring can have on health and wellbeing, finances, and employment.
- **Equality in the level of financial support provided to carers**, with everyone receiving the same amount of support and recognition, regardless of circumstances.
- **Recognising, respecting, and valuing differences in people** so that everyone feels included.
- **Equal opportunities for disabled carers and the people they care for**, so that everyone has the same chance to fully participate in society.
- **Support services that are tailored** and adapted according to individual need, rather than taking a one-size-fits-all approach.
- **Equal access to health and social care services**, with the same opportunities for support, regardless of location or individual circumstances.



Equal rights for carers

- **Equal opportunity for carers to live a fulfilling life**, with carers able to take breaks and look after their own health and wellbeing, so that they are not disadvantaged when compared to those without caring responsibilities.
- **Carers living a life that is free from discrimination**, where carers no longer experience unfair or unfavourable treatment due to their caring role.
- **Aspiring towards equity for carers rather than equality**, with carers given additional support enabling them to have the same opportunities as those who do not provide care.
- **More recognition within society and from Government** about the vital contribution made by carers and the impact caring can have on carers' finances, health and wellbeing, and employment.
- **More financial support for carers**, to prevent carers from falling into poverty and reduce the stress of worrying about how to make ends meet.
- **More support to enable carers to juggle work and care**, including more opportunities to work flexibly and take carer's leave.

The support that carers would like to see in the future



More recognition for unpaid carers

A significant proportion of carers wanted more recognition from the Government, the NHS, local authorities, public bodies and the general public. Many carers felt they were invisible – that they were caring behind closed doors, and forgotten about.

“I want to see a future for carers where we are not a forgotten army, out of sight and out of mind.”

“I want to see a future for carers where we are valued and recognised for the work we do. That we aren't an invisible workforce that is expected to care no matter what.”

“I want to see a future for carers where they are respected and appreciated, not hidden and ignored.”

“I want to see a future for carers where they are recognised for the role they perform behind closed doors.”

In particular, many carers wanted to see more recognition from the Government of the important role carers play in our society. This year's State of Caring survey found that over three quarters (78%) of carers disagreed that they were valued by the Government.

“I want to see a future for carers where they aren't dismissed by successive governments and not taken for granted because they love the person they care for.”

“I want to see a future for carers where the government realises what an important job carers do.”

“I want to see a future for carers where the invaluable roles they undertake are better appreciated and acknowledged by Governments and future policies and legislation give consideration to the impact that long term caring responsibilities can have on individuals.”

Other carers wanted a more widespread recognition across the whole of society.

“ I want to see a future for carers where they are recognised as an important part of society and shown respect and honoured for what they do.”

“ I want to see a future for carers where the general public value and support them in the way the NHS was valued and appreciated and supported during Covid. Publicity via TV dramas/streamed services in addition to conventional media/government messages.”

“ I want to see a future for carers where carers are recognised as the cornerstone of society.”

This year's State of Caring survey found that only 14% of carers agreed that they were valued by the general public.

In particular, several carers said they would like the general public to understand more about the impact caring can have on people's finances, health and wellbeing, and their ability to work in paid employment.

“ I want to see a future for carers where people who are not carers better understand the challenges faced by carers and the difficulties we overcome on a daily basis.”

“ I want to see a future for carers where we are appreciated and the general public realise what we have given up.”

“ I want to see a future for carers where there is more publicity and general understanding on how demanding caring is, especially emotionally.”

“ I want to see a future for carers where we are recognised for what we actually do every day of our lives, the sacrifices we make, things that we can't do or have in our lives because we care for someone.”

Some carers wanted to see a greater level of awareness of the economic contribution of unpaid carers. Recent research by the Centre for Care found that the combined economic value of unpaid care across the four nations of the UK was £184 billion in 2021/22, a 29.3% increase over the past decade (£119.4 billion in 2011).¹

The increase in the economic value of unpaid care is mainly due to the increase in the number of hours of care provided by unpaid carers in all four nations. Several carers highlighted the substantial amount of money they are saving the public purse.

“ I want to see a future for carers where carers aren't invisible to the general public and are recognised for the hard work we do and just how much we are saving the government who would have to pay so much more for paid carers to do all the things we do.”

“ I want to see a future for carers where they are recognised for all the work they do, how much they save the public purse.”

“ I want to see a future for carers where they are recognised for the vital role that they are playing in society and acknowledged for the billions that they are saving the economy.”

“ I want to see a future for carers where the government and society recognise the work, and dedication of unpaid carers, along with the savings they contribute to the NHS and social care services.”



¹ Petrillo, M., Zhang, J. and Bennett, M.R. (2023) 'Valuing Carers 2021/22: the value of unpaid care in the UK carersuk.org/media/mfbbmjbn/valuing_carers_uk_v3_web.pdf



Many carers felt they should be given more respect and recognition for the role they play in supporting health and social care systems. Centre for Care research found that the economic value of care in the UK is equivalent to the NHS budget across all four nations, and over four times the amount of publicly funded spending on adult social care services.² Without support from unpaid carers, the UK's health and social care systems would collapse.

“I want to see a future for carers where they are recognised for the service they provide without which the NHS would collapse and the vulnerable would be unsafe in their own homes.”

“I want to see a future for carers where there is a universal acceptance that carers are the unseen props of an inadequate social care system.”

“I want to see a future for carers where carers are recognised as an essential component of social care.”

“I want to see a future for carers where they are recognised for the care they provide and the pressure they take off statutory services.”

Many carers would like more recognition within the NHS and to be consulted more about the care and treatment of the person they care for. This year's State of Caring survey found that only a quarter (25%) of carers said they felt valued by the NHS (eg

hospital staff or GPs). Previous Carers UK research has shown that carers often find the hospital discharge process to be frustrating because they are not consulted with properly. For example, 60% of carers disagreed that they were asked about their ability and willingness to care during the hospital discharge of the person they cared for.³

Several carers said they wanted to be viewed by healthcare professionals as an equal partner in care – to be listened to more, and to have an input into decisions relating to the care of the person they care for.

“I want to see a future for carers where their opinions are listened to by health care professionals and social workers so that they and the person they are caring for get the help they need.”

“I want to see a future for carers where carers are valued and considered when professionals are making decisions. They should be included in decisions made to progress situations as they are often the ones that have to deal and carry out what the professionals recommend.”

“I want to see a future for carers where they are regarded as equals with the health professionals and their information and concerns are taken seriously and supported rather than judged and treated with suspicion.”

² Ibid

³ Carers UK (2023) State of Caring 2023: the impact of caring on health carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf

More financial support

Some carers felt that they had no choice but to take on caring responsibilities, and that this had a significant impact on their finances. Our State of Caring survey found that 40% of all carers had given up work to care, and 44% of working carers had reduced their working hours to care.⁴ Reducing working hours or giving up work to care can have a negative impact on carers’ finances. 55% of carers who had reduced their working hours to care said they hadn’t been able to save as much for their retirement.

As a result, many carers said they wanted the Government to provide more financial support to help prevent carers from falling into poverty, particularly if they had had to give up work to care.

“I want to see a future for carers where they are financially supported if a situation arises where they have to care for someone and have to reduce their working hours or have to stop working.”

“I want to see a future for carers where they are not condemned to live in poverty, unable to afford what most people take for granted.”

“I want to see a future for carers where they are much more financially supported for looking after the person they care, especially when having to sacrifice a career.”

“I want to see a future for carers where we are not financially penalised for providing essential care and support for our loved ones.”

Several carers also said that more financial support would improve their health and wellbeing. This year’s State of Caring survey found that over half (51%) of carers said that their financial situation is having a negative impact on their mental health and wellbeing, and 61% feel stressed or anxious when they think about their financial situation.⁵

“I want to see a future for carers where they can enjoy a full life without worrying about daily living costs.”

“I want to see a future for carers where we are not terrified of our own financial futures because we have devoted a large chunk of our own lives caring.”

“I want to see a future for carers where we don’t worry, day in, day out, about the endlessly rising living costs.”

“I want to see a future for carers where they don’t have to worry if they can afford to pay bills and buy essentials.”

Recent research commissioned by Carers UK found that the poverty rate for unpaid carers was 50% higher than for those who did not provide care (27% vs 18%), and one of the key drivers for this inequality was inadequate support from the social security system.⁶ Carer’s Allowance, the main social security benefit for unpaid carers, is one of the lowest benefits of its kind at £81.90 per week as of April 2024. Two-thirds (67%) of unpaid carers who receive Universal Credit live in poverty – around 900,000 carers, and 62% or approximately 500,000 Carer’s Allowance recipients live in poverty.⁷

Several carers said the level of Carer’s Allowance should be increased.

“I want to see a future for carers where we are financially supported more realistically to ease the pressure of a already stressful role. I’m paid a weekly Carer’s Allowance which is the equivalent to 2 hours care at a suitable day provision for my adult son, yet I provide a high level of support continuously every day and night on my own.”



⁴ Carers UK (2024) The impact of caring on employment carersuk.org/reports/state-of-caring-2024-the-impact-of-unpaid-caring-on-employment

⁵ Carers UK (2024) The impact of caring on finances carersuk.org/media/umaifzpq/cuk-state-of-caring-2024-finances-web.pdf

⁶ WPI (2024) Poverty and financial hardship of unpaid carers in the UK carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

⁷ *ibid*

“ I want to see a future for carers where Carer’s Allowance is raised to reflect that unpaid carers have had no choice but to give up paid work to provide 24/7 care because at present, we are financially poorer and unable to adequately prepare for our own retirement.”

“ I want to see a future for carers where we are better compensated for being a carer – we deserve to have more money a week than we currently do – at least in line with other benefits and should also be entitled to things such as cost of living payments.”

Many carers felt that increasing the amount of financial support available to carers would demonstrate that their contribution to society is truly valued by the Government. For several carers, this meant being given at least national minimum wage, in recognition of the caring they provide.

“ I want to see a future for carers where they are paid the national minimum wage as carers like myself struggle every month due to the cost of living, increase in public transport and the cost of food.”

“ I want to see a future for carers where we are fairly paid for the service we provide in line with paid carers instead of the pittance we currently receive.”

“ I want to see a future for carers where they are genuine equal partners and respected and paid as the professional roles that that they undertake.”

“ I want to see a future for carers where full time carers are paid for the work they do, especially if their caring role stops them from working.”

Older carers wanted to see changes made to the eligibility criteria of Carer’s Allowance so that those in receipt of a pension can access it. The Department for Work and Pension rules state that you cannot get the full amount of both Carer’s Allowance and a State Pension at the same time. This can be challenging for older carers who are still providing high amounts of care but may not have been able to save as much for retirement due to the financial costs of caring, or because they had had to reduce their working hours. Census data shows that it is the oldest carers who are most likely to be providing 50 or more hours of care per week.⁸

“ I want to see a future for carers where carers are given a substantial increase in the Carer’s Allowance for as long as they look after a person, irrespective of the carer’s age. A carer does not necessarily retire at 66!”

“ I want to see a future for carers where pension age carers can still get Carer’s Allowance – we don’t stop caring when we reach this age.”

Some carers also wanted a change to the earnings limit for Carer’s Allowance, which is currently £151 per week (2024/25 rates). The Government recently announced an earnings threshold increase for Carer’s Allowance in the Autumn Budget, to the equivalent of 16 hours at the National Living Wage. Government has recently commissioned an independent review of Carer’s Allowance overpayments.

While these are very welcome first steps, many carers said that the earnings limit should be increased even further, and some would like to see a new system for managing overpayments. This year’s State of Caring survey found that 62% of carers who had experienced issues whilst working and claiming Carer’s Allowance had been unable to work more hours or take on higher paid work.⁹ 20% had an overpayment of Carer’s Allowance, and 41% said that they left their paid employment as a result of the earnings limit.

“ I want to see a future for carers where they get paid Carer’s Allowance no matter how many hours they work.”

“ I want to see a future for carers where they are not hounded by the DWP for going a few pennies over the earnings allowance. The earnings allowance should be tapered.”

“ I want to see a future for carers where carers are able to work and claim Carer’s Allowance without the constant worry about going over the earnings limit.”

⁸ ONS (2023) ‘Unpaid care by age, sex and deprivation, England and Wales: Census 2021’ ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/unpaidcarebyagesexanddeprivationenglandandwales/census2021

⁹ Carers UK (2024) The impact of caring on finances carersuk.org/media/umaifzpq/cuk-state-of-caring-2024-finances-web.pdf

More opportunities to take a break from caring

Many carers said they wanted more opportunities to take a break, so that caring did not negatively impact their health and wellbeing. Our research found that 61% of carers said that being able to take regular breaks from caring would be a challenge over the coming year.¹⁰ Carers who receive support from respite services or paid care workers can find this helpful in improving their wellbeing. However, carers have told us that support services are often unavailable or unsuitable, making it much more difficult to take a break.

The ADASS spring 2024 survey found that adult social care budgets in 2023/24 were overspent by £586m, the highest levels for at least a decade. The complexity of individual adult social care needs means that more people now require more intensive care and support.¹¹ However, local authorities are struggling to cope with this increase in demand, with workforce issues and lack of resources leading to unpaid carers struggling to get the help they need.

Being unable to take a break can mean that carers are unable to prioritise their own health and wellbeing, and many continue to provide care despite having their own health issues. Last year's State of Caring survey found that over a quarter of carers (27%) said their mental health was bad or very bad, and of those, nearly three-quarters (73%) said they were continuing to provide care even though they felt they were at breaking point.¹²

“I want to see a future for carers where we don't have to feel we are constantly at breaking point because we aren't able to have enough breaks.”

“I want to see a future for carers where they have regular breaks so they don't become ill themselves.”

“I want to see a future for carers where there is recognition that we cannot provide free/altruistic care 365 days a year without damaging ourselves and where we can access support to let us take a break from caring responsibilities without guilt.”

“I want to see a future for carers where we can find time to look after our own mental and physical needs, to avoid becoming stressed, depressed and burnt out.”

Several carers said that taking a break would improve their wellbeing, by offering them an opportunity to spend time with family and friends, or engage in their hobbies and interests.

“I want to see a future for carers where they are supported to maintain a life outside of a caring role.”

“I want to see a future for carers where there is a fairer balance between caring and other aspects of their life.”



¹⁰ Carers UK (2023) State of Caring 2023: the impact of caring on health carersuk.org/media/xgw1j0gn/soc23-health-report_web.pdf

¹¹ Directors of ADASS (2024) '2024 Spring Survey' adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf

¹² *ibid*

“ I want to see a future for carers where caring for someone doesn't mean you have to sacrifice all of your own needs.”

“ I want to see a future for carers where we are not defined by being a carer. Carers generally don't have time for themselves, existing not living and that's not right.”

In particular, many carers said they would like to be given free respite. Currently, under the Care Act 2014, carers are entitled to a Carer's Assessment to identify whether they need more support. Despite being advised not to charge carers for support provided to them, some local councils will give carers a financial assessment to work out what they can afford to pay. As a result, some carers have told us that they cannot afford replacement care, and are therefore unable to take a break.

“ I want to see a future for carers with free care for two weeks a year so the carer can go on holiday or visit friend or just come and go as they please knowing someone is caring for their loved ones.”

“ I want to see a future for carers where they are given free respite care every six months for two weeks. Being a carer means you lose your sense of self and you need time to recharge and find a sense of personal meaning in your life other than caring.”

“ I want to see a future for carers where they are offered respite breaks at least twice a year, free of charge so they get an opportunity to have some rest and look after their own wellbeing for a change.”

“ I want to see a future for carers where all unpaid carers get option of two weeks respite every year, with costs of care paid for.”



Carers said there should be more available and better quality alternative care services. Previous Carers UK research found that a quarter (24%) of carers receiving support from social care services disagreed that they were satisfied with the quality of care.¹³ Many carers feel concerned about leaving the person they care for with replacement care services because they're not confident in the quality of this support.

“ I want to see a future for carers where we are able to enjoy our own lives as well, safe in the knowledge that our loved ones are being looked after properly by trustworthy people who enjoy their job.”

“ I want to see a future for carers where their loved ones are looked after properly so there can be proper respite, knowing they are looked after properly whilst you recuperate yourself.”

“ I want to see a future for carers where they can be confident that they can rely on trusted, ambitious, trained, professional carers to support the person they care for and safely hand over care to allow carers to also have their space.”

“ I want to see a future for carers where we feel secure to leave our loved ones knowing they are safe and happy with the people that are caring for them in our absence.”

Several carers said there should be more funding for social care services, to increase service capacity, and reduce the amount of unpaid care they were providing themselves.

“ I want to see a future for carers where there is sufficient support available from social care services to reduce demands on individuals and allow more flexibility and freedom for carers.”

“ I want to see a future for carers where social care services are given priority by the government – paid carers are treated as a profession like nurses, with a career progression. Make it an attractive career; good training; proper pay scale; carers to be valued and recognised as the vital people they are.”

“ I want to see a future for carers where social care is adequately funded so that unpaid carers do not have to give up their own lives to care for family members.”

¹³ Carers UK (2023) State of Caring 2023: the impact of caring on health carersuk.org/media/xgwjlj0gn/soc23-health-report_web.pdf



More support with health and wellbeing

Some carers said they would like more support with their own health and wellbeing. ONS research found that 1 in 4 people providing unpaid care reported they are in 'not good health' compared to less than 1 in 5 adults not caring,¹⁵ and research by Public Health England identified that caring should be considered a social determinant of health.¹⁶ Previous research by Carers UK found that 79% of carers felt stressed or anxious and 50% felt depressed, 54% of carers said their physical health had suffered, and 22% said that caring had caused them injuries.¹⁷ 61% of carers said they needed more support to be able to look after their health and wellbeing.

Many carers said they would like more opportunities to improve their mental health and wellbeing, such as counselling and wellbeing activities.

“I want to see a future for carers where the care they offer is additional “icing on the cake” rather than essential and the only source of support for the cared for person.”

Some carers said that more funding for social care services would give carers a greater choice over whether they take on caring responsibilities themselves. Recent research for Carers Week 2024 found that 62% of those who are currently providing or have previously provided unpaid care said that they had no choice in taking on the role because no other care options were available.¹⁴

“I want to see a future for carers where it is a choice to care rather than a necessity as there is no social care.”

“I want to see a future for carers where people should only have to care if they choose to. Not because they are forced into it because social care for their loved one is either inadequate or in our case non-existent.”

“I want to see a future for carers where carers can do as much or as little caring as they want.”

“I want to see a future for carers where they don't feel backed into a corner – they aren't providing care without proper support – and can make a better choice about becoming a carer.”

“I want to see a future for carers where councils are more aware of what we do and arrange for local keep fit/exercise classes which help with stress.”

“I want to see a future for carers where I have easy access to someone to talk to when I get stressed out and feel I can't carry on.”

“I want to see a future for carers where some of the millions of pounds that unpaid carers save Government is invested back into their wellbeing.”

Several carers said that their health and wellbeing would improve if they had more practical support with caring, and better information and advice about how to provide care.

“I want to see a future for carers where anxiety around caring is lifted – where fast and high-quality support is immediately available as needed.”

“I want to see a future for carers where there are more places we can drop into, when we need support or guidance during difficult periods.”

“I want to see a future for carers where you don't have to breakdown or be in crisis to get help.”

¹⁴ Carers Week (2024) No choice but to care carersuk.org/media/3dblytnt/carers-week-report-2024-web_final.pdf

¹⁵ ONS (2024) Unpaid care expectancy and health outcomes of unpaid carers, England: April 2024 ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/bulletins/unpaidcareexpectancyandhealthoutcomesofunpaidcarersengland/april2024#measuring-the-data

¹⁶ Public Health England (2021) Caring as a social determinant of health assets.publishing.service.gov.uk/media/60547266d3bf7f2f14694965/Caring_as_a_social_determinant_report.pdf

¹⁷ Carers UK (2023) State of Caring 2023: the impact of caring on health carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf



“ I want to see a future for carers where they have visitors who actually come to see them, like a Health Visitor used to be, and who help them with navigating the care system and advise on what help is available to them. This would be the single most useful thing to me and would greatly increase my mental health and general wellbeing and feeling of being cared for and valued.”

Other carers said that their health and wellbeing should be monitored more by healthcare professionals, that it should be easier to make appointments and to get support for their own health issues. Concerningly, carers are often postponing or delaying appointments or treatment due to their caring responsibilities: our previous research found that 44% of carers said they had put off health treatment because of caring.¹⁸

“ I want to see a future for carers where our mental, physical and emotional health is looked after a lot more.”

“ I want to see a future for carers where their own health is taken into account when the cared for person is discharged from hospital and it is reviewed annually so that deterioration is taken into account.”

“ I want to see a future for carers where they receive regular health and well being checks.”

“ I want to see a future for carers where all carers are registered with their GP and are invited to an eight weekly chat by someone on the practice team as to their mental health.”

It is vital that healthcare professionals ensure that carers are identified, and that their health and wellbeing is prioritised. This could be achieved if the Government introduced legislation placing duties on the NHS to specifically promote the health and wellbeing of unpaid carers and to identify carers.

Some carers also need more support to help them feel less lonely, such as peer support sessions. Many carers are unable to spend time with family and friends due to their caring responsibilities, or because of the costs involved in travelling to or doing activities outside the home. Previous Carers UK research found that 50% of carers feel lonely.¹⁹

“ I want to see a future for carers where we can be supported and have a network of other carers to share with. To become one big family as family become distant.”

“ I want to see a future for carers where we do not feel so alone.”

“ I want to see a future for carers where they get to interact more with other carers.”

¹⁸ ibid

¹⁹ ibid

More information and advice about caring

Several carers wanted more information and guidance about caring; others wanted information to be easier to access through a 'one stop shop'. Some carers wanted more joined-up support so that they wouldn't have to repeat the details of their situation to multiple health and social care professionals.

- “ I want to see a future for carers where there is a comprehensive list of services available and how to access them.”**
- “ I want to see a future for carers where they have access to a one stop shop for the services and support they and the person they care for need.”**
- “ I want to see a future for carers where everyone new to caring or experiencing a radical shift in the level of their caring can be supported by a social care worker in navigating the benefit and support systems designed to help them.”**
- “ I want to see a future for carers the system is much easier to navigate, it's so disjointed and you don't get all the info in one place – it's exhausting looking for it.”**



Previous research found that nearly half (48%) of carers said they needed to know what support might be available and how to access it, and 64% said they would like systems in which information about them or the person they cared for was shared across services.²⁰ Several carers said they wanted to spend less time on admin, with quicker access to support so that everything didn't always feel like a 'battle'.

- “ I want to see a future for carers where life is not a continual round of meetings, form filling and jumping through hoops with no better access to services at the end of it.”**
- “ I want to see a future for carers where we don't have to fight for help for our loved ones. It's the fighting that has broken me. EVERYTHING is a fight and it's a fight to understand everything and even find out what options, benefits and support there is.”**
- “ I want to see a future for carers where everything is more streamlined, less repetitive and more efficient so we can get on with the caring role without additional hindrances.”**
- “ I want to see a future for carers where more help is available. Less complicated form filling instead of going round and round in circles, wasting hours on hold on the phone.”**

More practical support with caring

Several carers said that they wanted to be given more practical support to help with their day-to-day caring responsibilities, rather than being signposted to information and advice. Local authority spending on support for carers has decreased, with recent data showing that 70% of carers who were assessed or supported by the local authority were only given information, advice and other universal services/signposting, or did not get any direct support at all.²¹

“I want to see a future for carers where services and options move beyond “tea and sympathy” and there is significant advice and support for those struggling to enact legal rights and protections for them and the people they are caring for.”

“I want to see a future for carers where we get more physical support not just booklets and links to websites.”

“I want to see a future for carers where social workers and mental health teams can respond in a timely fashion with real support or solutions accessible within a month. Currently waiting for my carers assessment from May 2022. Yes – over two years ago.”

Some carers said they needed more tailored support that felt relevant to their specific situation. Carers UK research found that over a third (36%) of carers receiving support from social care services disagreed that the support met their needs and the needs of the person they care for.²² This lack of tailored support can be a barrier to people seeking support, particularly for carers from under-represented groups.²³

“I want to see a future for carers where they are properly supported depending on their individual needs and circumstances.”

“I want to see a future for carers where they are provided with tailored options of specifically carer support instead of a one-size-fits-all approach.”

“I want to see a future for carers where LGBTQ carers have specific agencies to support them, plus allow them to meet other LGBTQ carers for mutual support.”



²¹ NHS England (2024) Adult Social Care Activity and Finance Report, England, 2023-24 digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2023-24/carers

²² Carers UK (2023) State of Caring 2023: the impact of caring on health carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf

²³ Carers UK (2023) Supporting ethnic minority carers carersuk.org/media/3izlulum/cuk-black-asian-and-minority-ethnic-carers-good-practice-briefing.pdf

More support to juggle caring with paid employment

Many carers wanted more support to enable them to combine their caring role with paid employment. Each year, thousands of carers end up giving up work to care or significantly reducing their working hours because they don't have the support they need to stay in paid employment. Previous research by Carers UK estimated that 2.6 million carers had given up work to care, and a further 2 million had reduced their working hours.²⁴ There is a significant employment gap between working-age carers and non-carers (62% vs 75% in employment), and difficulty combining paid work with unpaid care is one of the main drivers of poverty amongst carers.²⁵

While the new legislation which came into force in 2024 has enabled carers to take five days of unpaid carer's leave a year, and to request flexible working from day one of employment, more needs to be done to fully support carers to juggle work and care.

Through the passage of its Employment Rights Bill, the UK Government has a real opportunity to move quickly to build on carers' existing employment rights by laying the foundations for statutory paid Carer's Leave. This is a vital step as our research found that 56% of carers who are employees say they cannot afford to take unpaid carer's leave and need paid carer's leave instead.²⁶ 78% of carers who are employees said they would find paid carer's leave helpful in juggling work and care.

“I want to see a future for carers where they are entitled to paid leave in work.”

“I want to see a future for carers where unpaid carers who are able to work can get time off to attend appointments or other matters for the person they care for rather than having to take their personal allocation of leave of absence, toil or unpaid leave.”

“I want to see a future for carers where they have the ability to have paid leave when the person you care for needs hospital appointments etc.”

“I want to see a future for carers where employers don't chastise us for having time off for essential care duties, eg. hospital appointments etc if you are the primary carer.”



Carers also wanted to be able to work more flexibly, or work from home, to be able to fit in hospital appointments and other caring duties. Carer-friendly policies in the workplace are beneficial in reducing stress: 67% of carers who are employees said that flexible working already helps them, and a quarter (26%) said they didn't have this and would find it helpful

“I want to see a future for carers where our second employment of caring for someone which can sometimes involve long hours, emotional and physical stress is recognised by our employer – more flexibility around working hours.”

“I want to see a future for carers where they are recognised by employers as having additional, exceptional responsibilities and work place adjustments are considered to allow carers to fulfil their role as both a carer and an employee.”

“I want to see a future for carers where employers actually allow carers to work from home so they can fulfil their care duties for emotional support as much as physical support, yet still work and earn a living.”

²⁴ Carers UK (2019) Juggling work and care carersuk.org/media/no2lwyxl/juggling-work-and-unpaid-care-report-final-web.pdf

²⁵ WPI Economics (2024) Poverty and financial hardship of unpaid carers in the UK carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

²⁶ Carers UK (2024) State of Caring 2024: the impact of caring on employment carersuk.org/media/qlsly1mc/state-of-caring-employment-web-2024.pdf



Several carers said they would like more understanding from their manager, employer and colleagues about the demands of caring, and the impact this can have on their health and wellbeing. Our survey found that although the majority of carers said they already have an understanding line manager, a quarter (25%) said they didn't and would find that helpful.²⁷ 15% of carers who hadn't taken unpaid carer's leave said that feeling worried about how their manager or colleagues would respond was a barrier.

“I want to see a future for carers where employers are supportive and empathic.”

“I want to see a future for carers where they can work and care without feeling guilty, or less able in the workplace. Non-carers can not fully appreciate the full skills set needed to care and advocate for those who are unable to do this for themselves. A lots if those skills are directly transferable to the workplace.”

“I want to see a future for carers where employers in particular recognise the pressure on carers to hold down a job and meet their caring responsibilities.”

“I want to see a future for carers where you can work without having to worry about losing your job because you are a carer.”

²⁷ ibid

Equality for unpaid carers



Equality amongst carers

Equality in the gender provision of unpaid care

Many female carers said they would like to see more equality in the provision of unpaid care. Currently, in the UK there are nearly 3.5 million female unpaid carers, and nearly 2.4 million male unpaid carers. Research by the Centre for Care found that in England, over the period 2010-2020, on average 7% of women and 6.2% of men became unpaid carers every year.²⁸ Other research by the Centre for Care found that women have a higher chance of becoming a carer than men (70% vs 60%).²⁹

Some female carers said they would like to see a change in societal expectations so that a higher proportion of men take on unpaid caring roles, and that women have a greater degree of choice about whether they provide unpaid care.

“Equality means that care responsibilities should be shared between men and women, particularly when it comes to the care of elderly parents. There is a belief that women are best placed to provide care to loved ones and all too often I hear people say their brother/ husband/ son wouldn't know what to do to care for them. We need to stop letting this belief be commonplace and realise gender should not be a factor in care provision for loved ones.”

“I think women are often expected to provide care over men and this should not be an expectation.”

“Men [should] also [be] taking their share of the care role. The retirement age for women has risen to 67 or above, yet we are expected to do a full-time paid job and all the unpaid care also. This has created a situation that is more unequal than before.”

²⁸ Petrillo, M. and Bennett, M. (2022) Cycles of caring: transitions in and out of unpaid care carersuk.org/media/bgolg5u2/cuk-carers-rights-day-research-report-2022-web.pdf

²⁹ Zhang, Y. and Bennett, M. (2019) Will I Care? carersuk.org/media/b1rj5m4v/carersrightsdaynov19final-2.pdf



Because women are more likely to provide unpaid care, they are therefore more likely to experience the negative impacts of caring. Recent research commissioned by Carers UK found that women who provide unpaid care have a higher rate of poverty (28%) than men who provide unpaid care (25%).³⁰ Many women have to give up work to care, or significantly reduce their working hours and this can have a negative impact on their income and ability to save for the future. The State of Caring survey this year found that 46% of female carers in employment reduced their working hours to care compared with 34% of male carers in employment, and 26% have taken on a lower paid or more junior role compared with 22% of male carers in employment.

Many carers highlighted the fact that caring responsibilities disproportionately affect women's lives.

- “The majority of carers are women. Caring not only hits my finances now, but also my pension in the future and my savings. And because women on average live longer, chances are I will be poorer in my older years. So caring is a gender issue and equality is a right not a privilege.”
- “Having Carer's Allowance so low seems like sexism as most carers are women.”
- “Women are often at the forefront of informal and formal caring roles, which are undervalued financially and by society as a whole. There is a massive issue when it comes to women being undervalued...”
- “For women especially who have caring responsibilities it really can impact their lives. A survey in my place of work noted that 67.22% of respondents said that “a caring responsibility had prevented them from applying for a promotion or other development opportunities”. This is essentially unfair to women who are by nature of their gender more likely to be carers and therefore don't have the same opportunities as men.”

³⁰ WPI Economics (2024) Poverty and financial hardship of unpaid carers in the UK carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

Equality in the financial support provided to unpaid carers

Some carers felt that there should be more equality amongst carers so that everyone is supported to the same extent, regardless of their demographic characteristics or caring circumstances.

“Equality for all different types of carer in different situations.”

“Equality means that all carers should be recognised... I have been caring for my brother since our childhood but I’m not the main carer so my role isn’t always acknowledged.”

“It doesn’t matter whether you are a parent, caring for a child, or a child caring for a parent. You are a carer.”



For example, some older carers felt they were not treated equally to younger aged carers because they lost access to Carer’s Allowance when they reached State Pension age. This year’s State of Caring survey found that half (51%) of carers aged 65 and over are worried about living costs and whether they can manage in future.³¹ Some older carers also highlighted the loss of the Winter Fuel Payment, which will impact on their ability to pay for utility bills. Many older carers said that losing the Carer’s Allowance benefit has a negative impact on their ability to manage their finances, and many feel undervalued in comparison with younger carers as a result.

“Being a pensioner should not mean the end of financial support”

“All carers should receive an allowance – it shouldn’t stop when the carer reaches pensionable age. They still have to provide care.”

“Currently elderly carers/patients seem to get less support than others.”

“As we are both pensioners, being given the same support, financially, that younger people get.”

Other carers felt that Carer’s Allowance should be available to all carers regardless of their employment situation, or how many hours they care for. Currently carers are only eligible for the benefit if they care for at least 35 hours a week, are not in full-time education or studying for 21 hours a week or more, and are not earning more than £151 per week after tax, National Insurance and expenses.

“Carers are not treated equally. Some get Carer’s Allowance and some don’t.”

“There is no additional Carer’s Allowance for having to care for more than one person. I receive the same benefits as my friend who has a non-verbal ASD son but what I do care wise on a daily basis far outweighs what she does so definitely no equality.”

“Being able to get financial support with my caring duties. The idea that caring less than 35 hours a week entitles you to nothing is ludicrous. I am saving the NHS a small fortune.”

³¹ Carers UK (2024) State of Caring: the impact of caring on finances carersuk.org/media/umaifzpq/cuk-state-of-caring-2024-finances-web.pdf

Recognising, respecting, and valuing differences in people

Many carers felt that equality is about treating everyone with dignity, respect and compassion, and being kind and considerate to all.

“Equality for me means treating everyone with respect and consideration. Valuing each individual without judgment.”

“Equality means being kind to each and every one... We are not all made the same but deserve the same kindness and understanding. We all deserve love, support and understanding.”

Several carers said that people should be treated the same, regardless of their individual characteristics, such as ethnicity, age and sexual orientation.

“Equal rights for everyone regardless of ability, age, race, religion, culture.”

“Everybody should have access to the same support and help regardless of age, sex, nationality etc.”

Equal opportunities for disabled carers and the people they care for

Many carers highlighted the fact that people with disabilities are not treated equally, with issues around physical access preventing people from having the same opportunities. This is a particular issue for carers, who are more likely than non-carers to be disabled. According to the Census 2021, 28% of carers in England and Wales are disabled, compared with 18% of non-carers.³² Several carers said that there needs to be more support for disabled people, so that everyone has an equal opportunity to participate in society.

“Being able to have a social life with my husband where we can enjoy a meal a night out a coffee or a walk (my husband is in a wheelchair) without restrictions. Just like any other couple.”

“Currently mainstream education is not inclusive and often marginalises children with autism. This results in trauma and lack of access to education that meets our children’s needs therefore is not inclusive.”



³² ONS (2023) Unpaid care and protected characteristics, England and Wales: Census 2021 ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/unpaidcareandprotectedcharacteristicsenglandandwales/census2021#unpaid-care-and-ethnic-group

“ I am profoundly deaf and a BSL signer. I have massive additional barriers relating to this and no-one addresses these.”

“ Equality to me means for my partner to be able to participate in events and not be discriminated against because of his disability.”

Many carers felt that there can be a stigma around age, disability and illness in society, meaning that people can feel isolated.

“ I feel the elderly, sick and those with additional needs are sidelined.”

“ Everyone should be treated the same. Just because someone is disabled doesn't mean they should be given less respect.”

“ I really don't see how people who are carers can ever have equality in a world which puts such a low focus on old age and disabilities.”



Tailored support services that recognise individual need

Several carers felt that support services should recognise that each person has different needs. Carers UK research found that carers from ethnic minority backgrounds³³ and carers who identify as LGBTQ+³⁴ can face additional barriers and may need more targeted support in some cases. Rather than providing a one-size-fit-all approach, offering tailored support to specific groups can be beneficial.

Previous research by Carers UK found that over a quarter (28%) of carers with bad or very bad mental health said that a barrier to seeking help was feeling that support services would not meet their needs. It is vital that carers get support if they are struggling, and tailoring services to fit individuals' needs may encourage more carers to seek help if they need it.

“ Understanding carers' experiences are unique and a one size fits all does not work.”

“ Services designed for the people who need them rather than trying to fit a person into the services available.”



“ Awareness of everyone's individuality, and actions linked to what that means for them.”

“ That all people are treated according to their disability/need. Not every person with the same illness will require the same help.”

33 Carers UK (2023) Supporting Black, Asian and minority ethnic carers: a good practice briefing carersuk.org/media/3izluyum/cuk-black-asian-and-minority-ethnic-carers-good-practice-briefing.pdf

34 Carers UK (2023) Supporting LGBTQ+ carers: a good practice briefing carersuk.org/media/3tppsbcj/carers-uk-lgbtq-briefing-2023-web.pdf



Equal access to health and social care services

Some carers said that equality means having equal access to support services. Several carers raised concerns that support can vary across different regions.

- “Equality means rights and access to support should be equal across all council areas and not left for each council to decide what support is given as this creates a postcode lottery for services and increases inequality and poor health.”
- “Everyone having the same high standard of care and access to all services relevant to their diagnosis.”
- “Equality should mean that there is access to a standard level of services for all – regardless of where they live.”

Many carers also felt that some health conditions are not treated equally. Several carers said that mental health conditions or learning disabilities are not treated in the same way as physical health conditions, and that there is still a stigma around having a mental health condition.

- “Mental illness is still stigmatized and the services are not as good as for physical illness. People have to be a risk to themselves or others before they are even given any care. This is wrong.”
- “Having invisible illnesses recognised and not dismissed.”
- “I don’t think people with mental health problems are treated equally in and way, shape or form. I feel like we are all judged wrongly especially because most mental health conditions are hidden.”

Some carers said that the person they care for was not always treated with compassion within the NHS, particularly if they were older. These carers felt that equality means treating anyone who is unwell with dignity and respect, regardless of their age.

- “As a carer it means that my parents deserve the care and respect despite being elderly and not to be treated like a nuisance when they need more help after a fall for example. I shouldn’t have to fight so hard for extra help just because they’re elderly!!”
- “Our aged community being treated with dignity, empathy and basic general care to meet their needs, all sadly lacking with no consideration/apology or repercussions for the failings in the care system.”

Equal rights for carers

Everyone having an equal opportunity to live a fulfilling life

Many carers said that equality meant being able to 'thrive' rather than just 'survive' – to have the chance to live a rich and fulfilling life.

- “Everyone has the opportunity to thrive regardless of their personal circumstances.”
- “Everyone has an equal chance to fulfil their potential.”
- “Everyone having the opportunity to live their best life.”
- “Being able to enjoy life to the full.”
- “Making it possible for everyone to flourish.”

For many carers, being able to live a fulfilling life means having the freedom to decide how they spend their time, but this level of autonomy and independence isn't always possible because they are too busy caring.

- “Equality would mean carers have normal lives like everyone else, and only provide care as and when they want.”
- “[Equality is] the freedom to live life without constant obstacles and restrictions.”
- “Being able to life as freely as the next person.”
- “Having the same ability to make choices and live as other people are able to do.”

Carers often have to cut back on spending as a result of the costs of caring, insufficient support from the social security system, and challenges in juggling unpaid care with paid employment. This means carers have to make difficult decisions about what they can and can't afford, and are not always able to spend money on things that improve their wellbeing, such as seeing friends and family, and taking part in hobbies. This year, 68% of carers cut back on hobbies/leisure activities, compared to 58% in 2023 and 47% in 2022. 60% cut back on seeing family and friends, compared to 47% in 2023 and 34% in 2022.³⁵



Many carers also feel they are unable to take a break to do the things they enjoy, because they cannot find affordable or suitable replacement care. Our research found that 47% of carers said they needed more breaks or time off from caring.³⁶

Carers have also told us that they are not always able to progress in their paid employment and apply for promotions, because of the challenges involved in juggling work and care, and difficulties meeting their employers' requirements. This year, our survey found that a quarter (25%) of carers in paid employment had to take on a lower paid or more junior role. This can impact on carers' health and wellbeing as well as their finances.

As a result of these challenges, many carers felt disadvantaged compared to people without caring responsibilities.

- “Equality for carers should mean that a carer gets whatever assistance and support is necessary to allow them to live their lives without restriction and have the same opportunities as a non carer available to them.”
- “To have the same rights as regular people; to have breaks, holiday pay, time for hobbies, to not be forced to neglect my own mental and physical health to support the ones I care for, because nobody else will do it.”

³⁵ Carers UK (2024) State of Caring: the impact of caring on finances carersuk.org/media/umaifzpq/cuk-state-of-caring-2024-finances-web.pdf

³⁶ Carers UK (2023) State of Caring: the impact of caring on health carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf



Carers living a life free from discrimination

While carers are protected from discrimination by association under the Equality Act 2010, the law is poorly understood and implemented. As a result many carers continue to experience discrimination in their employment or when accessing public services. Previous research by Carers UK found that 22% of carers in paid employment said they had been treated unfairly or unfavourably at work, and nearly a quarter (24%) said that they had difficulties meeting their employer's requirements because of their caring role.³⁸

“Equality means not being disadvantaged due to my caring role, being able to fully take part in society in the same way as my friends who do not have a caring role.”

“I have no equality with the average person. I cannot just pop out or even go to lunch with husband and a friend without lots of prep. I'm not equal in any way.”

“Having the chance to do what everyone else does, all those things many people take for granted.”

Several carers said they needed more support with caring so they could spend more time focusing on their own needs. 42% of carers said they needed more support from the NHS or healthcare professionals, 46% needed better recognition from the local council of their needs as a carer, and 40% said they needed an increased choice of services they can access.³⁷

“[Equality is] easing the burden of caring on me as an individual. My life is restricted in what I can do as a carer – going out, holidays etc in terms of time.”

“That carers are seen as human beings too, with their own needs and emotions, not just robots to help and care for others.”

“[Equality is] enough formal and affordable (or free) support available, removal of the assumption that we are obliged to do it.”

“More funding for Social Care – it is the forgotten public service and yet the elderly population is rising.”

“Being treated the same as others, not discriminated against, directly or indirectly by others, including people and organisations.”

“Having equal opportunity to carry out normal day to day tasks without discrimination.”

“No carer should face discrimination of any kind due to the circumstances they find themselves in.”

Carers UK is calling for caring to be made a protected characteristic by updating the Equality Act 2010. Introducing caring as a protected characteristic would strengthen carers' rights to protection from discrimination and harassment, and further raise the profile of carers.



³⁷ Carers UK (2023) State of Caring: the impact of caring on health carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf

³⁸ Carers UK (2024) Making Caring the 10th protected characteristic carersuk.org/media/05upkpwu/carers-uk-protected-characteristic-report-web.pdf

Aspiring towards equity for carers rather than equality

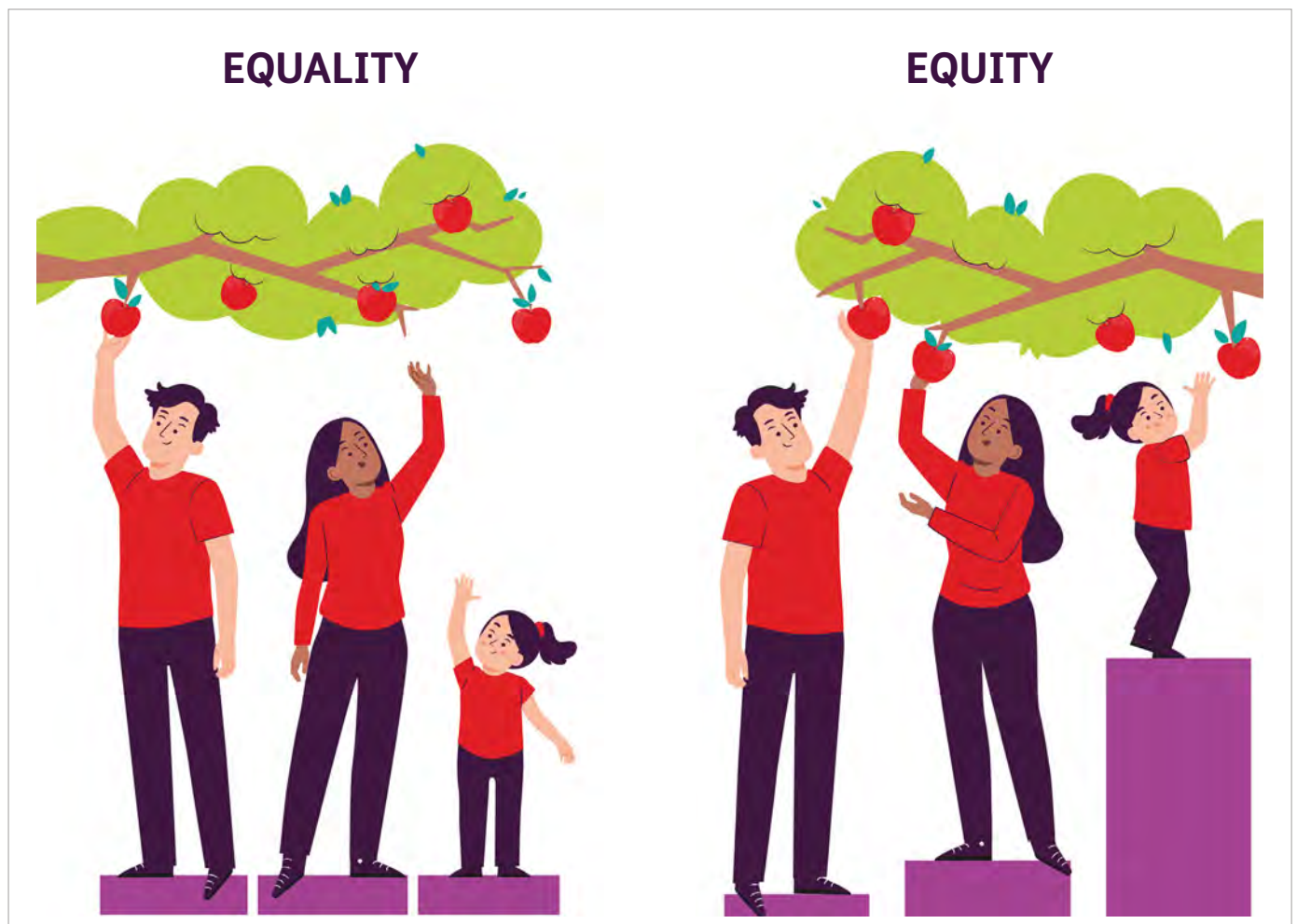
Some carers felt that what is needed is not equality, but equity – to ensure that everyone has an equal chance of overcoming barriers and being successful. Equity means recognising that people do not start from the same place and providing adjustments to address these imbalances.

Some carers said that equity rather than equality would create a level playing field.

- “ Equality to me isn't the same as equity. There's a big difference between treating everyone equally and making sure that everyone has equity. It's the climbing a tree analogy all over again. Give everyone gloves and a rope to climb it, but not everyone can. That's equal because they were all given the same equipment for the same task, but it's not equitable because some need different equipment or support.”
- “ Equality means ensuring people are able to reach the same goals and outcomes even if it means the support levels differ for each person.”



- “ Equality is everyone gets treated the same. I prefer the term equity where rather than giving everyone the same, it's giving people what they need to get the same outcome.”
- “ It certainly does not mean having exactly the same path for everyone – this sadly is a misconception. Sometimes equality means giving someone more help, I wish people would stop seeing this as unfair.”



More recognition for unpaid carers, who often feel undervalued

A significant proportion of carers said that equality is about being recognised and valued as a carer. Many carers feel invisible, not listened to, and not valued within society. Previous Carers UK research found that 55% of carers need more recognition from the general public,³⁹ and just under a fifth (19%) have felt discriminated against by the general public.⁴⁰

- “ Not having to justify myself or my existence! Unpaid carers are often “invisible” and don’t feel like a part of society.”
- “ Being treated as though I matter.”
- “ The work unpaid carers do should be recognised as contributing to society as they are helping take burden off authorities and this needs to be recognised!”
- “ Being noticed by those in power.”
- “ Being validated and valued.”
- “ Being seen and being heard.”

Being valued was particularly important for carers who were not working in paid employment, as they sometimes felt ‘looked down upon’ or judged by others.

- “ As a carer it means being valued for what I do and feeling that despite not going out to work that the work I do is of equal value.”
- “ As a carer, many people judge [me] because I don’t have a full-time job. They don’t realise that a unpaid carer is a job on its own. People shouldn’t judge people who get Carer’s Allowance.”
- “ When I’m asked what I do for a living and I say ‘I’m just a carer’ they ask ‘oh where do you work’ and I reply ‘I just care for family members’ they just look at me differently. It makes me feel worthless sometimes and feel people look at you in a different way because it’s not technically a proper job in their eyes... It’s a hard job that carers do and we save the government a fortune by doing this role. We all deserve to be treated fairly and equally and we shouldn’t be made to feel like we don’t matter.”
- “ People think because you are at home, and not going out to work, that you don’t do anything and they look down on you.”
- “ Would like to be equal to a full time employed person and respected as such. Not told by people to go and get a proper job.”



³⁹ ibid

⁴⁰ Carers UK (2024) Making Caring the 10th protected characteristic carersuk.org/media/05upkpwu/carers-uk-protected-characteristic-report-web.pdf

Many carers also need more recognition from health and social care services. Our research found that 42% needed more recognition from the NHS.⁴¹ For some carers, equality is about having their expertise valued as equal partners within the NHS.

- “ Being treated as an expert and professionals and care companies treating you with respect. I sometimes think that we are regarded as just an interference.”
- “ Often, carers are brushed aside in medical appointments for example, making advocating for your person that much harder: I had a situation recently where an interpreter was given the right to stay in the pre-op waiting room, but I (as a dual interpreter/carer) was not. I had to fight for my place in the room, which was an unnecessary source of stress...”
- “ [Equality is] carers being recognised and valued as expert partners in care.”
- “ Knowing that what I do, I do in my son’s best interest. I know what is best for him. It would be good that professionals recognised us.”

More financial support for carers

Many carers said that equality meant more financial support for unpaid carers, to prevent people from falling into poverty and to enable people to have a better quality of life.

The Carers UK State of Caring Survey 2024 found that 61% of unpaid carers are worried about living costs and managing in the future, and over a third (35%) don’t feel confident they will be able to manage financially over the next 12 months. A quarter of carers (27%) are struggling to make ends meet. 28% of carers said they have had to use credit cards, 22% have used their overdraft and 14% of carers are in debt because of caring.

Many carers said they wanted to see an increase in the amount of Carer’s Allowance, which is currently just £81.90 per week (2024/25).

- “ Equality would mean to me an increase in Carer’s Allowance.”
- “ Being acknowledged with an amount of government Carer’s Allowance that isn’t a pittance and allows you to pay your most basic bills.”
- “ Appropriate financial reward for all the caring duties that I do given that I retired early from NHS to look after my husband.”
- “ Being rewarded properly for giving up my life to care 24/7 for four people and not being expected to survive on less than the bare minimum”
- “ Carer’s Allowance should, at the very least, be on a par with the minimum wage.”
- “ Fair payment for work of being a carer. I gave up paid employment to meet the needs of my family member.”
- “ [Equality is where] carers are recognised for the work, hours they do and toll on their own health. This recognition has to be financial and treated as a profession.”
- “ Equality would be carers being paid a wage that is more inline with the importance of their jobs.”



⁴¹ Carers UK (2023) State of Caring: the impact of caring on health carersuk.org/media/xgwjlj0gn/soc23-health-report_web.pdf

Equal access to employment opportunities

Many carers said their caring role was not always recognised by their employer. 73% of carers in employment said they had found it stressful to juggle work and care,⁴² and less than half (40%) of carers in employment said they felt valued by their employer.

Some carers said that equality meant being supported to juggle caring with paid employment. These carers wanted their employer to be more understanding about taking time off for caring, with easier access to Carer's Leave or flexible working.

- “Increased rights at work – caring conversations normalised, more in work support and recognition.”
- “Employers understanding what caring roles mean and enabling better wellbeing in the workplace with a supportive policy.”
- “I've had to take three months off work due to my daughter being Palliative care and instead of being special circumstances and paid, I had to take it as being off sick with sick pay – this should be as special circumstances with full pay not go on my sickness record like it has.”
- “Allowing carers time to look after their loved one's needs without fear of losing out on opportunities in work.”

Some carers also said they wanted more support to be able to return to paid employment.

- “Not being discriminated against for being a carer when seeking employment.”
- “Opportunities for carers to train/quality/maintain qualifications to make a return to work more possible, more legislation like the Carer's Leave Act that makes it easier for carers to be in employment.”
- “Treated equally in job opportunities.”



⁴² Carers UK (2024) State of Caring 2024: the impact of caring on employment carersuk.org/media/qlsly1mc/state-of-caring-employment-web-2024.pdf

Recommendations

As a priority, the UK Government should commit to introducing a **National Carers Strategy**, covering all ages, with feedback sought from stakeholders and carers through a consultation. A national strategy would harness the power of different Government departments and allow them to work together to support the lives of unpaid carers, recognising that many elements of caring are interlinked.



UK Government is carrying out a huge consultation on the future of the NHS. It could take this opportunity to make the NHS fit for the future by transforming the way the NHS interacts with unpaid carers to make it the most carer-friendly health service in the world. Key elements of this would include:

- using legislation to place new duties on the NHS to promote unpaid carers' health and wellbeing – to underpin a fresh new approach
- using data and digital to systematically identify unpaid carers and provide support where it is most needed
- harnessing the power of digital, informed by carers' views on how technology could be helpful. This would enable carers to have more control in caring, and maximise the potential of the NHS App to let unpaid identify themselves
- empowering unpaid carers by updating the NHS Constitution to clearly set out the future
- equipping carers with the information, advice and support to care safely and well where they choose to do so
- ensuring equal access to treatment and support for carers across the NHS.

UK Government should urgently address the underfunding of social care by:

- urgently invest in social care including investing an additional £1.5 billion in breaks and respite services in England (with consequential funding for Devolved Nations)
- legislating so all carers have a statutory right to regular and meaningful breaks.

UK Government has already announced an independent review into Carer's Allowance overpayments, and will be increasing the earnings limit for Carer's Allowance to £196 per week in April 2025, equivalent to 16 hours at the National Living Wage rate. However, there is an opportunity to go further and improve financial support for carers by:

- reviewing the current support provided to unpaid carers through the social security system, including setting objectives for carers' social security benefits as well as timescales and options for change
- increasing the value of Carer Element, Carer Premium and Carer Addition by £11.10 per week, to lift at least 30,000 people out of poverty and 40,000 out of deep poverty
- preventing the accumulation of Carer's Allowance overpayments, by writing off past substantial overpayments where carers could have been notified sooner and bringing forward options and timescales to introduce a taper to earnings similar to other benefits
- improving the process for claiming Carer's Allowance to make it less complicated for claimants by modernising delivery, increasing staffing and improving staff training, improving information sharing between DWP departments, and improving carers' understanding of eligibility rules
- reforming the eligibility rules for Carer's Allowance, such as removing the 21-hour study rule
- providing additional financial support to carers of State Pension age through a new non means-tested payment, and reviewing pension rules for carers to get carers up to similar pension levels as non-carers.

UK Government should support unpaid carers to combine work and care by:

- building on the Carer's Leave Act 2023 by laying the foundations in the Employment Rights Bill to turn the existing statutory right to one week's unpaid leave to paid Carer's Leave
- continuing to strengthen flexible working rights in the Employment Rights Bill
- exploring opportunities to provide employees with the right to take a longer period of unpaid Carer's Leave of up to 6 months so people do not fall out of the labour market when they have particularly complex and intense periods of unpaid care
- reviewing and implementing changes to the social security system to better support carers to remain in work, removing any aspects that act as a disincentive to paid employment
- investing in structural support to enable carers to return to work following a period of absence related to their caring responsibilities, including establishing a new national network of carers' partnership managers, to coordinate carers' pathways back into work
- undertaking a full and independent review into issues relating to work and unpaid care reconciliation, to better understand the range of policy interventions and shifting practice within job roles
- making caring a protected characteristic by updating the Equality Act 2010 to strengthen carers' rights to protection from discrimination and harassment in the workplace
- introducing a new campaign to increase employers' awareness of carers in their workforce and to help employees who have caring responsibilities to better understand their rights.

Employers should support carers to juggle work and care by:

- raising awareness of unpaid caring within the workplace and promoting a positive culture of understanding and support
- training all managers on carer recognition and how to support employees within their workplace who are unpaid carers
- considering joining Employers for Carers or Employers for Carers Wales to make the most of leading knowledge and expertise in the sector
- being “early adopters” of the new legislation on unpaid carer’s leave and going one step further to introduce the leave as paid Carer’s Leave
- recognising the range of skills that carers gain through their caring role, to support their return to work.

This is the third in a series of reports based on data from State of Caring 2024.



2025 is the 60th anniversary of Carers UK, and while we've achieved many successes to make life better for carers, we know there is still much more to do to ensure carers have equality in all walks of their life.

That's why our theme for the year is 'Equality: today and tomorrow'.

So, while it's good for us to look back at how things have changed, our focus is very much on the needs of unpaid carers today – and what we need to do to create greater equality, support and recognition in the future.



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

T 020 7378 4999 | E info@carersuk.org



@carersuk



/carersuk



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