



IT'S HARDER THAN ANYONE UNDERSTANDS

**THE EXPERIENCES AND THOUGHTS OF
YOUNG CARERS AND YOUNG ADULT CARERS**

A CARERS TRUST REPORT, MARCH 2022

**CARERS
TRUST**

ACKNOWLEDGEMENTS

Thank you to:

- The 571 young carers and young adult carers who gave their time to complete our survey.
- The young carers and young adult carers who guide and inform our work.
- The committed and skilled teams across the Carers Trust Network and in the wider sector who continue to provide invaluable support.
- Our partners and colleagues in governments across the UK, arm's length bodies, local authorities, local health boards and trusts, education consortia, research bodies and third sector organisations who supported so many young carers and young adult carers to have their say.

About Carers Trust

Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners and through the provision of grants to help unpaid carers get the extra help they need to live their own lives. With these locally based Network Partners we are able to support unpaid carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for unpaid carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is that unpaid carers count and can access the help they need to live their lives.

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FOREWORD

I'm a 20-year-old student from Scotland. I've cared since I was eight years old for my parents.

My caring responsibilities were only properly acknowledged in my last two years at high school. This lack of understanding and support had an impact on my quality of work and my grades. Once I was identified, some help was put in place, but I never felt fully supported. This feeling has stayed with me even at university. It makes me feel lonely, like it's just me on my own.



When you are supported, it feels great having a network of people to help you. I've experienced this support through my local young carers service. The respite this group gave me was so important.

Knowing where to go for help and who to reach out to would help tackle social isolation. Particularly young adult carers who are going through a transitional period in their lives. From a rural community, I've experienced geographical as well as social isolation.

We need to break down barriers for young carers to take breaks and be with friends. I want decision makers to read this report and push for greater support and opportunities for young carers and young adult carers.

REATHA BRUNJES
Young adult carer

INTRODUCTION

Lonely. Exhausted. Burnt-out. Worried. Stressed.

This is what young carers and young adult carers told us they feel. While no child or young person should feel like this, for young carers and young adult carers it's more complex. They are a group of children and young people who are having to put others first, often at the expense of their own education, work, mental health and wellbeing.

In 2020, Carers Trust conducted the only UK-wide survey of how the coronavirus pandemic was affecting young carers and young adult carers.

While we continue to live with the pandemic, albeit in a less acute phase, we wanted to go back to young carers and young adult carers for their thoughts this year. We asked them about the pandemic again. We also asked them about their education and work, their feelings and mental health, their lives alongside or outside of caring, and what support they get and need.

Our findings highlight the enormous challenges young carers and young adult carers are facing, and the impact that these challenges are having on them.

More than half reported that the time they spend caring had increased in the past year, while at least a third said they were worried, lonely or stressed as a result of being a young carer or young adult carer.

While young carers and young adult carers understandably want the best for the person they are caring for, there is a real danger that the balance of caring is falling too heavily on their shoulders. Too often young carers are having to step in due to a lack of alternatives, and too often there is not enough support to enable them to lead their own lives and plan for their future.

“It’s harder than anyone understands and I feel like I’m drowning.”

The young carers and young adult carers who shared their thoughts and experiences with us are clear about what needs to change so that they have:

- Breaks and respite from their caring role, and help from services that understand them.
- Support for their emotional wellbeing and mental health.
- Help from their place of education and employer, so that they can succeed.
- Connections to friends and their communities.
- Better support for those they care for.

At Carers Trust we believe there are no limits to what young carers and young adult carers can achieve in their lives, when they have the right support.

However, when this group of children and young people don’t receive the right support, this can have a lasting impact on their life chances, their physical and mental health and their income.

Who are young carers and young adult carers? What do they do?

A young carer is someone aged 18 and under who cares for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support. Older young carers, aged 16-25, are also known as young adult carers and they may have different support needs to younger carers.

Young carers and young adult carers undertake a range of tasks to support family members or friends. This might include shopping, cooking, cleaning, managing medicines or money, providing personal care, helping people get out of the house, keeping an eye on someone or providing emotional support.

RECOMMENDATIONS

1. More commissioned breaks and time outside of caring.
2. The UK Government, Scottish Government, Welsh Government and the Northern Ireland Executive should monitor how local authorities are meeting their statutory duties to identify and support young carers and young adult carers.
3. Education providers need to take an integrated approach to support.
4. Prioritise access to mental health support for young carers and young adult carers.
5. Free or discounted leisure and transport.
6. More financial support for young adult carers.
7. Sustainably fund the wider social care system.

For full recommendations, see page 26.



WHAT'S DIFFICULT AND WHAT HELPS YOUNG CARERS AND YOUNG ADULT CARERS

In January 2022 Carers Trust asked children and young people aged between 12 and 25 about their current experiences of caring.

What's difficult about being a young carer and young adult carer?

Significant numbers of young carers reported feeling worried, lonely, stressed or without anyone to talk to about how they felt. Given what is known about the importance of a safe and supported childhood and early adulthood, and of mental health problems that develop in childhood and adolescence, we are not, as a society, providing enough support for young carers and young adult carers.

“It's harder than anyone understands and I feel like I'm drowning.”

“It's too much pressure and responsibility for something I didn't choose.”

“When things get really bad, I don't always know what to do and it's hard to help.”

“It is very hard to go out even if you know they are okay and you have helped them there is always a constant worry on your mind.”

“ It affected my friendships as they didn’t understand why they couldn’t come inside the house.”

“ It’s quite lonely and I don’t feel like anyone understands or is there for me. I got really upset the other night cos of my mum, it was really intense and school was really hard the next day.”

36%

of young carers or young adult carers ‘always’ or ‘usually’ feel worried because of being a young carer or young adult carer.



33%

of young carers or young adult carers ‘always’ or ‘usually’ feel lonely.



42%

of young carers or young adult carers ‘always’ or ‘usually’ feel stressed.



23%

of young carers or young adult carers ‘never’ or do ‘not often’ have someone to talk to about their feelings.



“ My mental health is awful and I really struggle to take time for myself at home. The only time I have away from my family is at school but I don’t even like going to school because I get so nervous for everything and I’m always so exhausted.”

“ I get sad a lot. I don’t like seeing my sister ill and my mum and dad getting upset.”

“ I feel like not a lot of people understand how I feel so I can't really talk to people. I don't have anyone to talk to if I wanted to talk about it.”

“ I sometimes feel like my sibling is the favourite child because he ... needs more attention and support. He always comes first because he has to and I have to learn to deal with it. I don't feel like I can share this with my mum because it might upset her.”

“ It is very lonely all the time.”

“ It's quite lonely when Mum is ill as I felt really awful and had no one to talk to ... when it was really bad. She tried hard but she gets snappy or cries or is in bed or she buys loads of chocolate to comfort eat. And there's just the two of us so there no one [else to talk to] really.”

What helps with being a young carer and young adult carer?

Young carers and young adult carers told us that the three things that help them most as a young carer or young adult carer are:

- 1.** Listening to music.
- 2.** Talking to my family or friends.
- 3.** Having a break from being a young carer.

Funders, commissioners and providers of young carer services should consider non-traditional, or new ways of working and providing support for children and young people, fit for the 21st century. For example, it appears to be the case that – alongside a wider package of support that promotes taking time to talk to family and friends as well as taking a break – funding a young carer to receive a music streaming or subscription service on the platform and device of their choice could be a helpful intervention to young carers.

60% of survey respondents said that they 'always' or 'usually' get enough support from young carers or young adult carers services.

“ The support from the carers centre is amazing but they are limited with what they can do due to the support/funding they receive. It would be lovely to have more support from other local services.”

YOUNG CARERS AND YOUNG ADULT CARERS AND THEIR WELLBEING



30%

of young carers or young adult carers said that they 'never' or do 'not often' get enough rest.



36%

of young carers or young adult carers said that they 'never' or do 'not often' get enough sleep.



28%

28% of young carers or young adult carers said that they 'never' or do 'not often' feel like they get enough time for themselves.

“ My mental wellbeing isn't great. It's probably because I don't really have time for myself. I don't like asking for help though because I guess I'm just used to figuring things out on my own. School offers help but I always find it embarrassing to go and talk to someone.”

“ Mum and dad have to put my sister first when she's ill, I understand, but I don't like to worry mum and dad about me.”

“ I don't sleep because I worry a lot.”

“ I want to do sports and competitions and I want to go on holiday with my family but I can't. I get mad and sad about that.”

“ I suffer with really bad sleeping patterns and ... not feeling like I'm allowed any time to myself.”

“ It's never ending, don't eat, don't sleep and constant stress and worry.”

“ I usually have to stay up at night to complete homework or chores, and sometimes when I'm sleeping [the person I care for] will wake me up too, so I wish I could get a bit more sleep as waking up early for school is a bit of a struggle!!”

“ My sister makes it a lot harder because of her needs she always wants to be in my room with me watching TV or playing on my phone, so I don't get hardly any time to myself.”

“ I have very high expectations for myself and it's hard when I don't exceed them. I want to be able to care, go to work and school, play rugby and much, much more but I do exhaust myself a lot.”

“ I hurt my skin a lot as I scratch when I get worried.”

“ My brother wakes up at all sorts of times so I don't get a lot of sleep.”

“ At the minute I share a room with my disabled brother, he wakes constantly and I don't get rested enough.”

YOUNG CARERS AND YOUNG ADULT CARERS AT SCHOOL, COLLEGE OR UNIVERSITY

It is imperative that educational establishments can make a meaningful offer of support to young carers and young adult carers. They are uniquely well placed to do so. Well-funded, meaningful and impactful partnership working and support pathways must continue to be created between education, the local authority, NHS and the voluntary sector, so that young carers' and young adult carers' needs can be met.

Only just over a third of young carers and young adult carers agreed that their school, college or university 'always' or 'usually' understands about them being a young carer (34%) or young adult carer (36%). This means that around two-thirds of young carers and young adult carers are spending their days in environments where they don't feel fully understood. It is not acceptable that a group of children and young people identified in both children's and adults' legislation, are indicating that they need greater support.

We must also see improvements to equivalent offers by higher and further education establishments for young carers and young adult carers.



27%

of young carers and **51%** of young adult carers say that they 'struggle to balance caring with school, college or university work'.



52%

said they do 'not often' or 'never' get help from school, college or university to balance their school, college or university work.



40%

said they 'never' or do 'not often' have someone at school to talk to about being a young carer or young adult carer.

Having a dedicated Student Carer Support policy which takes account of reasons behind lateness, absences, late or missing homework or coursework, and mobile phone usage, would all support young carers and young adult carers. This could include offering space in school to do homework, prioritised use of the library for college and university students, flexible deadlines, adding young adult carers to bursary criteria and allowing appropriate mobile phone usage.

Young carers and young adult carers who are struggling mean that more support may be needed for them and their families. Education providers should provide additional support, as well as refer young carers and young adult carers for more support from the local NHS, local authority and voluntary sector.

“ They don't understand when I'm late arriving to school ... my mum can't get up most mornings.”

“ They don't seem to understand it's a long-term thing, they just keep offering to delay things.”

“ They understand that I need extra time because of my caring responsibilities but do not have a facility to help me equate my studies to my caring to create more balance. Thus, I feel worse within myself because I don't want extensions, I want to complete things on time with help caring.”

“ We have a no phones rule which makes it difficult to keep in contact if needed.”

“ ... teachers don't understand why I have to check my phone or I'm distracted in school.”

“ My school doesn't care that I'm a young carer, they force me to come to school even when I've been up all night looking after [the person I care for], I am so burned out.”

“ School don't often understand the complexity and how draining caring can really be.”



Even when support is provided, it's clear that sometimes school staff do not always have the capacity or the training and awareness to support young carers appropriately:

“ There’s one person for all 1,000 in the school, and she is the lead mental health person, not just young carers, so while I can talk to her, she’s often [a] bit in her office. School knows I’m a young carer, but it’s not communicated with teachers, and I don’t get help.”

“ My support worker at college assumes I don’t do anything else apart from care. Coronavirus has meant my attendance is low due to [paid care support workers] not turning up. This means I may not get on to my A Levels.”

“ There’s this teacher you’re supposed to talk to if you’re worried, but this teacher seems really snappy and busy and I don’t know how you’re supposed to get in touch with them.”

“ No-one really understands what it’s like to be a carer at university. I don’t have the same level of support that I had at school.”

“ It can sometimes be difficult to balance college work and my home life, this often leaves me with work handed in late.”

“ It’s very hard to find a balance of university work and being a carer, especially with the lack of understanding and support I had from the university.”

“ University support services overwhelmed at the moment by students with coronavirus-related mental health difficulties so they have no capacity to help.”

“ Universities don't have enough support in place for young adult carers, my caring responsibilities aren't taken into account with marking and timing of assignments and assessments.”



YOUNG CARERS, YOUNG ADULT CARERS AND PAID WORK

Paid work is as important to young carers and young adult carers as it is to other children and young people. It helps young carers gain valuable work experience and build their CV, it means young adult carers can afford to study at university, and for both groups, it may be used to top up their family's income.



For those young carers and young adult carers who work,

35%

'always' or 'usually' struggle to balance caring and work.

Only

34%

said work 'always' or 'usually' understands about them being a young carer or young adult carer.



Only

29%

said they 'always' or 'usually' have someone at work they can talk to about being a young carer or young adult carer.



Only

24%

said they 'always' or 'usually' get help from work to balance caring and their life.



Employers need to do more to support young carers and young adult carers at work. Carers Trust welcomed the UK Government's proposed five days of unpaid leave for unpaid carers. However, we do not believe unpaid carers who also work should be further financially disadvantaged, which is why this leave should be paid.

The proposed flexible working from day one of employment will contribute to a positive working culture for unpaid carers of all ages. Membership of schemes such as Employers for Carers or the Carer Positive Award may also help.

“ I nearly lost my job due to my caring responsibilities and my probation (from starting the job) was extended. I now have a new job with far fewer hours. I am looking at a job with more hours again but am worried about my employability.”

“ I had an extremely short part-time job throughout the summer. I quit the job during training due to the bad experiences with staff and being given too many hours of work (up to 30 weekly, yet, I was looking for up to 16-20) after discussing the situation.”

“ I ended off having to leave because I couldn't balance it.”

Work can also be inaccessible for some:

“ With my university studies and caring for my father who has stage 4 cancer and my mother with cardiac issues I do not have any extra time to find paid work.”

“ I work holidays from uni rather than consistently. When I do they're all lovely people I work with but there's no flexibility with management.”

“ As a young carer I was unable to get a part-time job whilst at school because I live rurally and my single parent was unable to give me lifts to work, was only able to start working when I had a car. Public transport is too unreliable where I live.”

CORONAVIRUS, YOUNG CARERS AND YOUNG ADULT CARERS

While we are no longer in the acute stages of the pandemic, it continues to impact on young carers' and young adult carers' lives in different ways to their peers who don't have caring responsibilities.

The top five ways in which coronavirus is affecting young carers and young adult carers, as carers, in their own words, are:

1. I'm feeling more stressed: 59%.
2. I'm feeling less connected to others: 47%.
3. My education is suffering: 46%.
4. My mental health is worse: 44%.
5. I feel concerned about my future prospects: 41%.

With the existing challenges of education for young carers and young adult carers, the pandemic is making things worse for their futures.

It's clear that young carers' isolation and loneliness is impacting on their ability to form meaningful connections, and to be out and about in the world. It has also meant that they have not always been able to take advantage of easing restrictions in the same way as those children and young people who aren't unpaid carers. It is also clear that young carers and young adult carers are weighed down by worry, from concerns about the whole family's finances, to feeling like they are responsible for the life of the person they care for.


In their own words:

“ ... constantly worried about catching it and bringing back into the household, passing it on to my immunocompromised parents. I did less things with friends and still do. And I avoid public transport as much as possible as well as large gatherings.”


“ Coronavirus has isolated me from a lot of my support networks and also made my caring ... more difficult.”




“ I feel anxious and sometimes hurt by the approaches people now have towards coronavirus; for them it is no issue but with my mum’s medical conditions, she is just as vulnerable as she was at the start. The fact people don’t care puts us at greater risk and is often on my mind.”




“ Being a young carer for me in coronavirus means being on edge in public with the young person I care for on a daily basis.”



“ I never got a break in almost two years, I worked hard to keep Mum out of hospital as I was scared what would happen if she went in. I never get any thanks or praise for what I do, and my bank account was the real victim.”




“ The government hasn’t provided enough support to young adult carers during the pandemic, we have been completely abandoned.”



“ Due to coronavirus, Mum’s treatments and referrals have been delayed and it’s been three years since she first started needing care ... I [took things on three years ago] not knowing I was taking up this big of a role.”




“ Lockdown cut me off from the people I relied on to stabilise my mental health and trapped me in close quarters with the person I care for who quickly became dependent.”



“ Scared about rising food and heating prices and PIP [Personal Independence Payment] and Universal Credit rates ... not rising to cover these things.”



“ I don’t know how I would have got through the last two years without carers centre help as not seen teachers or friends that much but they [carers centre] always keep in touch.”



INCREASED TIME AND INTENSITY OF CARING

More than half (53%) of the young carers and young adult carers who responded to our survey said that the number of hours they spend caring had increased in the last year.

More than a fifth (22%) of young carers and young adult carers are caring for one or more people than they were in the previous year.

Figure 1: Has the amount of time you spend caring increased in the last year?

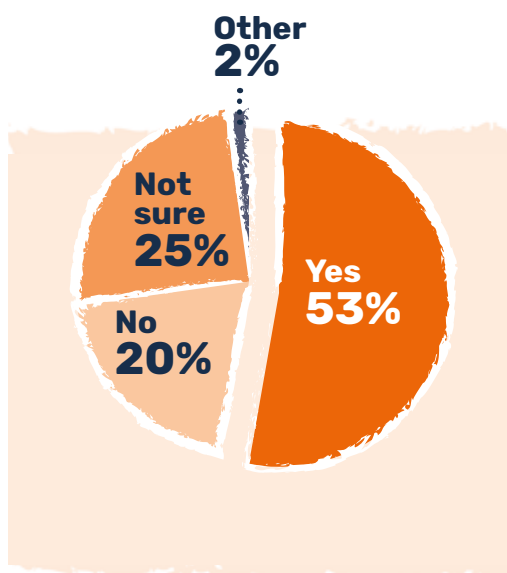


Figure 2: On average, how many hours a week do you care for?

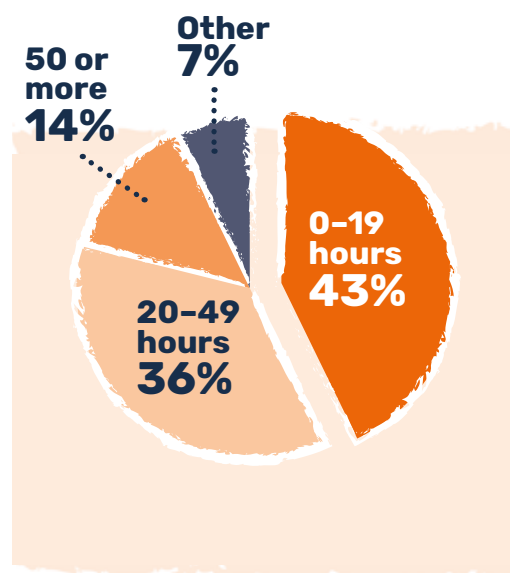
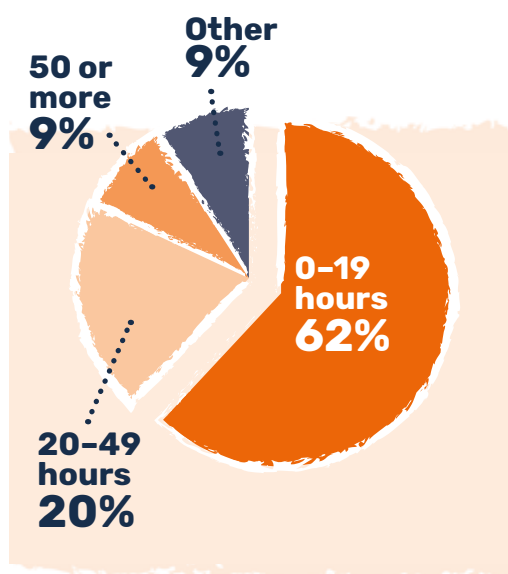
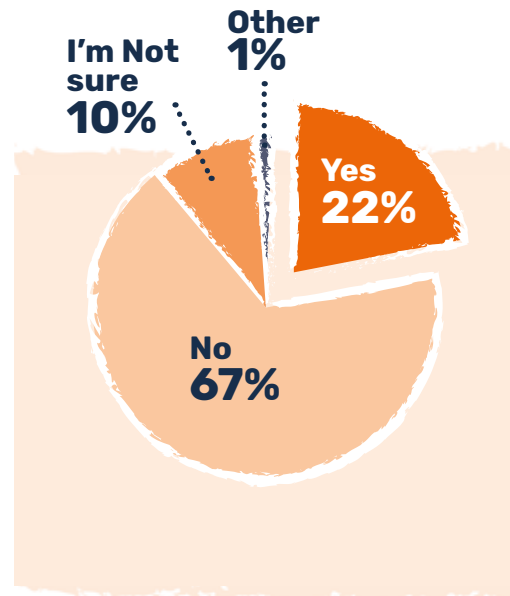


Figure 3: If you spend more time caring than you used to, how much more time per week do you spend caring?



“ It’s lots of smaller things but all throughout the day. So yes, I rest now and then but as soon as I’m up or needed I’m doing something.”

Figure 4: Do you now care for more people than you used to?



“ Well, it’s just the way it is but it would be nice if we didn’t have the situation. I miss being able to be normal like other people.”

“ It’s never-ending, it doesn’t stop when I leave, I’m constantly worried about her and I have to always have my phone on me in case she calls needing to go to the hospital or something.”



“ It isn’t set [hours] like this [referring to our question options], it could be lots one week and then none the next day. It’s depression so it’s better some days.”

“ Dealing with the person I care for via the phone when I’m at work trying to make money and they’re at home with no support is the most horrid thing in the world, it’s added time to my role.”

“ I used to care for both of my parents, but my dad passed away two and a half years ago, so now it’s just my mum again, however her health and mine have deteriorated since my dad’s passing.”

“ School is respite from caring. It’s not just learning, it’s getting to spend time with friends too.”

FULL RECOMMENDATIONS

The UK Government, Scottish Government, Welsh Government and the Northern Ireland Executive must take a coordinated and strategic approach so that young carers and young adult carers are properly supported in all areas of their lives.

1. More commissioned breaks and time outside of caring

The UK Government, Scottish Government, Welsh Government and the Northern Ireland Executive must ensure that sufficient funding is available for local funders, commissioners and providers of services for young carers and young adult carers.

Based on UK wide findings from the Carers Trust survey, the funding needs to be for services that young carers and young adult carers want: prioritising breaks, leisure opportunities and “down-time” without caring responsibilities, as well as non-traditional support such as music. Working co-productively with young carers and young adult carers, who are experts by experience, and the services that support them, will help. This research may provide a useful basis for conversations and tenders.

2. The UK Government, Scottish Government, Welsh Government and the Northern Ireland Executive should monitor how local authorities are meeting their statutory duties to identify and support young carers and young adult carers

Governments across the UK should monitor how local authorities are meeting their statutory duties to identify and support young carers and young adult carers. Transformative legislation for young carers and young adult carers is not making the leap from policy into practice and being implemented thoroughly.

3. Education providers need to take an integrated approach to support

The UK Government, Scottish Government, Welsh Government and the Northern Ireland Executive should monitor how schools, colleges and universities are identifying and supporting young carers and young adult carers, and take action to support them.

While some systems for children and young people are working well for some young carers and young adult carers, it's clear that is by no means a universal picture. Schools, colleges and universities remain ideally placed to initiate and provide support for young carers and young adult carers, in partnership with the NHS, local authorities, and the voluntary sector. Practical policies which support young carers and young adult carers would help, such as allowing appropriate mobile phone usage.

4. Prioritise access to mental health support for young carers and young adult carers

The NHS should ensure that mental health services recognise and prioritise support for young carers and young adult carers. Any young carer or young adult carer seeking primary or secondary mental health care, either as a result of their caring role, or where caring was a factor in their mental health, should also be referred for wraparound support from local authorities and the voluntary sector. Their family's needs should also be re-assessed in case providing more support to their family would help the young carer or young adult carer.

5. Free or discounted leisure and transport

Providing universal free or discounted access to leisure opportunities and transport would enable young carers and young adult carers to: connect with other young carers and their friends; take up paid work or work experience; look after their health and have fun. Given what evidence shows about the impact of isolation and loneliness on physical and mental health, it cannot be acceptable that young carers and young adult carers are facing these issues in childhood and adolescence.

6. More financial support for young adult carers

Carer's Allowance should be extended to those young adult carers in full-time further or higher education. This will break down barriers for young adult carers to access college and university and realise their aspirations.

7. Sustainably fund the wider social care system

Reforming, and sustainably funding, social care, for disabled people or older people, would make a significant difference to young carers and young adult carers by increasing the availability of support provided by statutory sources for the person they care for.



METHODOLOGY

To obtain the qualitative and quantitative data used in this report, we asked young carers and young adult carers to complete a survey.

571 young carers and young adult carers, aged 12-25 across the UK, completed the survey on our invitation: 342 from England, 170 from Scotland and 48 from Wales.

The survey was anonymous, and no identifying data is held about any of these children and young people.

Young carers and young adult carers self-identified as young carers or young adult carers, in the UK, aged 12-25. A short definition of a young carer and young adult carer was provided in the introductory text of the survey.

Survey completion was voluntary. Carers Trust offered a prize of a £25 value wellbeing box for young carers or young adult carers who wished to supply their email address (not stored with their data). Not all young carers or young adult carers chose to enter their email. No other reward or remuneration from Carers Trust was offered to complete the survey.

Young carers and young adult carers were able to choose which questions they did and did not answer, including any free text, and to stop completing the survey at any time. An email address was provided for any questions. We signposted all participants to support, for any young carers and young adult carers for whom completing the survey may have brought up difficult or intense feelings, or led participants to realise they needed more help or to talk to someone.

We promoted the survey via Carers Trust Network Partners, other charities and external organisations we work in partnership with, and on our social media channels.

For our fieldwork, we collected responses via Microsoft Forms from 12 January to 3 February 2022. The survey had 32 questions of various types, such as: radio buttons, free text, Likert scales. The survey was available in English and Welsh.

While the survey results haven't been weighted by demographics and so are not necessarily nationally representative, it is nevertheless intended to provide an invaluable snapshot of young carers and young adult carers' experiences and views from across the UK. There were not stark differences of the results across nations, which is why a breakdown of nation specific data has not been presented in the main report.

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