BEING A YOUNG CARER IS NOT A CHOICE
IT’S JUST WHAT WE DO

THE VOICES AND EXPERIENCES OF YOUNG CARERS AND YOUNG ADULT CARERS FROM ACROSS THE UK

March 2023
ACKNOWLEDGEMENTS

Thank you to:

• The 1,109 young carers and young adult carers who gave their time to complete our survey.

• The young carers, young adult carers and local carer support organisations who helped co-draft the recommendations and voted on the title for this report.

• The committed and skilled young carers and young adult carer support workers within Carers Trust’s network of local carer organisations and our partners in the wider sector who continue to provide invaluable support.

ABOUT CARERS TRUST

Carers Trust works to transform the lives of unpaid carers. It partners with its UK-wide network of local carer organisations to provide funding and support, deliver innovative and evidence-based programmes, raise awareness, and influence policy. Carers Trust’s vision is that unpaid carers are heard and valued, with access to support, advice and resources to enable them to live fulfilled lives.

Carers Trust hosts the Young Carers Alliance, a network of over 150 organisations and 300 individuals committed to improving identification and support for young carers and young adult carers. Carers Trust also hosts the Scottish Young Carers Services Alliance, an informal network of young carers services across Scotland. It has 51 members who provide support to young carers.

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WHO ARE YOUNG CARERS AND YOUNG ADULT CARERS?

A young carer is someone aged 18 or under who cares for a friend or family member who, due to illness, disability, mental health problems 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 the house, keeping an eye on someone or providing emotional support.
“Being a young carer is not a choice. It’s just what we do.”
My name is Ollie. I’m 17 and a member of the Welsh Youth Parliament who represents Carers Trust Wales, but more importantly, I am a young carer.

I care for my younger brother, who has many complex additional needs. I’ve cared for him since I was 5. I wouldn’t say that my caring role impacts my life; I would say that it is my life, it’s all I know, and I wouldn’t have it any other way. I care for my brother and family because I love them, and that’s what family does.

However, it does put a strain on other parts of my life. School has always been hard for me, teachers haven’t always been understanding or willing to understand in my experience, and my caring role has made it very hard for me to stay up-to-date with coursework or to focus in lessons. It has also been difficult to maintain a social life because of the demands of my caring role.

This year has been hard for everyone, especially unpaid young carers. The cost-of-living crisis has affected us all in different ways, and it’s been quite tough for my family this year.

But there is a lot to be positive about in the upcoming year! I’m hopeful this will be the year young carers can have better access to mental health support and services. Over the years I have represented Carers Trust, we have implemented many positive changes for all of us, and I only see that continuing. So bring on 2023 because Carers Trust is ready!

Ollie Mallin
Welsh Youth Parliament Member and young carer

“I wouldn’t say that my caring role impacts my life; I would say that it is my life.”
INTRODUCTION

MANY YOUNG CARERS AND YOUNG ADULT CARERS FEEL OVERLOOKED

“We save the government lots of money by doing the work of caring, but we don’t get the help or support we need. I just want to enjoy my childhood as well as being a young carer.”

In early 2023, Carers Trust conducted a UK-wide survey of how young carers and young adult carers felt about their education and work, mental health, their lives alongside or outside of caring, and what support they get and need.

We found that more than half of young carers and young adult carers (51%) care for 20-49 hours each week. They do this while balancing their studies, work, and lives outside of caring. It was unsurprising, therefore, that young carers and young adult carers spoke about the struggle to find time for themselves and the mental toll placed on them by their caring responsibilities.

Our findings highlight that whilst some progress is being made in supporting the lives of young carers and young adult carers, many still feel very alone, overlooked and unappreciated. Almost three quarters (74%) of young carers and nearly half (45%) of young adult carers said politicians did not understand their needs as an unpaid carer either ‘very well’ or ‘at all.’
Carers Trust asked young carers and young adult carers, ‘what would you say to politicians about what it’s like to be a young carer or young adult carer’? The prevailing emotions were sadness, anger and frustration:

“Being a young carer feels like we have been forgotten. There is not enough support to help us.”

“There is just not enough help, and especially not coordinated approaches. This is a lifetime job, and respite is truly minimal. Care work needs to be valued more, paid more and funded, so we aren’t just relying on the burnout of families.”

“We should stand out to you for how much we do. Being a carer is draining physically, mentally and emotionally, but we do it. We are people, and we need help too. Caring comes with many side challenges that aren’t talked about enough. Let us be heard!”

“Unpaid carers save the government a huge amount of money looking after their friends or loved ones. They give up their time and put their life, work and relationships on hold.”

In this context, young carers and young adult carers urgently need access to the necessary support and services required for them and their family. Young carers and young adult carers told us their top priorities for the support they want are:

1. MENTAL HEALTH SUPPORT.
2. SUPPORT WITH THEIR MONEY AND FINANCES.
3. MORE SUPPORT WITH THEIR EDUCATION.
4. SUPPORT TO HAVE A BREAK FROM CARING.
KEY FINDINGS FROM RESPONDENTS:

56% of young carers and young adult carers said the time they spend caring has increased in the last year.

47% now care for more people than they used to.

56% said the cost-of-living crisis is either ‘always’ or ‘usually’ affecting them and their family.

44% ‘always’ or ‘usually’ feel stressed because of being a young carer or young adult carer.

45% who work ‘always’ or ‘usually’ struggle to balance caring with paid work.

40% either ‘never’ or ‘not often’ get help in education to help balance caring and school, college or university work.

40% of young carers and young adult carers said caring ‘always’ or ‘usually’ affects how much time they can spend with their friends.
In response, Carers Trust makes the following recommendations:

1. UK Government urgently publishes a **national strategy for unpaid carers** in 2023, and all governments across the UK develop a national action plan co-produced with young carers and young adult carers.

2. All governments across the UK to ensure **every local authority has a dedicated young carer and young adult carer offer** that enables young carers and young adult carers to realise their statutory rights.

3. Put young carers’ and young adult carers’ **mental health and wellbeing at the forefront of planning locally and nationally** by ensuring timely referrals to wellbeing services, such as CAMHS, from all statutory services.

4. Ensure that **all schools, colleges and universities appoint a Young Carers Lead** with strategic responsibility and oversight for identifying and implementing appropriate support for young carers and student carers.

5. All governments across the UK to **introduce a fully resourced right to short breaks** for unpaid carers with dedicated funding to ensure age-appropriate choices of breaks for young carers and young adult carers.

6. All governments across the UK to develop specific **employability programmes and apprenticeship pathways** to support young adult carers who experience additional disadvantage in accessing employment, designed in partnership with specialist local carer organisations.

7. **Improve access to financial support** for young carers and young adult carers, including increasing Carer’s Allowance and extending eligibility to Carer’s Allowance to unpaid carers in full-time education.
“Being a young carer is not a choice. It’s just what we do.”

Caring never stops. Especially when it’s time to sleep, your brain constantly worries about how tomorrow will be, hospital appointments, money etc. It’s in overdrive.”

More than half (51%) of young carers and young adult carers said they spent 20–49 hours per week caring. This is an increase from Carers Trust findings in 2022 in the report “It’s harder than anyone understands” (36%).

Young carers and young adult carers emphasised that these hours often do not reflect the additional time they spend worrying about the person/people with care needs. Therefore, it is likely that these recorded hours are underestimations of the amount of time young carers and young adult carers are actually spending in their caring role.
“Being a young carer is not a choice. It’s just what we do.”

“When you live with the family you care for, it’s very hard to define how many hours you care. There is no ‘off’ time. You are always available to help at all times.”

“It’s hard to quantify. Caring isn’t just the time I’m physically spending with the people I care for; it’s also the free time I spend worrying.”

OUR SURVEY FOUND THAT:

56% OF YOUNG CARERS AND YOUNG ADULT CARERS SAID THE TIME THEY SPEND CARING HAS INCREASED IN THE LAST YEAR

47% NOW CARE FOR MORE PEOPLE THAN THEY USED TO

The intensity of care provided by young carers and young adult carers affected their responses across various measures of wellbeing. A higher proportion of those caring for more hours per week reported challenges around financial wellbeing, having time to socialise, feeling stressed and worried and getting enough rest, sleep or time for themselves.

Figure 1: Young carers and young adult carers’ responses to the question “has the amount of time you spend caring increased in the last year?” (n=1095)

21% I’m not sure
23% No
56% Yes
Many young carers and young adult carers are still struggling to balance their education with caring and are consequently at risk of adverse educational outcomes. This can include lower educational attainment for young carers and young adult carers and them spending less time than their peers in education, either through missing classes or deciding to leave. Furthermore, balancing caring with education can be incredibly stressful and overwhelming for young carers and young adult carers, with likely negative impacts on their wellbeing.

Young adult carers spoke about the challenges they experience in balancing caring from a distance if they move away for opportunities such as university or starting employment. They commented on the difficulties they encounter in coordinating care whilst away from home, their concerns about being unable to respond to situations quickly, or worrying about what was happening at home:

“I spend more time worrying about the person I care for because I’m not always there to help.”

Young carers and young adult carers need to have someone in school, college or university who understands their responsibilities, advocates for them and ensure the necessary support is provided.

This year’s survey findings show an improvement in young carers and young adult carers having someone at school, college or university who understands about them being an unpaid carer: 28% reported either ‘never’ or ‘not often’ had someone at school, college or university who understood about them being an unpaid carer in 2023, compared to 40% in 2022.
However, much more progress is still needed.

Despite this improvement in understanding, 40% said they either ‘never’ or ‘not often’ get help in school, college or university to balance caring and school, college or university work.

Respondents to our survey provided examples of when it would have been helpful for teachers and lecturers to understand about them being late, missing class or needing to have their mobile phones in class to be contactable. In some instances, young people spoke about their experiences of continuing to face sanctions even after disclosing that the reason for their absence or lateness was related to caring responsibilities, with professionals failing to connect the dots between instances of conduct. For example:

“There is no empathy or understanding towards young carers. I still get detention if I cannot finish my homework on time because my brother has had a seizure. If I’m late because I’m helping him, again, I get late marks even when my mum phones and explains. They are really harsh when things go wrong.”

Policies relating to students’ conduct must consider the potential impact of young people’s caring situation. Education professionals must be better supported to recognise these possible signs of caring responsibilities and to support young carers and young adult carers to be identified as such. In turn, education professionals should seek to understand the challenges their young carers and young adult carers are experiencing:

“Places of education need to be more aware of what young carers have to go through. It can be difficult and draining. We aren’t lazy; we are tired and overworked.”

Schools, colleges and universities should use the available data they have on pupils to monitor the attendance and attainment of young people, which might help to identify young carers and young adult carers who need additional support. Including young carers in the school census in England, SEEMiS school data collection in Scotland and UCAS applications is welcome and has the potential to improve awareness, identification and support for young carers and young adult carers.

As part of our recommendations, Carers Trust believes that all schools, colleges, and universities should appoint a Young Carers Lead with strategic responsibility and oversight for identifying and implementing
appropriate support for young carers and student carers. Within this, support must be coordinated between Young Carer Leads across educational institutions. Coordinating support is especially important during critical transition periods, such as between primary and secondary school and between school/college and university, where young carers and young adult carers often ‘fall between the gaps’ in professionals’ awareness of young people’s caring responsibilities and in receiving support.

In addition to this, young carers and young adult carers would also like to see an increased provision of forums, such as clubs, to facilitate peer-to-peer support and encourage more expansive learning about caring roles.
PAID WORK

“Being a young carer means you have to work twice as hard as everyone else every single day.”

Balancing work with caring responsibilities can be incredibly challenging.

More young carers and young adult carers are saying they struggle to balance caring with paid work. For those who work: 45% of young carers and young adult carers said they either ‘always’ or ‘usually’ struggle to balance caring with paid work.

All young carers and young adult carers must be appropriately supported in their workplace. Professionals must be trained and confident to support young carers and young adult carers’ needs.

43% said they either ‘always’ or ‘usually’ get help from work to balance caring and their life.

41% said they either ‘always’ or ‘usually’ have someone at work to talk to about being a young carer or young adult carer.

Young carers and young adult carers highlighted that they found it difficult to identify themselves as unpaid carers to their employers, especially if they were working part-time. Young carers and young adult carers must be supported to identify as unpaid carers to management as soon as possible to ensure they can access the support they need.

Conversations about caring need to be normalised in the workplace from the point of application. This will help young carers and young adult carers feel more comfortable sharing their caring journey, which may help others recognise that they may also have caring responsibilities and make it more approachable to talk to employers about required support.

Young carers and young adult carers also emphasised the importance of flexibility in their workplace, such as being able to adjust their
working hours or in employers demonstrating understanding and accommodation of last-minute absences. However, we heard from young carers and young adult carers who were finding accessing flexibility from their employer around their caring role difficult:

“I wish there were more people that understand the struggles and that sometimes I won’t be able to attend because the person I care for may be ill that day.”

“There is little leeway if I’m marginally late or need to leave a few minutes early because of my caring role. It can become really stressful”.

Several young carers and young adult carers also spoke of the challenges of their caring role alongside thinking about their career aspirations and worrying about making sacrifices to their future employment goals:

“It takes over your future. I can’t think about my goals without considering my caring role implications - this makes me feel guilty and trapped”.

Worrying about making future sacrifices can impact young carers’ and young adult carers’ mental health. They need to know how they can access employment and training opportunities and what support they can benefit from.

The Carer’s Leave Bill currently passing through the House of Lords aims to provide the legal right to unpaid carer’s leave for employees with caring responsibilities and is a welcome step towards ensuring greater workforce recognition and support for unpaid carers.
“Being a young carer is not a choice. It’s just what we do.”

I’d love to have kid problems. Instead, I’m saving up to try and pay our rent and to see if I can squeeze in some food at the end of the month.”

Many young carers and young adult carers are contributing to or managing the finances of those they look after. Our survey found that:

32% ‘ALWAYS’ OR ‘USUALLY’ FACE ADDITIONAL COSTS BECAUSE THEY ARE AN UNPAID CARER

Many young carers and young adult carers and their families are under enormous pressure with rising energy prices and increases in the cost of living. Our survey found that:

57% SAID THAT THEY EITHER ‘ALWAYS’ OR ‘USUALLY’ WORRY ABOUT THE COST OF LIVING AND THINGS BECOMING MORE EXPENSIVE

56% SAID THAT THE COST-OF-LIVING CRISIS IS EITHER ‘ALWAYS’ OR ‘USUALLY’ AFFECTING THEM AND THEIR FAMILY
Several young carers and young adult carers provided examples of the financial difficulties they are facing in their families’ ability to buy the things they need. Some comments included:

“**They require equipment, access to a car, and heating to help them live a normal life. I worry daily!”**

“**I find it difficult to pay the bills and buy groceries because I’m not in employment as I had to give it up for my caring role.”**

“**I’m paying for two people out of my small part-time income, and it’s even more impossible to do during the cost-of-living rise**.”

Furthermore, some young carers and young adult carers stated that increasing costs had limited their ability to afford to attend social opportunities, such as after-school clubs:

“**I’m worried about not being able to afford after-school clubs as it is the only space I get from being a carer.”**

No unpaid carer should be at risk of financial hardship or poverty due to their caring role, including young carers and young adult carers. This must be a major focus for governments across the UK. Carers Trust calls for an increase in Carer’s Allowance and that it be extended to carers in full-time education.

Furthermore, education providers, clubs and organisations must ensure that young carers and young adult carers are prioritised when allocating funding to improve attainment and wellbeing. Young carers and young adult carers should be supported to access opportunities, which has the additional benefit of enabling them to take breaks from their caring roles. Information should be made available to young carers and young adult carers and their families on financial support they can access.
MENTAL AND PHYSICAL WELLBEING

"You don’t get to have bad days. If you have a bad day, the whole house can fall into disarray. It’s exhausting and traumatic."

Many young carers and young adult carers spoke about the self-worth they feel in caring for other people and their role in making a positive difference in people’s lives. However, at the same time, many struggle with their emotional wellbeing and feel tired and run down from worry and stress:

Since Carers Trust’s survey findings in 2022, young carers’ and young adult carers’ worries are still a cause for significant concern:

44% ‘ALWAYS’ OR ‘USUALLY’ FEEL STRESSED BECAUSE OF BEING A YOUNG CARER OR YOUNG ADULT CARER

38% SAID THEY ‘ALWAYS’ OR ‘USUALLY’ FEEL WORRIED BECAUSE OF BEING A YOUNG CARER OR YOUNG ADULT CARER, COMPARED TO 36% IN 2022

27% SAID THEY EITHER ‘NEVER’ OR ‘NOT OFTEN’ FEEL THEY GET ENOUGH SLEEP

Feelings of stress because of their caring role were particularly highlighted by female young carers/young adult carers in this year’s survey: 47% of females stated they were either ‘always’ or ‘usually’ stressed because of being an unpaid carer, compared to 37% of males:

"I’m just exhausted. I’m not ‘me’ anymore."
“No matter how much I try to get my life together with caring, it always feels like I’m chasing my tail.”

Young carers and young adult carers described how frequently they put their feelings aside to provide care:

“I feel quite unhappy, but at the same time, I am making it easier for someone else and making their life easier.”

“I tend to turn my emotions off while being zoned into my caring role. It’s when I take a step back that things spiral with all the things I’ve kept in.”

Many young carers and young adult carers also spoke about feeling like they had to hide or manage their emotions due to the fear or guilt of upsetting the person they care for. These feelings may explain why young carers and young adult carers can struggle to speak about their emotions or ask for help:

“You can experience massive neglect, and there may not be space in the family to share your own problems due to feeling like there is so much going on already. You can really start to suffer in silence.”

When asked what types of support they would like, a higher proportion of female young carers and young adult carers said they would like mental health support, with 49% of females stating they would like access to mental health support compared to 32% of males.

Many young carers and young adult carers spoke about the challenges of accessing support and treatment and their struggles of experiencing long waiting lists for support from Child and Adolescent Mental Health Services (CAMHS). There continues to be an urgent need for professionals working across health and social care services to proactively identify, assess and offer support to help the health and wellbeing of young carers and young adult carers.
Over one third (37%) of young carers and young adult carers said the NHS did not understand their needs as an unpaid carer either ‘very well’ or ‘at all.’ All healthcare settings must have systems in place to identify and support young carers and young adult carers.

Furthermore, healthcare professionals, especially within mental health services and GPs, must recognise the significant challenges that being a young carer or young adult carer can bring and offer support specifically relevant to young people with caring responsibilities.
TIME FOR THEMSELVES AND THEIR FRIENDS

“I can’t think about the things I’m missing out on as it only gets me down. I’ve been a carer my whole life; it’s just who I am.”

While some young carers and young adult carers spoke of how rewarding their role as unpaid carers is, many described the experience as isolating, impacting their ability to spend time with their friend(s), having time to themselves or pursuing their interests:

“Being a young carer can make you feel invisible. Finding the time for hobbies or socialising is basically impossible.”

40% of young carers and young adult carers said caring ‘always’ or ‘usually’ affects how much time they can spend with their friends.

Many young carers and young adult carers spoke about the difficulties of spending time outside of the home because of the guilt or worry they felt about leaving the person they care for and the fear that something would happen in their absence. Many often feel unable to entirely switch off from their caring role, creating challenges in being fully present with their friends and feeling as though their friends do not understand the gravity of their caring responsibilities:

“I’m not able to leave my house out of fear my mum or brother would take a turn for the worst, and I wouldn’t get the chance to say goodbye.”

“It’s a constant worry - you can never escape, and it’s always at the back of your mind. It’s not like you can take a break because when you are physically elsewhere, your mind is still focused on worrying about what is going on at home.”
OUR SURVEY FOUND THAT:

26% of young carers and young adult carers said that they either ‘never’ or ‘not often’ feel included in all the things their friends do.

24% said their friends did not understand their needs as young carers/youth adult carers either ‘very well’ or ‘at all’.

Many young carers and young adult carers spoke about the benefit of local carer organisations facilitating social opportunities such as days out or evening clubs. Many commented about how their local carer organisations had enabled them to meet new people and the benefits the peer-to-peer support bought them in interacting and talking with other young carers. This helped them to feel less alone as they could relate with people who had been through similar experiences to them:

“There is so much self-doubt over if you are doing it ‘right’. Having support groups like young carers are essential for these bad days. They help you find the inner strength to carry on.”

“The trips are really good to help with loneliness.”
SUPPORTING YOUNG CARERS AND YOUNG ADULT CARERS

“Who cares for us when we have done what we need to do to ensure everyone else is safe?”

ACCESSING SUPPORT

Within our survey, young carers and young adult carers who could access support from young carers’ services were vocal about the value they place on available specialist support. They stated that these services offered respite from their caring roles, offered a space for young carers and young adult carers to be themselves, and were often integral in young people identifying themselves as having caring responsibilities.

A few of the positive comments about the value of local carer services included:

“Young Carers are brilliant. They are the only support I get with my caring role.”

“The support has been an absolute godsend to our family. I have received so much time out and the chance to talk about my stresses with people who understand. It helped me worry less about leaving the family home to pursue drama school. They have been incredible to us.”

“I can struggle with being on my own and not having any friends being a young adult carer. Young adult carer days out helped me get out and socialise with people in the same boat as me.”
However, many young carers and young adult carers remain isolated, speaking of the challenges they face in accessing the relevant support they need. Our survey found:

42% SAID THEY EITHER ‘NEVER’ OR ‘NOT OFTEN’ GET ENOUGH SUPPORT FROM YOUNG CARERS OR YOUNG ADULT CARER SERVICES

Some of the challenges of accessing support included:

- Having to reach out to access support. In many cases, young carers and young adult carers did not know about the existence of specialist unpaid carer support that they could receive help from.

- Challenges in finding and accessing young adult carer-specific services. Many young adult carers stated that they felt they had slipped through the net in receiving support and were left worried about transitioning to their adult life without this specific support.

- Worrying about losing or having lost access to young carer services due to funding restrictions on services.

Young carers and young adult carer’s comments included:

“Since Young Carers stopped having their drop-in nights, I have no support or time away from life as a young carer.”

“Young Carers pick me up and support me for a few hours. These few hours give me a boost; that is all I get in the line of help. I wish I could get more support to get me through the dark days, but the people in Young Carers are wonderful.”

“More needs to be done for when carers transition into adult carers services to ensure we are not left behind or forgotten.”

It is essential that young carers and young adult carers know about the support and advice available to them and that professionals refer and signpost to specialist unpaid carer support services. Local authorities need to ensure that support is available with the transition to adulthood. Furthermore, young carer and young adult carer services need appropriate ring-fenced funding to continue delivering vital support to these children and young people.

“Being a young carer is not a choice. It’s just what we do.”
APPENDIX

METHODOLOGY:

1,109 young carers and young adult unpaid carers aged between 12 and 25 completed our survey. Respondents came from across the UK. The survey ran from 21 November 2022 to 15 January 2023.

The survey was anonymous; no identifying data is held about any of these children and young people. Young carers and young adult carers could choose which questions they did and did not answer and could stop completing the survey at any time. Young carers aged 16 and under were encouraged to talk to their parent, guardian, or young carers support worker before completing the survey.

We promoted the survey via Carers Trust’s network of local carer organisations, the Young Carers Alliance, the Scottish Young Carers Services Alliance, other charities and external organisations we work in partnership with and on our social media channels.
Survey completion was voluntary. Carers Trust offered a chance to enter a prize draw for a £45 value wellbeing box and an Apple iPad for young carers or young adult carers who wished to provide their email address (not stored with their data). No other reward or remuneration from Carers Trust was offered to complete the survey.

Respondents self-identified as unpaid carers aged 25 and under before completing the survey; a short definition of an unpaid carer was provided in the survey’s introductory text.

While the survey results have not been weighted by demographics and so are not necessarily nationally representative, it provides an invaluable snapshot of young carers and young adult carers’ experiences and views from across the UK. Where notable differences exist between demographic groups in analysis, this has been noted in the report. This includes variables such as sex, having a long-term health or physical condition or identifying as LGBTQI+. The sample size was insufficient to conduct further analysis on ethnic minority groups.

This research follows on from research we conducted in 2022 entitled: It’s harder than anyone understands”. Some comparisons between the 2022 and 2023 survey findings have been provided within this report.

If you have any questions or would like any information on any of the findings discussed as part of this report, please get in touch with our Policy Team (policy@carers.org) or Young Carers Team (youngcarers@carers.org).