

**CARERS
TRUST**

WALES



SUPPORT NOT SYMPATHY

A call to action from Wales' young and young adult carers

July 2020

INTRODUCTION

Struggling to access food and medicines. Having to care day and night without a break. Worrying about keeping the people they care for safe. Coping with a mental health condition without support. Feeling lonely. Falling behind at school, college or university.

This is what the pandemic has meant for thousands of young and young adult carers across Wales.

“Covid 19 has made me realize how much I need my friends and young adult carers group. As I'm not getting much rest or being very social I have fallen behind in college work and gained a lot of weight. My confidence is gone and I feel really lonely”

Young adult carer, 18



In June 2020 Carers Trust Wales surveyed 366 carers aged between 12 and 25 to understand their experiences of living and caring during the pandemic. Whilst some have found positives, such as learning a new skill or building a closer relationship with the person they care for, many more describe feeling stressed, unable to cope and overwhelmed by the pressures they now face.

The young and young adult carers who shared their thoughts and experiences with us have been clear about what they want and need:

- Support for their emotional wellbeing and mental health
- Help to stay connected to friends and their communities
- Breaks from their caring role and the support of specialist young carers services
- More help to balance caring, education and employment
- Support to stay fit and healthy.

In 2018 Carers Trust Wales' Youth Council, developed their **#SupportNotSympathy** campaign. Through it they have consistently called for better support to enable young and young adult carers across Wales to live happy, healthy, fulfilling lives. This research demonstrates the need, now more than ever, to listen to and act on their call.



Carers Trust Wales Youth Council Meeting, 2019

This briefing sets out the growing pressures young and young adult carers are facing, often in their own words. It aims to amplify their voices and start a national conversation about how we can ensure they get the recognition they deserve and the support they need.

With the right support young and young adult carers can lead healthy and successful lives alongside their caring role. However, struggling without adequate support can have a lasting impact on physical and mental health, financial wellbeing and wider life outcomes.

Sadly, our research has shown that 67% of young carers and 73% of young adult are now more worried about their future.

“I love the person I care for and they’re not a burden to me, but I feel having no time away from them is taking its toll mentally as I already suffer mental illnesses separate from my circumstances, I feel like it’s given me more time to think of my future and it seems bleak and full of heartache and grief”

Young adult carer, 23

Building on this research, Carers Trust Wales will continue to work with young and young adult carers, our Network Partners, decision makers and professionals to shape policy, programmes and practice to ensure that the right support is in place.

We ask you to join us in committing to raise awareness of the pressures young and young adult carers face every day and to take action to address them

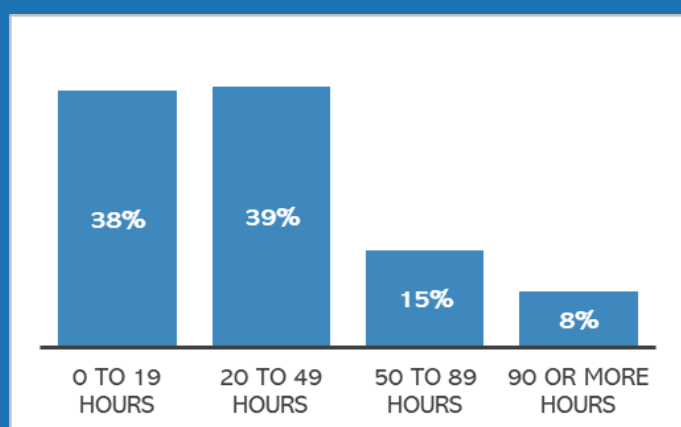
You can pledge your support or get in touch with our small and ambitious team to discuss how you can join us in making a difference by emailing wales@carers.org

Or join in the conversation online [#SupportNotSympathy](https://twitter.com/SupportNotSympathy)

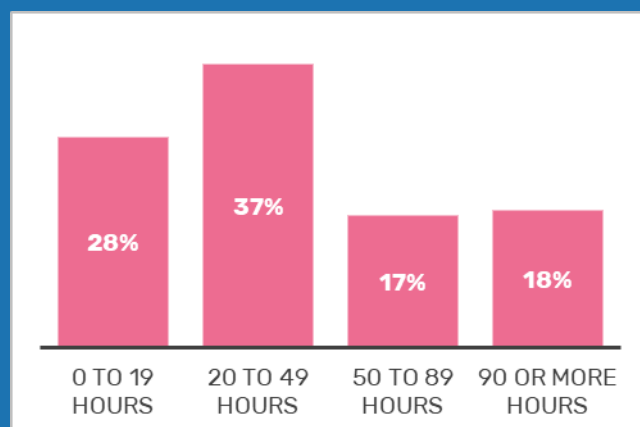
WHAT DOES IT MEAN TO BE A YOUNG OR YOUNG ADULT CARER?

Young and young adult carers undertake a range of tasks to support family members or friends who could not cope without their support. This might include shopping, cooking, cleaning, managing medicines, providing personal care or giving emotional support.

Our survey shows this has taken up a lot of time during the pandemic.



YOUNG CARERS



YOUNG ADULT CARERS

"I now provide round the clock care for the person I care for and unable to get a break. Found it more isolating than usual and it's having an effect on my mental and physical health with having to lift more"

Young adult carer, 23

**58% OF
YOUNG
CARERS AND
56% YOUNG
ADULT
CARERS NOW
CARE FOR
MORE HOURS
EVERY WEEK**

"... I have no time to myself I'm not sleeping, I cry everyday because I cant cope, I'm not able to look after myself or my illnesses I'm looking after three people now instead of one"

Young adult carer, 23

1 IN 5 YOUNG ADULT CARERS AND 1 IN 10 YOUNG CARERS HAVE SEEN THEIR CARING ROLE INCREASE BY 30 HOURS A WEEK OR MORE

35% OF YOUNG AND YOUNG ADULT CARERS REPORT THAT THEY NOW CARE FOR MORE PEOPLE THAN THEY DID BEFORE THE PANDEMIC



EMOTIONAL WELLBEING AND MENTAL HEALTH

37% of young carers and almost half (47%) of young adult carers say their mental health is worse than it was before the pandemic began.

30% of young carers and 44% of young adult carers feel overwhelmed by the pressures they are now facing which is having an inevitable impact on their mental health and wellbeing.

"I am more suicidal"

Young carer, 17

"I'm alot closer to mental breakdowns then before. The problem is that I look after my own father but spending time with my family makes me feel worse about myself"

Young adult carer, 19

"Everything is uncertain. It's really hard to make plans. I worry that some one I love will die"

Young carer, 12

**MORE THAN 2
IN 3 YOUNG
AND YOUNG
ADULT CARERS
ARE MORE
STRESSED**

**29% OF YOUNG
CARERS AND
37% OF YOUNG
ADULT CARERS
FEEL LESS
ABLE TO COPE**

Despite their emotional and mental health needs 20% of young carers and 29% of young adult carers are struggling to access any emotional support.

1 in 4 young carers and nearly 1 in 3 (32%) young adult carers would like support with their mental health but don't currently access any.

"... I feel more trapped, feel more pressure To help the person I care for. I don't sleep as much, and personal hygiene has lowered since my mental health has declined"

Young carer, 17

JUST 5% OF YOUNG CARERS AND 2% OF YOUNG ADULT CARERS CURRENTLY ACCESS REMOTE COUNSELLING OR THERAPIES



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Despite the pressures they face, young and young adult carers have found things to help them cope. 73% of young adult carers and 72% of young carers describe listening to music as an important coping mechanism for them.

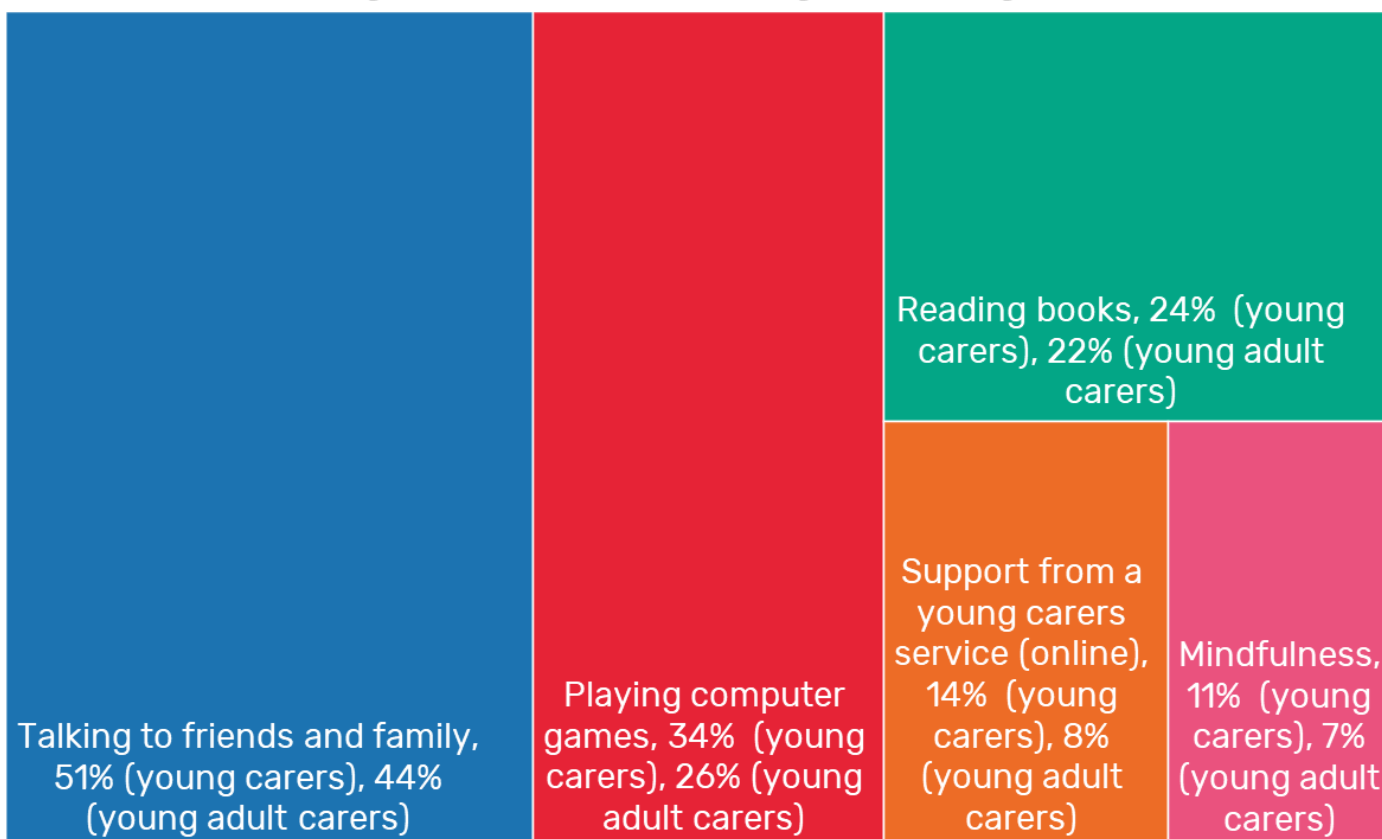
Worryingly, 18% of young adult carers are drinking more alcohol and 3% are using illegal drugs to help them cope.

14% OF YOUNG CARERS AND 18% OF YOUNG ADULT CARERS WOULD LIKE MORE INFORMATION AND PRACTICAL ADVICE OR TIPS TO HELP THEM COPE

"... Before the lockdown my mental state got worse. I was in hospital. CAHMS said they would help. I have not spoken to or seen anyone since that day at end of February. My parents and me are trying our best but I need to see someone. Paranoia and mood swings are the worst. I dont know who to be"

Young carer, 15

Other coping mechanisms for young and young adult carers



EDUCATION

Most young and young adult carers are juggling their caring roles alongside school, college, university or work.

45% of young carers report that they are not able to spend enough time on their schoolwork and 58% feel that their education is currently suffering.

"It has put more stress on me and my education and has made my anxiety so high"

Young carer, 13

"I have been caring alot more than usual and expected to spend more time with the person I care for meaning I don't have much time for me I've not done any school work cuz of caring and other things so I'm falling behind massively"

Young carer, 14

**42% OF YOUNG
CARERS
WOULD LIKE
MORE
SUPPORT WITH
THEIR
EDUCATION**

**27% OF YOUNG
ADULT CARERS
WOULD LIKE
MORE
SUPPORT WITH
THEIR
EDUCATION**

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36% of young adult carers say that their education is suffering, impacting on their hopes and opportunities for the future.

However, for some young and young adult carers studying has proved to be a valuable opportunity to focus on something other than caring. Almost 1 in 5 find that studying helps them to cope.

1 in 10 young carers also describe that support from school or an individual teacher has helped them to cope with life since the Coronavirus.

Additionally, young people have identified that lockdown has given them more time to learn skills, with siblings or those they care for.

"I am spending more time caring for others (members of my family who are unable to leave the house). I am unable to focus on university assignments and prepare myself for going back as I feel I am relied upon more"

Young adult carer, 19

"Being home 24/7 means extended caring hours and more daily tasks but also, I've grown closer my little brother and we've learned new skills together"

Young carer, 17

44% OF YOUNG CARERS AND 22% OF YOUNG ADULT CARERS HAVE LEARNT A NEW SKILL, SUCH AS COOKING, DURING THIS TIME.



MAINTAINING HEALTH AND ACCESS TO FOOD AND MEDICINES

30% of young carers are struggling to look after themselves. By this we mean being able to eat healthily, exercise, or get enough sleep. This rises to 44% amongst young adult carers.

It is concerning that such a large number of young and young adult carers feel unable to take care of themselves. As well as being concerning in the short term it may have long term implications for their health and wellbeing.

31% of young adult carers and 34% of young carers have been able to take some positive action to stay healthy describing that they use exercise to help them cope with their caring role at this time.

9% of young carers and 16% of young adult carers find it difficult to access basic things like food and medicine.

This will undoubtedly add to the stress they are experiencing and has the potential to impact negatively on their ability to stay fit and well.

**1 IN 5 YOUNG CARERS AND
1 IN 4 YOUNG ADULT
CARERS WOULD LIKE
SUPPORT TO HELP THEM
STAY HEALTHY.**

**“[coronavirus has]
made life harder to
access food,
especially on a
budget. We have had
to adjust what we buy
to get essentials”**

Young carer, 14

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Almost half (48%) of young adult carers report that they are spending more money. Although it is unclear what they are spending money on, given that young people living in poverty are more likely to have caring responsibilities, this additional spend may not be affordable for some.

"I can't even care for myself anymore"

Young adult carer, 18

"I've been feeling like I haven't been able to speak to anyone, like I'm trapped. "

Young carer, 13

"[I am] Having to spend more money to travel to and from the person I care for"

Young adult carer, 18



BREAKS, INFORMATION AND SUPPORT

1 in 5 young carers and 1 in 3 (31%) young adult carers are currently unable to take any break from their caring role.

A lack of respite is inevitably having a significant impact on their mental and physical health and wellbeing.

We know that breaks can be very beneficial for young and young adult carers, giving them time to recharge and do things they enjoy.

15% of young carers and 16% of young adult carers have made clear that spending time away from the person they care for has helped them to be able to cope during lockdown.

**“Feels never ending
I’m getting angry all
the time with the
person I care for
although they haven’t
done anything
because I feel so on
edge unable to have a
break or get away”**

Young adult carer, 21

**19% OF YOUNG CARERS AND 24% OF YOUNG ADULT CARERS
WOULD LIKE SUPPORT TO BE ABLE TO TAKE A BREAK**

**“I feel trapped at home. I feel overly stressed
and drained because the person I care for needs
to be cared for all day. (Huntington’s disease)
Before Covid, I went to school and could go
places with friends. Now I feel like I’m stuck at
home”**

Young adult carer, 17

Just 3% of young carers and 1% of young adult carers receive help in the home from a paid care worker or personal assistant although more have described needing support in the home.

Without access to additional support young and young adult carers face greater caring responsibilities with fewer opportunities for respite and time and space to do other things that matter to them.

Despite the impact social distancing measures have had on the ability of services to work directly with young and young adult carers, 69% of young carers and 54% of young adult carers who accessed services before the pandemic continue to receive the support they need from them.

It is important that more young and young adult carers are given the right information at the right time about the support services available to them.

9% OF YOUNG CARERS AND 14% OF YOUNG ADULT CARERS WOULD LIKE TO BE ABLE TO ACCESS SUPPORT FROM THEIR PEERS THROUGH THINGS LIKE ONLINE FORUMS BUT DON'T CURRENTLY.

"It is difficult, my dad doesn't have a physical condition like some others. However he is Bipolar and this can be extremely stressful to deal with, not know what mood he's going to get in and whether my mother can take any more of it. I love him, but since lockdown I haven't really had any breaks from his dramatic mood changes"

Young carer, 17



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**6% OF YOUNG CARERS AND 12% OF YOUNG ADULT CARERS
WOULD LIKE MORE HELP TO PLAN FOR EMERGENCIES**

“Less available care staff from care companies to provide cover, No chance of placing person I care for into a respite setting due to Coronavirus as people in care homes are more exposed to catching it., Feeling of being trapped”

Young adult carer, 25

**45% OF YOUNG CARERS AND 35% OF
YOUNG ADULT CARERS WOULD
VALUE IDEAS FOR THINGS TO DO
WHILST AT HOME.**

“The amount of Carers my grandfather get have been reduced. I am now expected to feed my grandfather and give certain medications due to his calls being cut”

Young adult carer, 21

“It has given me a higher amount of responsibility as I have to care for someone who is extremely vulnerable during this time as their usual carers do not come as frequently as they used to. I'm a lot more stressed but I am getting help”

Young carer, 17

FRIENDSHIPS AND CONNECTEDNESS

Maintaining friendships is a challenge for young and young adult carers with almost 2 in 3 (65%) now less able to stay in touch with friends. This has contributed to many feeling lonely and isolated.

Alongside concerns about friendships, a significant number of young and young adult carers describe feeling disconnected within their communities.

**66% OF YOUNG CARERS AND
61% OF YOUNG ADULT CARERS
SAY THEY FEEL LESS
CONNECTED TO OTHERS THAN
THEY DID BEFORE THE
PANDEMIC**

**"I have lost contact
with my friends and
I have lost
confidence in
myself. My overall
motivation is very
low"**

Young carer, 12



One positive aspect of lockdown has been that 39% of young carers and 28% of young adult carers have built a closer relationship with the person they care for.

"I've become closer to the person I care for. It has helped increase my relationship with my siblings as we now play games together as a family"

Young carer, 16



"I'm closer to my parents, we laugh more"

Young carer, 15

"I feel completely isolated and just left to my own devices. Before I could at least ask a neighbour to be on call while I went out but now no one will come near the house"

Young adult carer, 20

JOIN THE CONVERSATION



#SupportNotSympathy

We would like to thank the 366 young and young adult carers who gave their time to complete our survey, our amazing Youth Council who have guided our work and the dedicated young and young adult carers support workers within our Network Partners who continue to provide invaluable support.

Thanks also go to Welsh Government, Sally Holland (Children's Commissioner for Wales), local authorities, local health boards, education consortia, research bodies and third sector organisations who supported so many young carers to have their say.

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