2020 VISION: HEAR ME, SEE ME, SUPPORT ME AND DON’T FORGET ME.

The impact of Coronavirus on young and young adult carers in Scotland, and what they want you to do next.

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 Scotland.

“I have no help or support whatsoever now - I’m caring 24/7 and I’m exhausted and mentally drained. My young carers service is closing before lockdown ends so I now won’t have any support and I don’t know how I’m going to cope”

Young adult carer, 22
In June 2020 Carers Trust Scotland surveyed 214 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 and young adult carers services
- More help to balance caring, education and employment
- Support to stay fit and healthy.

Young and young adult carers across Scotland have consistently called for better support to enable them to live happy, healthy, fulfilling lives. This research demonstrates the need, now more than ever, to listen to and act on their call.
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.

“I am not able to have time to myself other than before the person I care for gets up, before coronavirus I got my break at school and then I would get to see my friends. I feel extremely isolated even though I am living with others”

Young carer, 17

Building on this research, Carers Trust Scotland will continue to work with young and young adult carers, carer services, 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 ambitious team to discuss how you can join us in making a difference by emailing scotland@carers.org

Or join in the conversation online #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.

“I am incredibly concerned for the person I care for and I feel incredibly overwhelmed with everything. I now face more pressure with greater care commitments, difficulty in getting food, fears I could make the person I care for very unwell, fearing for my own health and theirs, lacking food, lacking money (reduced hours due to Covid) and I’m also not eligible for any benefits due to being in full time education. My mental health is suffering greatly and I have no support, alongside no escape”

Young adult carer, 22
“It has made my caring role more pronounced/taken away other outlets of my life such as study. It has made me feel more isolated from my friends who don't have caring responsibilities”

Young adult carer, 24

1 in 10 young and young adult carers have seen their caring role increase by 30 hours a week or more

24% of young carers and 34% of young adult carers care for more people than they did before the pandemic
45% of young carers and more than 2 in 3 (68%) of young adult carers say their mental health is worse than it was before the pandemic began.

40% of young carers and 56% 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’m stressed with having to care and take care of myself as well as struggling to sleep”

Young carer, 17

“Has made me more anxious, lost, unconnected, unsure and very sad that we can’t hug our dad, nanna, aunts/uncles, cousins and friends. Future so uncertain “

Young carer, 15

“I fell more lonely and isolated than I ever have “

Young adult carer, 21
Despite their emotional and mental health needs, 33% of young carers and 37% of young adult carers are struggling to access any emotional support. 32% of young carers and 50% of young adult carers would like support with their mental health but don’t currently access any.

“Anxiety has dramatically increased and find myself crying at night and don't know why”

Young carer, 15

JUST 4% OF YOUNG CARERS AND 15% OF YOUNG ADULT CARERS CURRENTLY ACCESS REMOTE COUNSELLING OR THERAPIES
Despite the pressures they face, young and young adult carers have found things to help them cope. 68% of young adult carers and 63% of young carers describe listening to music as an important coping mechanism for them. Worryingly, 21% of young adult carers are drinking more alcohol and 6% are using illegal drugs to help them cope.

13% of young carers and 26% of young adult carers would like more information and practical advice or tips to help them cope.

“I now spend all day with the person I care for, this is stressful and has a negative impact on my mental health as it makes having dedicated time for school much more difficult. I also am furloughed right now meaning I don’t have work to use as a form if respite”

Young carer, 16

Other coping mechanisms for young and young adult carers

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage of Young Carers</th>
<th>Percentage of Young Adult Carers</th>
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</thead>
<tbody>
<tr>
<td>Talking to friends and family</td>
<td>49%</td>
<td>36%</td>
</tr>
<tr>
<td>Playing computer games</td>
<td>38%</td>
<td>35%</td>
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<tr>
<td>Reading books</td>
<td>24%</td>
<td>24%</td>
</tr>
<tr>
<td>Support from a young carers service (online)</td>
<td>11%</td>
<td>19%</td>
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<tr>
<td>Mindfulness</td>
<td>6%</td>
<td>17%</td>
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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.

“My work from college isn’t getting finished so I hope I still get my next course”

Young carer, 16

“I am a lot more stressed about doing school work and normally the days I do care I don’t have to do a whole day due to school now I’m caring all day and I’m struggling with school work”

Young carer, 12
40% of young adult carers say that their education is suffering, impacting on their hopes and opportunities for the future.

However 17% of young and 23% of young adult carers say that studying has helped them to cope.

11% of young carers also describe that support from school or an individual teacher has helped them to cope with life since the pandemic.

Some young adult carers who had lived away for education moved back to the family home as a result of lockdown to provide unpaid care.

“I was already finding it hard to do school work but I no longer have a device to do my work on as mine has broken”

Young carer, 12

“I moved away for university and had to move back due to lockdown. Trying to finish assignments and do the caring role that was usually done by carers that came in is very difficult”

Young adult carer, 22

35% of young carers and 28% of young adult carers have learnt a new skill, such as cooking, during this time.
35% 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 59% 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.

40% of young adult carers and 46% 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.

14% of young carers and 18% 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.

25% of young carers and 40% of young adult carers would like support to help them stay healthy.

“I can’t get out of the house for a day and we can’t afford to do or get anything. We are just getting by with only making 80% of our wages. It’s a lot harder to keep on top of the rent and we spend more money on alcohol and cigarettes which makes it harder to afford electricity and some foods. It’s harder to eat fresh and healthy because we can’t afford it at the moment. I have gained a lot of weight since lockdown and it really affects my mental health”

Young adult carer, 19
51% 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 worry about money and if we can pay the bills. I am fine about school work, and I love being home with my family. But I worry can we afford things we need”

Young carer, 12

“It's hard to care for someone when I can't even care for myself”

Young carer, 17
25% of young carers and 42% of 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.

17% of young carers and 21% 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.

“Coronavirus has made it harder to get a break from my caring role and has made me feel more unsafe at home”

Young carer, 14

“Has been more stressful and can’t get a break as we are shielding. I also have very little access to digital equipment to be able to stay in touch with friends and keep up with school work”

Young carer, 15

32% of young carers and 33% of young adult carers would like support to be able to take a break

“It makes you very isolated mentally. Support you used to be able to get from family and friends suddenly stops as no one can come and step in to give you a break as they’re not allowed near you or even in the house”

Young adult carer, 20
Just 1% of young and 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, 74% of young carers and 67% 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.

“Since the pandemic started and lockdown began, my time caring has doubled since the time where I would have been at work is now spent caring so my mum can work. The lockdown has made the person I care for more agitated and he has had more meltdowns since it started which have been extremely stressful to deal with. He has no services at the moment so my mum and I can’t get a break”

Young adult carer, 22

15% of young carers and 23% of young adult carers would like to be able to access support from their peers through things like online forums but don’t currently.
11% of young carers and 21% of young adult carers would like more help to plan for emergencies.

“It’s made it harder. I don’t get any respite, no time away or family support”

Young carer, 12

“Made things harder, as we never get a break from each other but I can’t leave because I need to care for my mum”

Young adult carer, 19

48% of young carers and 46% of young adult carers would value ideas for things to do whilst at home.

“I’m more stressed and anxious and I just feel like I need a break”

Young adult carer, 20
Maintaining friendships is a challenge with 69% of young carers and 76% of young adult carers 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.

“It’s made my life become very isolated and unenjoyable”

Young adult carer, 18

“No seeing my friends has been hard as was a good way to switch off”

Young carer, 13
One positive aspect of lockdown has been that 42% of young carers and 29% of young adult carers have built a closer relationship with the person they care for.

“It has made me closer to the person I care for, and it has made me realise that we shouldn’t take what we have for granted”

Young carer, 16

“The person I care for has seen the biggest improvement in their mental health that I’ve ever seen due to lockdown and stressful work slowing down and this has relieved my duties by a huge number of hours, they now feel able to help with housework and we have a better relationship in general at the moment”

Young carer, 17

“Made me think more about family and to spend more time with the people you love”

Young adult carer, 22
We would like to thank the 214 young and young adult carers who gave their time to complete our survey, our amazing Young Adult Carer Advisory Group and Members of the Scottish Youth Parliament who have guided our work, and the dedicated young and young adult carers services across Scotland who continue to provide invaluable support.

Thanks also to Scottish Government, National Carer Organisations, local authorities, local health boards, our strategic education partners and third sector organisations who supported so many young carers to have their say.