

COVID-19 Guide for Carers

Lifeworks Leaflet

Introduction

- COVID-19 has a disproportionate and often devastating impact on autistic people and their families (autism.org.uk)
- 9 in 10 autistic people have been worried about their mental health during lockdown and 85% said their anxiety levels got worse (autism.org.uk)
- 1 in 5 family members responding to a survey had to reduce work due to caring responsibilities (autism.org.uk)
- 7 in 10 parents say their child has had difficulty understanding or completing schoolwork and around half said their child's academic progress was suffering (autism.org.uk)

Aims of the leaflet:

This leaflet is aimed at carers of people who have autism and/or ADHD, whether that is paid professional care of patients, or if it is informal care, where you are caring for a family member or a friend. We hope this leaflet will be able to provide you yourself with support whilst you are busy supporting others. We hope to give you guidance, and to ensure you that you are not alone! Many carers across the UK have struggled to find a balance, particularly during the pandemic, of looking after their persons needs, and looking after their own needs too.

How has it affected the person you care for:

- They may disagree or not understand the rules of current lockdown, which can make adhering to social distancing rules more difficult for you as a caregiver.
- Feeling stress and anxious about how the world has changed, and this may lead to your persons mental health deteriorating.

- No privacy on personal matters and worried about coping with family tension.
- Having anxiety about the vaccine.
- Feeling isolated as they can't see their friends or other family members.
- Troubles with a lack of routine as lockdown takes place, which can also lead to troubles sleeping.
- On the other hand, they may feel quite at ease with a lockdown, and it may suit them – but it is important for them to still try to keep to normality and not regress.

How might it have affected you:

- No privacy on personal matters, worried about coping with family tension, and talking about issues may become difficult if you can't leave the house.
- Having anxiety about the vaccine, especially regarding how soon it will be for carers to receive it.
- Worry of getting ill and unable to take care of loved ones.

- Worry about the difficulty of accessing healthcare services, with appointments being cancelled or rescheduled.
- Some healthcare staff might not be very knowledgeable about autism and ADHD, so it can feel difficult to communicate with them, or feel that they understand.
- Current patients with autism and ADHD may feel forgotten, as the pandemic has shifted to become the priority.
- Feeling isolated from friends and family, and those who may normally support you, as well as the person you care for.

Support and Guidance:

Emotional and social support:

- Feeling isolated has been a common emotion for us all in this pandemic, but it's important to know that if you want to talk to someone, there is always someone you can turn to. Lifeworks holds weekly carers support groups, where carers join Zoom calls, and talk about anything and everything.

The meetings are confidential and private, and they are always welcoming and friendly. This is a great way to talk about how the pandemic has affected you and the person you care for, as well as gaining helpful advice from people who may be in very similar situations to you.

- Further to this, meeting friends outdoors, whether it's for a socially distanced walk in the park or to grab a takeaway coffee together, can really help. This is a COVID-19 friendly way of meeting friends and family, but also ensures that you can leave the house for a few hours and get some much-needed fresh air! Lifeworks offers a service, friends to walk with – like Sue.
- Exercising a couple of times a week is also an excellent way to relieve any stress you may have and has been shown to have a huge impact on mental health.
- Formulating a well-being action plan can also be beneficial and can involve planning times in

the day for you to do an activity you enjoy, and taking time for yourself, away from news and social media, to help reduce stress. [Carers UK]

Physical:

– Keeping active and well can really help to apply some routine to your day, as well as releasing some endorphins to make you feel less stressed. You can even implement nature into your exercise by going for walks around your local park. Yoga and other classes may be free and available to view online as a live exercise class during the pandemic, ensuring you can still keep fit, or even try something new while you are indoors.

Economic:

– One key way if you need economic assistance is to check your eligibility for Carers Allowance. If you care for someone over 35 hours a week, no matter their relation (and even if it is remotely during the pandemic) you could be eligible for up to £67.50 per week, which can help provide vital care for the person you care for. There are also Personal Independence Payments

(PIPs) which can help financially support people with long term disabilities and illnesses, and this does include autism. This can be important as not everyone knows whether they are eligible for this, so it could be very beneficial to check!

Practical:

– Some practical aspects that might be important, especially during the pandemic, include gaining access to personal protective equipment (PPE) if you are a carer for more than one person, or if the person you care for does not live with you. The Carers UK website has a step by step guide on how to arrange this, to ensure that you and those around you remain safe. Locally, North Staffs Carers support those you care for, and can help in arranging a Personal Assistant to care for the person for a few hours a week, which can be really helpful for giving carers time to do something they enjoy, and give them some much earned rest. Also, carers are eligible for the Covid vaccine so please feel free to book your vaccination appointments!

What Carers themselves say:

- One carers advice was “to be kind to yourself”. Many parents/carers may feel guilt, or blame themselves for their child being neurodiverse, but it’s important to be kind, and know that just because a person may not be ‘normal’ this is not a bad thing!
- Carer 1: It has and is very difficult and stressful some days especially. One thing that really helped was talking to Louise. She listened, gave reassurance and advice. It has been a real lifeline. We have James his personal assistant to take our son out for a walk and pick up takeaways. We have been in a care bubble with our grandchildren which also helped. Keeping ourselves calm and a sense of humour as much as possible are important. Our son has been watching Bond films over and over and enjoying them, which I think it is important to understand and accept these things. His sleep

patterns have been a bit crazy, but he does not worry about it, so I am being relax about it and it seems to help. It is good for him that he enjoys talking to people from all over the world late at night and it is important to have some time on his own. He bangs the wall with his fist when he gets angry, but we try and encourage him to hit something soft instead. Music can be a very good influence as well. Keying into interests is so important and feeling valued, our son has put some old slides and photographs on to the storage for us which is great. Many thanks to LifeWorks!

- Carer 2: Sue has helped me during the lockdown when nothing or no one else did. Sat in floods of tears as only other parents of autistics know.
- Carer 3: I have been supporting other carers as a volunteer for Lifeworks. Supporting them helps support me and makes me feel useful. My son has direct payments via adult social

care to pay for a personal assistant who takes him out for a walk, shopping or before lockdown to a pub or café. Without this it would be something else I would have to do. I also take part in meetings within the NHS helping to put forward the needs of people on autistic spectrum and their families. Recently I am being part of a regional expert by experience, autism meetings on Teams. My son has a community psychiatric nurse who listens, doesn't judge or talk down to him. He also has a psychiatrist who understands autistic spectrum conditions and is totally on his wavelength. I am lucky to have good health so I can go out and do my own shopping. I visit garden centres, look at plants, walk, watch birds and scenery and enjoy the nature. I also watch TV drama series and reading. Gardening and growing plants and vegetables during summer and is very relaxing. My daughter may not

understand her brother keeps in touch and is part of our bubble.

- Carer 4: Things that have supported me during lockdown include watching YouTube channels, going onto Facebook or social media with friends, watching The Watches TV series, walking with kids or alone, having Zoom meeting with friends and Lifeworks or calling mum and dad. I also have support from school with my sons' work. I also have birdwatching, ordering food online and having Amazon delivery.

Resources:

Lifeworks Staffordshire is available to contact, whether it's for a one-to-one meeting, or to join the Carer Support Group. Messages are picked up and dealt with as soon as possible.

Contact: 07182 615222 or 07401811582, 07450002289

email:

info@lifeworksstaffordshire.org.uk.

North Staffs Carers also provide support for carers which is now run online, and can be contacted on:

[01782 793100](tel:01782793100)

<https://www.carersuk.org/help-and-advice/coronavirus-covid-19/coronavirus-covid-19>

<https://www.mentalhealth.org.uk/coronavirus/mental-health-tips>

<https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care/guidance-for-those-who-provide-unpaid-care-to-friends-or-family>

<https://www.autism.org.uk/what-we-do/news/coronavirus-report>