



Myth-busting and survival guide to the Covid-19 pandemic: lived experiences of young adults identifying as autistic or neurodiverse



The purpose of this document is to describe some of the responses of young adults identifying as autistic or neurodiverse during the Covid-19 pandemic. The hope is to share this with others to help them understand more about the lived experience of autistic and neurodiverse people in this situation and to share their skills and ideas for coping with others who may be experiencing some of the same things.

The idea for this document came out of conversations with a young person in the UK who was finding life during the lockdown very difficult and feeling that others did not always understand the specific challenges they were facing. We decided that it might be helpful to investigate this further in an interview to find out more about the effects of Covid-19 and the lockdown but also to explore their responses and ideas for survival. The young person helped to design the interview guide and after being interviewed themselves went on to interview a friend who also identified as autistic.

These were feeling like pretty fruitful conversations so we decided to roll out the interview to a few other young people we knew and create a collective document. We shared the interview questions with the young people who had agreed to take part beforehand so they could do some preparation in advance if they wanted to. Personal and identifiable information were removed from the shared document and then a draft was sent to everyone involved to make changes or additions and everyone knew they could change their mind and have their responses removed if they wanted before it was shared more widely.

Hopes for taking part

"I want more people to know about what it's like when you have autism and you go through these circumstances and for people to have an increased understanding. If something like this happens in the future, there will be more support and the world will know how to deal with it."

"Showing other people how different people are coping with lockdown. To share some of my own ideas to other people."

"I hope it helps some people and I'm also incredibly bored! It's a nice way to change things up. I'm also interested in the paper to pick up any tips which I hadn't used myself."

"I guess to share my experiences in case it helps anyone else. It has been a crazy time so we have had to adapt to a lot of changes quite quickly which I know can be quite difficult for autistic people so if my experiences can provide some guidance for people then I guess that is a positive."

"It's important that people struggle less so if it happens again I may not find it so hard. I care and value always trying to do my best so if people have an increased understanding of autism I'll be in a better position to achieve that."

"I'm missing friends and my grandparents and I'd like people to know that's one of the ways this has impacted on me."

"I like to think I'm a nice guy, I'm always willing to lend a hand to people who need it. Interviews are my favourite way of lending a hand. I like clearing up a lot of the misconceptions which have been floating around. Like all autistic people are like Rain Man."

"I like underrepresented populations to be given a voice. And if I have that opportunity then it's wrong for me to turn it down. I like helping people I guess, and this is a direct way of helping people."

"I think because I was only diagnosed a couple of years ago, I didn't really feel like it was necessary to speak up but now I know how much one person's voice can help people so I like to participate in as much as I can. Not that I wasn't always helpful but now I feel like what I say can have a positive impact on other people."

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The effects of the pandemic on our lives

"The drastic change in routine. So, from having a very structured life to it completely falling apart within the space of two weeks."

"It's made me realise how much of a busy life I lead and that even though I have autism I still manage to do it."

"Even though I'm often described as 'high-functioning' one thing people don't realise is even though you look like you're coping, when you have autism and you're described as high functioning you still need support. It's above what the average person would need."

"I've been missing my regular activities that help me to manage stress such as wheelchair basketball, being a brownie leader and going to drama club."

"I'm struggling with stress a bit which makes me go into my head quite a lot and over-think things. It drives me mad because my head keeps going and going. I've got strategies for managing it but they don't always work."

"It has made my plans to move on with my life in terms of looking for a new job and moving home more difficult."

"My experiences with the virus itself have been difficult including the fatigue and irritated throat. It has gone on for a long time but I have been able to get through it and I am now hoping the virus will stay away this time."

"Being locked in has meant being unable to go out which is like when I have been unable to go out due to anxiety but government mandated instead."

"When the virus started going down before the next wave came on there was always a period of stir craziness and cabin fever when I was not able to go out because I was waiting out the mandatory quarantine time."

"I have had to create a new routine which was difficult at first but now I am back in the swing of things, I am ok. I have had to be a bit more spontaneous with my work schedule so if I wasn't feeling well during the day, I could just take half an hour off and go cool down for a bit and then come back which would have been a bit hard working in the office."

"I think something that I'm still working on is remembering to take care of my needs outside of my little bubble as I am now spending loads more time on my special interests and sometimes forget to eat, taking medication and showering and leaving the house."



Some of the effects on our relationships

"Not being able to have the social contact that makes me feel reassured. I just miss seeing people."

"I'm missing my grandma. I've been in touch with my cousins more in America online on facetime. They are usually too busy with uni so there's been more time to be in touch."

"I miss my friends so much because we are very close. And I almost see one of my friend's half of the week because we study together and it's just routine. It's really hard when you don't have that routine."

"The thing that's really kept me going is seeing my boyfriend. He's the only person outside the house who I've seen regularly. If I didn't have that I'd be so much worse than I am now."

"If anything my relationships have gotten better with people as they've also been indoors so they've been more available. Easier to schedule things. Before I felt out of things because people have got their own lives. With everyone being in the same place at the same time it's been easier. People have more time."

"I've had to comfort quite a lot of people who were worried about the virus and the panic that came with it."

"It's been overwhelming as everyone now is talking online and it creates loads of notifications which can overwhelm me really easily. I think I have learnt how to switch off notifications after a while. I think it has taken a couple of months but now I am starting to miss hugs as that is my main way of showing affection. I couldn't do that for my grandad who lost his wife."

WHEN IS THE END? #COVID19

Some of the effects on our families

"Things were tough for my family when my uncle passed away from covid 19 early on. It was mostly helping them out but also they were worried about me because I had it too but I knew that for me it was just going to be flu-like because of my age. But because especially back then there were so many unknowns I had to tell a lot of people that I was fine. Living on my own far away from everyone didn't help matters. After a while things had calmed down a bit and things are more stable now."

"With my family, things are the same. Things are mostly the same except my older sister can't attend my grans funeral. We are quite an affectionate family so that has been hard for all of us."



Some of the effects on our communities

"Everything stopped and I can't wait to get back to it. People who've known me for a long time and understand me."

"People's panic has done more damage than the virus because all you had to do was the right thing. Staying in, not bulk buying. I got lucky with the toilet paper, I managed to get some before the panic buying purely by chance."

"I was very mad about people bulk buying and over-reacting, treating it like the end of the world. But that's because they were being unnecessarily selfish. Especially flour. At least eggs are available now. I've had to ration my flour so can't make as many pancakes as I'd like."

"I live in a small village with lots of old people, so people are shopping for neighbours and getting prescriptions which, I think is really nice."

"Waiting in line to get in the shops. I hate waiting!"

"I got lucky with the toilet paper, I managed to get some before the panic buying purely by chance!"



Some of the most difficult effects for us

"Worrying I'm going to get it and worrying if my dad's going to get it because he's shielding. I love him and I want him to stay safe. Also missing all my activities."

"Managing my anxiety because autism really affects anxiety a lot in the way you ruminate a lot more and become fixated on it. It becomes out of control very quickly. Things can escalate really quickly. In my life usually I'd be really busy, having routines seeing friends and my support structure which means there's less time for my head to get out of control!"

"My experience of the virus was that it came in waves like the flu. Before the fever came, I had to deal with depression relapse which for the first time I didn't realise it was connected to the virus. I had no idea what was going on or that it was even a symptom so it caught me with my guard down multiple times. One thing that got me was how quickly it came on as you go through the depressed phase to fever and fatigues in the space of about an hour or two. I've never had anything that worked that quick! Also just the sheer tiredness, The throat irritation is the scariest because I was genuinely worried that something would happen while I was asleep. It also made it very difficult to get to sleep. No matter how much water I drank I would still be thirsty and it kept me awake at night. Luckily I only had to deal with it for a few days unlike the fatigue which was the most damaging as the fatigue lasted a long time so I've needed to sleep the whole time. Staying up for more than three hours was very difficult so trying to maintain a semi-normal sleep schedule was pretty tough."

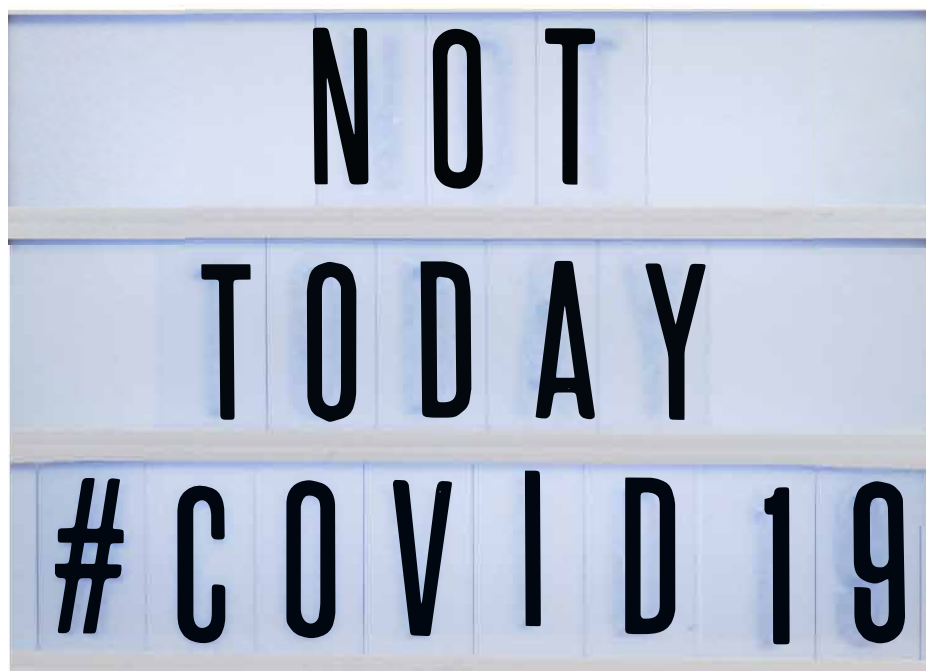
"Change in routine. Given the slightest change in routine has messed up my sleeping, eating and I think I have forgot to take my meds four times in a week so that's been difficult."

"Rationing out food has been tough but it's gotten easier now that supplies are available again. Luckily I live on my own so I didn't need to ration the toilet paper!"



Our stories of survival and resistance in front of Covid-19

"I tried to think what it was like when I was carrying out my normal life and the key interactions with my friends and my tutor. The times when I was really happy and laughing."



What's kept us going

"When the government says 3 weeks more lockdown I have that date in my head – let's just get to that."

"I've been texting, face-timing and emailing and using messenger to keep in touch with people and groups."

"Keeping busy doing art, writing, dancing and some college work. Staying in touch with people has helped. Long phone calls with friends. Using meditation app to calm down. Watching lots of old films like Charlie's Angels and James Bond, I like mystery and action movies."

"I'm getting on with my academic work because I know after this I'll still have my masters degree and I want to do the best that I can do."

"Lots of video calls. My workplace is very caring and we have weekly social activities online. I have been able to volunteer online for research studies which has been quite enjoyable."

"Being self-compassionate that this is a global crisis and I am doing the best I can with what we got."

"Remembering past times playing basketball and looking forward to future times. I think about my drama sessions with my friends. I think about brownies, try to remember all my activities that I enjoy."

"I tried to think that it's not always going to be like this, we will get through it."

"Sleeping and gaming. Gaming keeps the mind sharp. When the fatigue is on I just sleep through it."

"Lots of complicated video games like Europa Universalis IV. A game so complicated people 500 hours into will still consider themselves beginners."

"I kept my mind in the present and focused on getting better as dwelling on the past and future doesn't really help me right now."



What we look forward to

"Going out for curry with my uncle and grandma. Chicken Korma."



"Knowing I'm going to be able to go back to things at some point."

"Getting a job. Meeting new people. Earning some money."

"I am looking forward to doing further academic training in my field. I'd also like to get off my antidepressants and have a family."

"I still want to move to the US, Australia or Canada. Also to find a job which doesn't hurt my soul. While this has slowed it down a little it won't stop it. All I have to do is work a bit harder to find the opportunities."

"Going back to work and seeing all the things on my daily commute that I didn't think I would miss like seeing as many people at the train station or my desk in the corner of the office and going out for lunch with my friends."

"Probably the smells of the office. I am really sensitive to smell, and I can tell who is in the office before I walk in so I am trying to remember those old scents and knowing that it is going to be a big reunion when we all get out."

"I'm looking forward to finding a new job where people accept me for who I am and while it's a bit of a set back everyone is set back and I imagine that everyone else is in the same boat and hopefully I'll find something soon."

"I think that people can see that working from home is possible and actually works well for a lot of people. I think that people realise that a big sudden change was hard for them to cope with overnight and we deal with that every day."



"Probably the smells of the office. I am really sensitive to smell, and I can tell who is in the office before I walk in so I am trying to remember those old scents and knowing that it is going to be a big reunion when we all get out. "

Who has helped us most



"My tutor . . . she knows that I'm really strong and determined and I've got a fire in my belly. A fire that never really goes out."

"My support network understanding how hard it is for me. For them to acknowledge that I will find it hard reassures me that I am allowed to find it harder than other people."

"Probably my boss and my supervisor who just check in at the end of the day just for a quick convo."

"My mum and dad have helped by noticing when I'm stressed by bringing me back to earth or the present. My PA who comes twice a week to help me with washing, college work, cooking, learning independence skills."

"My previous therapist helped me learn some tools to help with stress which I've been using."

"Close friends have helped when the mood has got a bit low. My mum who has also kindly helped provide financial assistance while also lending a sympathetic ear. As much as I enjoy my self-sufficiency there is only so much you can deal with on your own."

"I've always had a small group of friends they are important to me. I've been playing basketball for 11 years. I've been involved in girl guiding since I was 5 or 6 and I've progressed to being a brownie leader in training. I've been doing drama since I was five. The friends there know me and understand me. I'm still zooming with drama group."

Our Survival Tips

"Talk to people and get help if you need it."

"Create a routine really quickly. If you're stuck in the house, create different spaces for different things so I've split my desk in half and one is work and one is play."

"Open the window for fresh air because it is really easy just to create a little safety bubble. It's worth doing."

"Try and keep as much contact as you can with your support network."

"Even though it might be really hard try and get dressed in the morning but don't push yourself too hard, be realistic."

"Take time to think about how much you have achieved in your life. Autistic people learn resilience because if you've got through all of that you can get through this."

"Sleep through it when you can. Play a very low maintenance game like pokemon when you're dealing with the fatigue and you want a nice distraction until you can get back to sleep again."

"Make sure you have enough food. Don't panic buy it makes things worse for everyone. Tough it out and you'll be fine."

"Hot chocolate with marshmallows is really good."

"Keep doing the things that mean the most to you."



Acknowledgments

We would like to take this opportunity to thank those young people who helped to create this document.

We would also welcome any responses and additions from other young people which we will pass onto those involved.

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