



Coping with unexpected change

Coronavirus has caused huge change and uncertainty, which we were unable to prepare for. Our Helpline Adviser **Dani** offers some guidance on how to create structure when a person isn't fully able to prepare for change, and outlines ways of managing anxiety during these times

Many autistic people find that coping with change can cause a lot of stress and anxiety. Much of the advice people receive around this involves doing advance preparation. This can be really helpful, but is not always possible. So, what can you do when a change is unexpected?

Find the similarities

When unexpected change happens, it is

easy to feel like everything is different and overwhelmingly uncertain. A good activity if this is how you are feeling can be to make a list of the key points that are not changing in your life. This could be family members, the people you can talk to, or elements of your daily routine that can stay the same. You could even think about your favourite things, which may not have changed. For example, TV shows or films you enjoy watching, games you like to play, or music to which you enjoy listening.

Adding perspective

Once the change has happened, it can be helpful to identify what coping strategies can be used to manage anxiety. You can consider whether you have been in a similar situation before – not necessarily the same

event, but something that made you feel the same way. Try to remember what was helpful then, and see if it would be relevant and useful to try doing that again.

You might also want to rate your anxiety or negative feelings on a scale of 1-10, with 10 being the highest level of anxiety or stress you could imagine being at, and one being totally relaxed. If you can place yourself somewhere in that range, ask yourself what you need to do to help you move to the next number down. For example, if you place your anxiety at seven, it may not be realistic to jump straight from there to a one or a two. Instead, ignore the lower numbers for the moment and just focus on moving down to a six. From there, you can repeat this to continue moving down the steps.

It could be valuable to write down your solutions somewhere you can access them quickly, because it is easy to forget what you were planning at the point of feeling very anxious. Some people find it helpful to stick a message on their fridge, or write a note in their phone. It may be beneficial to keep this note updated as you find new strategies that were particularly rewarding, or make notes on what hasn't worked and why.

Focus on what you can control

It may be worthwhile to identify whether or not what is going on is within your control. It can be easy to feel anxious about things that are not within your control, and there is no magic answer to stopping negative thoughts about these things. Some people find it useful to identify what is within their control in the situation and focus on creating methods to cope with those elements. What is going on in the wider world is often outside of our control, so it can be more effective to think about what is going on in your immediate environment.

For example, the layout and changes made at supermarkets have been stressful for many people in recent months. While

Tracy's story



"I have a fantastic, bright boy; he's 15 and in the top set in every subject at school. He is also a talented musician, who plays four instruments.

My son has Asperger syndrome. Life was very difficult when he was younger, but with patience and a supportive school, he was quite settled.

That was until the day schools were told to close. My son's world fell apart. He couldn't cope, and it didn't make any difference what we said or did. He had meltdown upon meltdown. He couldn't eat; he and I sat up at night, maybe getting two hours' sleep. He wouldn't engage with anything. The most distressing thing was that he couldn't understand why he felt like this, and kept saying so. He usually has some brilliant coping strategies that we've worked on for years.

Eventually, I got him to engage with some of his teachers online and participate in lessons. At week four, I persuaded him to come on a bike ride. It's the one activity he loves to do outside - it helps him relax. This became part of the daily routine. After six weeks, he began to have some music lessons online, which gave him a bit of focus to practise between lessons. Although he still wasn't sleeping or eating much, we managed to get a bit of routine established.

Now, he gets up and does his school lessons, and will practise his instruments. He eats at the same time every day. That is all he can cope with; any suggestions of change or the possibility of going back to school are too much for him.

My son is exceptionally clever at schoolwork. People have said I just need to make him do things because he's bright enough to understand. They don't get that it's nothing to do with being bright; it's the ability to cope with change and the unknown. Our family's bubble burst on the day of lockdown. It has made me realise how brilliantly he does normally, but that he will always need support and a routine."

you may not be able to control whether the supermarket is changing and how people get around (one-way systems, closing certain areas), it may be helpful to identify what you can do. Can you contact your local supermarket, or check their website and social media accounts, for a description of what they have put in place? Can you call them before you leave home, to check what the queues are like? Is there a better time of day that you could go?

You will have been spending more time at home lately. Although you may not be able to control this, are there things within your control that can be put in place to manage this? For example, you can make conscious choices about your environment and daily schedule, all of which can give you a stronger feeling of managing the situation.

Manage input

It may also be valuable to limit the input you receive about things that are out of your control or causing anxiety. Recently, it has been very easy to spend a lot of time seeing things in the media and talking to other people about COVID-19. While it can be very helpful to keep up to date with changes, it is not always beneficial to make this a central focus. For many people, this information makes them feel very anxious, and managing how much time is spent focusing on this can be tricky, but powerful.

If you find that reading all of this information makes you feel very anxious, it may be worthwhile to 'switch off' from this kind of input for a while. Some people find that allocating a small, set amount of time each day – or every few days – to look at the updates and keep on top of them can be helpful.

If you know that this kind of input makes you feel anxious, you could choose to arrange a calming activity from your coping methods to use immediately afterwards.

Further support

It's completely natural to feel anxious when big changes happen, and that anxiety can



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be even worse when it's something we didn't expect. If you are feeling extremely worried, and it is affecting your day-to-day life, it may be worthwhile to speak to someone who can offer more tailored solutions for you. This could be your family and friends, who may know you very well and have some ideas on what works for you. You may also want to consider speaking to your GP, or a counsellor who has experience of working with autistic people, who can help you to identify ways to manage extreme anxiety.



For more information:

Preparing for change: www.autism.org.uk/dealing-with-change

Managing anxiety: www.autism.org.uk/anxiety

Our Online Community: community.autism.org.uk

Brain in Hand: www.autism.org.uk/brain-in-hand

Our autumn appeal focuses on dealing with change and the challenges of coming out of lockdown. Read more at:

www.autism.org.uk/appeal