

# Scottish autism

WHERE AUTISTIC PEOPLE  
ARE VALUED

**Autism Advice Live**  
**Joanna Panese, Practice Development Manager**  
**29 April 2020 at 8pm**

## Question

**Can there be clarity around relaxed rules for autistic people leaving the house? I use a wheelchair and need 2:1 carers when I go out in my car, and this is not allowed at the moment.**

## Answer

For those not aware, the UK and Scottish Governments clarified their position on individuals leaving their home to take exercise. For people with a learning difficulty or with autism they are permitted to leave their home for exercise more than once a day. They can also visit a place to take exercise out with their local community. We are aware that some people have been challenged when doing this and we have now made an alert card which you can carry to help explain why you are leaving the house. You can find more details about the alert card on our [website](#).

In this case, however, the individual is using a wheelchair and requires 2 carers to help them in and out of the car which we have been told is not allowed at the moment. You are permitted to leave the house with your carer and you don't have to observe the social distancing rules with them. You must remain 2 metres away from anyone who is not part of your household, or who is not your carer. You can find more information on these guidelines on the UK Government website.

Make sure you are washing your hands regularly and when you come back into your home. Use a hand gel when you are out, to help stop the spread of infection.

If you are supporting someone to take exercise, you are permitted to do that, as long as you are not displaying any symptoms of covid-19, including a high temperature or a persistent cough. You must ensure no one from your household is showing symptoms either. You must be under 70 years old, not be pregnant or have any underlying health conditions that would make you vulnerable to coronavirus. If you fulfil all these conditions, then you can leave your house to support a vulnerable person. There is lots of guidance you can find, which we have signposted for you on our [website](#).

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### Question

**I'm wondering if you can offer any advice. My 10 year old daughter is becoming more and more withdrawn and angry as lockdown continues. I am struggling to even get her to come outdoors. She has a severe phobia of wasps and bees after accidentally disturbing a wasps nest a few years ago. I am unable to even open windows in the house without her screaming and having a panic attack. Is there anything you could advise on how to help her?**

### Answer

This must be such a difficult situation for the whole family, particularly for this young girl. First and foremost, take things slowly and be kind to yourselves. This is an exceptional situation, and we are now entering week 6 of this situation and our resilience might come under threat from time to time.

She might need an outlet for some of that anger and frustration and you could look at things that might help with that. You could rip up bits of paper or books. A worry box might be helpful. She can write down things that are really worrying her and pop them in the box. Sometimes it helps that they are somewhere else, but it can also be used as a reflective tool to help talk through some of the things that might be worrying her. Try to open up these dialogues to discuss about what is really worrying her and making her feel really anxious, but go at a pace that suits her.

With regards to the phobias around wasps and bees, it is a very common phobia for people to experience. It stems from quite a traumatic experience and your local camhs team can help work through that with her. They are overstretched at the moment, however it is worth asking your GP to make a referral to get the support around that phobia if it is preventing her from leaving the house and enjoying her life.

In the meantime, you could look at some ways of helping her understand her phobia of wasps and bees, and what to do if you see a wasp or bee. Doing some sort of role play around that, for example, if you see a wasp – stop, stand still and walk away calmly. This may take a lot of practice, but sometimes seeing you behave in that way can be a useful way to help someone understand. Sometimes, knowledge about things can be useful, the more we know about something, the less scary they become, so would she like to find out more information about wasps and bees? Bees don't actually want to sting us, if they sting us they die, and sometimes that information can be useful to know. It might just help alleviate some of those fears that she has.

On a more practical note, sometimes putting net coverings over windows can be helpful so that windows can be open but you can see that things can't come in. Try putting something over the window and then inch by inch open the window. Give her the control about doing that, so she decide how much the door or window will be open.

Wearing long sleeved clothing, or long trousers so there is less skin showing might give her a little bit of security knowing that she is protected in that way could help her.

Give gentle encouragement to help her get some fresh air. Go at a pace that suits her, and let her lead the way with it. If she doesn't want to do it, then just leave it and try another day. This might be something that takes a bit of time. A specialist from your cahms team will be able to give you more specialised support, specifically for your child.

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#### Question

**My daughter has two young autistic children and lives alone. The youngest is highly destructive as well as stripping off and removing his nappy then smearing. Today, he broke yet another television and things are getting really difficult for my daughter. I feel she has no support at all at the moment, funds are of course limited also. She has not been outside in weeks and the children are finding lockdown really difficult. She cannot get a minute to herself either. Can you please advise me on what support is available to her here and now?**

#### Answer

We will contact you personally in the next couple of days, to talk about this in more details as there is a lot going on here. We will also offer your daughter the opportunity to speak to one of our advisors to talk about the things she is finding difficult at the moment. We will keep the lines of communication open so that she doesn't feel so alone in this and that she knows she has someone to talk to and we will try to help as best as we can.

In a more general sense, the primary step in this is to try and establish why some of these behaviours might be happening, and to understand them better. Is the stripping and removing the nappy, and smearing, a stress response, or is he enjoying this? Is it a form of sensory play so we would want to learn more about that?

In these sort of circumstance we would always want to know if the little one is feeling well. Sometimes children behave in unexpected ways when they may not be feeling well, so check for temperatures, rashes etc to know what you are dealing with.

Smearing is not unusual; lots of children smear using different materials and textures. He may be enjoying it, he might enjoy the texture, feeling or movement of his body as he smears. It is worth exploring if he is enjoying it, is there other activities he could do that he could smear e.g. shaving foam or paper mache that have a similar texture but are safe, and cause less mess. He could be involved in making paper mache and the other children in the home could help. Shaving foam is a reasonably cheap item you can get from most supermarkets.

On the other side he may find having a soiled nappy extremely uncomfortable against his skin. Or the feeling of the nappy around his waist or his legs might be feeling uncomfortable and the way to alleviate that discomfort is to remove the nappy. It might be worthwhile trying different types of nappies. Sometimes pull ups

can be useful as they are less tight around the tummy and the legs. They can also be a bit more difficult to get off.

Many children do find certain items of clothing uncomfortable; zips, seams, waistbands, elastics, certain textures or cottons, or rough wools can be very uncomfortable and elicit a kind of overwhelming sensory experience. This little one is still quite young, so you are still getting to know him and what he likes and dislikes, so it might be worth trying some different types of clothing to see what he finds comfortable and be led by him.

When we are feeling stressed or anxious, our senses can go into overdrive, and for autistic individuals and autistic children in particular when there's too much information, too much sensory information, and they're struggling to process that all, it can be extremely difficult. This can result in what some people refer to as meltdown or shutdown. In those cases it can result in things getting broken and a difficult situation within the home. It might be worthwhile seeing if there is something that has changed within the home that may be resulting in what you refer to as destructive behavior. Are there people in the home that aren't normally there? Is one of the children normally at school but now at home because the schools are shut? These examples can change routine and lead to the feeling of being overwhelmed. An advisor can talk this through with you to see what might be leading to some of this, and look into some more individualised approaches that might be helpful for you.

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### Question

**How can I create a calm environment for my 11 year old daughter and minimize self-harm? She's autistic and selectively mute. She has always had high anxiety, but since we've been in lockdown it's escalated massively. She's started hitting herself so hard it bruises far more regularly. She's worried about people she knows catching coronavirus, and also when she'll be able to get back to school. She's so panicked by school work online and just mentioning it can cause a meltdown, so we've stopped doing any school work. Now she's worried about falling behind in school work, but doing it is causing such anxiety that it seems better to stop. She doesn't like talking to her friends of FaceTime due to her SM, so is having little contact with others. She can't sleep at night due to panic and feeling sick, unless she's sleeping with mum and listening to her relaxation track. I'm worried about her level of anxiety, and also her falling behind in school work. How can I reduce her anxiety, reassure her, and get her through this strange and difficult time?**

### Answer

This is a very strange and unsettling time for a lot of families and for autistic people. We've been in this situation for a number of weeks now and we don't know how much longer it will continue. That can be very difficult for a lot of families and autistic people too.

For this young girl, it sounds like you are doing a lot of lovely things to support her, cuddling into mum and having that contact with mum. It might be worth looking at

putting more times for her to do that throughout the day, and seeing if that helps reduce her anxiety. It is not unusual for children to want to be with a place of safety when they're feeling that their whole world is upside down and in a state of flux. Spending more time with mum, or someone else that makes her feel safe and using some of those strategies to help her feel relaxed, including listening to her relaxation track, might be helpful to her.

With regards to her communication, having written information or pictures, to take away that expectation that she must or she needs to communicate verbally may help. If verbal communication is not her preferred way of communication, then supporting her to explore other ways she can do that and reassuring her that that is absolutely fine and that people will listen to her and will recognise her voice in the way that she prefers may help her. Sometimes having a digital chat, can be helpful to unlock some of those worries, for her to write things down and for you to write back to her. This may help open up that safe space for her to start communicating what is worrying her.

You mentioned that she is worried about people she knows catching coronavirus. Could you arrange for her to regularly check in with them? If there are specific people she is most worried about, whether it be grandparents or aunts or uncles could she check in with them and get reassurance from them that they're fine? Also look at the ways in which people are protecting themselves from getting coronavirus because having knowledge about a situation can make it less scary.

Accessing online learning is something we are getting a lot of questions about through our advice line at the moment. It's an extremely difficult way for children to learn and some children find it harder than others. Don't worry, we are in exceptional circumstances at the moment and your daughters mental health and wellbeing are far more important at this time that anything else. Go at a pace that suits her, if she has any ideas herself about how she might like to do her work, you could explore that with her. Is it about breaking some of these tasks down into much smaller tasks for her to do? Can she access them in a different way, does it have to be done online? Is it possible for you to have a chat with her teacher, or someone in the school to find another way to access her learning? It's about finding that balance where she feels comfortable. Perhaps she could listen or read a piece of learning, to approach it in a different way. Another idea would be to read a chapter of a book, and then have a chat with someone about it through an email or a message or another way she might prefer. If she is able to do some work, then really celebrate that she's been able to do that, and build up her confidence. Getting the balance right, is really the trick and having a chat with her teacher might be help with that.

Structure to her day might also alleviate some of her anxiety including putting some times in the day where she can use some of her relaxation tools. On top of her current coping strategies including relaxation tapes and time with mum, she could try a rescue box. We have details of what a rescue box looks like in our wellbeing resources on our [website](#). This is a box that may have photographs, pieces of fabric, or anything else that makes her feel better so that when she feels anxious she knows that she can go to her rescue box and find something that might help her.

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### Question

**Since lockdown my child has become increasingly distressed. I am therefore keen to find out what support is available at this time?**

### Answer

This is a common enquiry that we have had over the last few weeks.

A lot of shops or facilities are closed or have amended the way they are operating which can leave parents feeling quite isolated and quite alone. We are currently in unprecedented times, Covid-19 has changed the way we are all living our lives and it is important to keep reaching out to people and to try and build those networks of support.

We've created a number of resources around schooling, well-being, stress and looking after yourself. These are available on our [website](#) and you will find details of these on our resources page.

There's lots of information there to help understand where that stress might be coming from. Our advice line will also be open out with our normal operating hours and will now be open 8am – 8pm, 7 days per week for people to call and discuss individual circumstances. We will endeavour to find ways which you can help reduce some of the stress your child is experiencing. It's also very important to look after yourself in that situation, and we can talk though that with you.

As a parent, you can contact your local carers centre, they are offering online support at this time. They are being creative in what they are offering including virtual support groups that you can join. There is also parent to parent support that you can join in. It is very beneficial to contact your local carers centre to see what support is available in your area.

Within our online resources on our website, you will find information about how this stress can impact on the wider family unit at home and also about where you might find support for yourself and how you can reach out to people to help you navigate your way through.

Stress can present differently for a lot of people and it's a very unique thing to us. It is important to take time to understand what stress and distress looks like for your child and to understand what their stress response looks like; and how best to respond to it. For many autistic children the change in the environment and the fact that we're now all spending the majority of our time at home is really challenging. Some are finding it easier than others, therefore it is important to look at your routines as a family and find something that works for you.

It is important to understand what that stress and distress looks like for your child, and get an understanding of how they are processing the world around them. What is their social imagination like, how are they interacting, and how are they

communicating. You can find lots of resources on our [Right Click programme](#).  
Alongside the programme, you get access to an autism advisor.