



How to talk the children and young people with Autism Spectrum Disorder about COVID-19

Firstly, what qualifies us to give you this advice?

We are a group of Clinical Psychologists. This means we are trained to Doctoral level in Clinical Psychology and are professionally registered with the Health and Care Professions Council. We have years of experience in child and adolescent mental health services and paediatrics and have seen lots of children and young people with Autism Spectrum Disorder.

A note on writing about children and young people with ASD

Obviously Autism Spectrum Disorder is a huge spectrum with many people included, all of whom are individuals. It is therefore difficult to cover everyone with ASD in this guide. We have tried to give generally helpful information but please do not hesitate to get in touch for more individual advice.

Should we talk to children about COVID-19?

Yes. Given the anxiety everyone is feeling about COVID-19, we have been asked whether children should be protected from this and not told about COVID-19 but it is important that we do talk to children and young people about this for a number of reasons:

Firstly, to keep them safe. We need to talk to children and young people in order to tell them how to protect themselves from COVID-19 by using the public health advice.

Secondly, children and young people may be hearing about coronavirus anyway from a variety of sources even if it is just overhearing conversations. If they pick up pieces of information but don't have a full understanding, they can put these pieces of information together and come to a misunderstanding which might make them anxious.

Thirdly, there is evidence that children and young people pick up on people not being truthful with them and pick up on the anxieties of adults around them, particularly those they are close to. Obviously picking these things up is quite a social skill and this may be difficult for some people with Autism Spectrum Disorder. If children and young people are picking up anxiety, given the understandable population level anxiety at present, without having an understanding of why this anxiety is around at the moment, they can become anxious.

Fourthly, whether individuals get coronavirus or not, the changes caused by it are having an impact on everyone. The changes in routine, uncertainty about further potential change and uncertainty about timescales of return to more typical routines is likely to be something that is very difficult for children and young people with Autism Spectrum Disorder. While speaking about coronavirus may not take this away, some understanding of the reasons behind all of the changes in their lives can be helpful.

How to start the conversation

Most importantly, communicate about coronavirus in the child or young person's preferred communication style. This may be words or pictures or stories or any other method. Communicating in a preferred style will not only aid understanding but is also likely to reduce anxiety in children and young people with Autism Spectrum Disorder.

If possible, ask if your child has heard about coronavirus. If they say "no", then this is your opportunity to talk to them about it and give the most up to date information from official sources so that you know they have the best understanding they can have. If they have heard about coronavirus, you can ask, where possible, what they know about it and where they heard about it. This allows you to correct any misunderstandings they may have or any misinformation they may have been told.

If you are unable to communicate with your child or young person with Autism Spectrum Disorder to the extent described here, or if they will not tell you what they know about coronavirus, we would advise that you tell them about coronavirus anyway. This is for all the reasons listed above and because it allows you to know that they have been given information about this in a preferred style by someone they know well to aid understanding to the best of their ability.

Be truthful

It's important to be truthful with children as there is evidence that they pick up on people not being truthful with them. Allow them to ask questions but remember that you don't have to have all the answers. Nobody has all the answers about coronavirus at the moment and while you may feel that children look to you for the answers and there is therefore a pressure on you to have the answers, it is ok that you don't.

The main thing is to be truthful about this and to say something like “I don’t know the answer to that right now but I will try to find out” or “...let’s try to find out together”. This allows you to model to the child that it is ok not to have all the answers, that you are a team and you can look for answers you don’t already have together and is an opportunity for you to talk to them about the importance of looking at official sources of information.

It may be very difficult for children and young people with Autism Spectrum Disorder to be told that we don’t have all the answers about this. This is very difficult for everyone. The main thing to do is acknowledge that this is very difficult and use any soothing strategies which have been successful in the past to manage this anxiety.

Discussing practicalities

Please follow the public health advice on what the practicalities are. This guide is only about how to communicate these things to children and is in no way meant to replace public health advice. Also, be aware that public health advice may change over time so please keep an eye on this.

At time of writing, there is public health advice about handwashing and covering coughs/sneezes. Around telling children about this, it is important to talk to children but also to demonstrate these things to children. Talking will mean they remember the information in the part of their brain that deals with words, demonstrating will mean they remember it in different parts of their memory system and the combination of both may make it easier to remember. Some brains like words, others like pictures so giving both will hopefully mean most people are covered. Demonstrating for children also means you can show them and then get them to show you. This allows you to check they were paying attention, they have remembered what to do and there are no misunderstandings.

Around handwashing, many people are using a song to make sure children wash their hands for long enough. Some are using the Happy Birthday song sung through twice. This is just because lots of children know that song but you can choose to use another method if you prefer as long as the child learns to wash their hands for long enough. For some children and young people with Autism Spectrum Disorder, the Happy Birthday song is for particular times and occasions and they may struggle with using this out of context so other methods may be more helpful. Around covering coughs and sneezes, it may sound like a funny thing to do to demonstrate this but it is important for the reasons given already.

It is important to talk to children about the symptoms of coronavirus. This allows you to talk about the importance of letting you know if they feel unwell. Alongside this, speaking about the symptoms means you can reassure your child if they are feeling unwell with symptoms that are not like those of coronavirus. Sometimes we feel different things in our bodies and we can misinterpret these as symptoms. For example, when we are anxious we

often feel a feeling of butterflies in our tummy. If children feel this, they can misinterpret it as symptoms of illness, particularly if you have just talked to them about a health issue like coronavirus. If you have told them about the symptoms of coronavirus and they come to you with a sore tummy, then you can remind them that this was not one of the symptoms of coronavirus and agree to resolve the sore tummy as a separate issue.

Knowing if a child or young person with ASD is unwell

It may be difficult for a child or young person with Autism Spectrum Disorder to tell you if they are feeling unwell. Look out for changes and ask others to do so as well as this may signal that the child or young person is not feeling well. Of course, changes could also mean they are anxious, or processing what you have told them about coronavirus, or something else entirely. Remember you know your child or young person best so if you are worried that they are unwell, get advice from official, qualified sources.

Discussing emotions around COVID-19

Children will be at different ages and stages and therefore have different levels of understanding of emotions. This can be an area of particular difficulty for children and young people with Autism Spectrum Disorder. They may only be able to label emotions; or they may be able to talk about how some emotions feel; or what happens in their bodies when they feel different emotions; or how they know when others feel different emotions, such as by looking at facial expressions. It can be helpful for you to bring up the issue of emotions around COVID-19 with your child so that they know that it is ok to feel things about this and to talk to you about how they feel, if they are able to do so.

In general, people are understandably anxious about coronavirus but this may be a difficult concept for a child. They are likely to use other language and that's fine. Go with the language they use. This is how to make things understandable and child-friendly. You can talk about how you feel and give a message that it's ok to feel different things at this time but it is also important to talk to your child about what to do when they feel different emotions. You can put across the idea that you are a team and it is important to talk about how you feel together and to think of things to make you all feel better.

If your child or young person with Autism Spectrum disorder can't speak or finds it difficult to talk about emotions, you can talk to them about this anyway to acknowledge that it is ok to feel different things at this time.

Sources of help for children

It is helpful for your child to be aware of where to find help should they need it. You should talk about this in relation to each of the environments they are likely to be in.

One of the main sources of help for your child is you. This means it is really important to look after yourself at this time. Partly this is so that you can best look after your child. The other part of this is that if you look after yourself then you are modelling to your child that self care is important. Often adults who look after children put themselves and their needs last but think about what message this gives your child. Imagine them in the future; you would want them to look after themselves so you need to do this too. Think about your own sources of support, particularly at this time.

How to end the conversation

Children may pick up from you whether this is a topic that you are now finished discussing and never expect to return to or whether this is something they can talk to you about again. This is a social aspect of communication, however, and it may be difficult for children and young people with Autism Spectrum Disorder. They may come back to the conversation lots of times anyway as they try to process what they have been told. They may ask lots of questions. They may repeat and act out parts of what they have been told. All of this is fine and shows they are trying to understand. Make sure children know this is something they can come back to you to speak about again. Talk about yourselves as a team explaining that you can talk about anything and that you will always help them. This will reassure them now about coronavirus but also about talking about other things in the future.

What if they don't like to talk?

Draw pictures, paint, use stories or social stories or any other method you have found helpful in communicating with your child or young person in the past. There are lots of ways to communicate the information with children so go with your child's preferred method of communication. If possible, get them to "teach" you about coronavirus as a way of checking they have understood.

General advice for talking to children

There is no magic wand or magic fairy dust. There is no "right" way to have a conversation or perfect thing to say to make everything child-friendly. Listening is key and the main thing is to keep trying. If you try to talk to your child or young person about coronavirus and they are distracted by other things then try again another time. Remember you don't have to have all the answers and fix everything. You are teaching them resilience skills to know that even without all the answers and without being able to fix everything all of the time, we can be strong together and manage really difficult things.

What to do about changes of routine

This can be really difficult for children and young people with Autism Spectrum Disorder but regardless of how difficult it is, it looks likely to happen during the pandemic. By explaining coronavirus, you are giving some reason for all the changes and while this may not look like it's helpful initially, it is likely to help with processing of what is happening.

The changes are difficult for everyone at the moment and you may have seen lots of advice for people moving to new routines such as working from home. Lots of this advice includes things like setting up routine and if you live with a child or young person with Autism Spectrum Disorder you may well be ahead of the game here. Maybe you could even give tips to others!

One of the things you may be able to do is to stick to things you already have in the routine so anything you already did at home is likely to be better. If, for example, you use a visual timetable, then keep this going but change the content. This allows some stability and sense of control for your child or young person with Autism Spectrum Disorder. We have heard that some people are drawing a representation of coronavirus and sticking this around their visual timetable to indicate that this is the timetable during the pandemic and to allow for this to change back at some point. Please be aware that for some, however, having this on the timetable is in itself another change and it can be overwhelming.

In general, the main things to try are setting up a routine early on, acknowledging that this is a difficult time and trying to use strategies you already have to manage anxieties. We appreciate that this is going to be extremely difficult in some cases and we would urge you to use your own coping strategies and sources of support. We are also happy to support you.

What if you think your child is becoming anxious?

Remember that anxiety is a natural reaction and it's normal during a pandemic to feel anxious. Most people are feeling anxious at the moment so it's not surprising if children and young people feel it too. The processing of all of this is what is different for children and young people with Autism Spectrum Disorder and we appreciate this will be a pressure on the adults around them as well especially if you are stuck at home. It is important to try to use the strategies you already have so think about things that have helped in the past around coping skills and try them again. If they are not so successful, it may be because the child or young person is older now or it may be that this situation is more overwhelming than previous ones they have experienced.

We are happy to support you if you are worried about your child's anxiety or that of yourself or someone else.