

Supporting someone with the testing process

The Covid-19 test will be new for your child, or for the person you support. Each person will respond to medical procedures (e.g. blood tests, temperature tests, dental work) differently, and each person will have a different physical and psychological perception of discomfort and what procedures are "invasive".

You may already know that the person you support, or your child, will find the testing process too difficult. Alternatively, your child, or the person you support, is normally happy to engage with medical procedures – but you are unsure how they will respond to the Covid-19 test. Similarly, some autistic people may wish to know if they are Covid-19 positive when symptomatic but may be anxious about the testing procedure.

Autistic people may have differences in how they imagine an event not yet experienced, or may find that current guidance on what happens during the Covid-19 test is not written in a way that is understandable to them. We have compiled some suggestions to help you provide support to someone who may be a candidate for Covid-19 testing.

Consider how you normally support this person with medical procedures

Your child, or the person you support, may have had medical procedures in the past such as injections, dental work, or tests for other physical health conditions. You may be able to reflect on what strategies have worked in the past, and what may be incorporated into supporting them to have the test.

Here are some questions to help you reflect on what support they may need:

- Does the person you support require a Social Story before a test procedure?
- Do they like to see photographs of the room, test kit, or person who will be administering?
- Do they prefer to hold somebody's hand or hold a comfort item?
- Do they prefer to have procedures completed by somebody who is fun and conversational?
- Do they require a lot of notice and processing time for procedures, or prefer to be told closer to the time?
- Would listening to their favourite song during the procedure help?

Show the person what the testing procedure will look like

The person you are supporting may wish to see what the test will look like through video, infographic, or by watching someone else have the test in-person.

Videos

We have selected a few videos which show the swab test being completed. You may have to decide whether or not the video content is appropriate for the person you are supporting and the method in which they will receive the test.

Supporting your child during Covid-19 nasal swab test (Mayo Clinic)

How to take a coronavirus self-test swap (Department of Health and Social Care)

Coronavirus tests: How they work and what they show (The Guardian)

How to take a combined throat and nose swab (Public Heath England)

What happens during a drive-through coronavirus test? (STV News)

Coronavirus testing tutorial for care homes (Department of Health and Social Care)

Please be mindful that some images showing the testing procedure may not be appropriate for the person you are supporting. For example, some images may show the insertion of a swab into the nasal cavity as a cross-section, which may be misinterpreted by some people.

In person

If you are also being tested, or using a self-swab, you can show the child or person you are supporting, you having the test administered.

Animated stories

Stories should be written bespoke to the person's own communication style. If your child, or the person you support, receives a formalised support service or has a speech and language therapist, ask if they can support you to compile a story. An Autism Advisor at Scottish Autism can help you too: but it is always best to have them written by someone who knows the individual.

Be honest about the procedure, and answer any questions

At the end of this document, we have a list of resources to help you understand the different types of test that are administered (self-test swab, swab supported by non-medical professional, drive through test). Find out as much as you can about the procedure that will take place, so you are ready to answer questions and explain this to the person who will receive the test. They may ask questions about some aspects of the test which are unusual, or some people might find uncomfortable.

Will the swab go right to the back of my nose/throat?

The swab will require to go to the back of the nose/throat. This can be an unusual sensory experience for most people, and particularly for those with tactile hypersensitivities. It is important that the person receiving the test is informed of this, and is not given misinformation.

Will it hurt?

This is a difficult question to answer, and should be answered as accurately and honestly as possible. This will be dependent on that individual's perception of pain and what they usually report as painful. You may need to think back to past experiences they have had in order to answer this question for them. For example, you have to consider how they have reported pain and discomfort in the past, and use this to help them accurately judge whether or not this will be a painful experience for them. Here are ways to help communicate this accurately:

It might not feel very nice.
Some people have said that it hurts.
It might hurt.
It will feel very strange.

It is important not to inform the person or young person that it will not be painful/uncomfortable unless you are sure that this will be an accurate illustration of their experience.

Will it take long?

The test should take no more than a couple of minutes, but it is important to consider the person's perception of time, and if this will be "long" for them. It may be reassuring for them to have a timer, or to have a supporting person count down from a specified number, to inform them of how long the procedure will take, and to help them judge during the procedure

Communicate a method of withdrawing consent

Consenting to having the test is important (see <u>Do I have to get tested?</u>) However, if a person experiences extreme distress or discomfort during the test, it is important that they can communicate that they would like the procedure to stop or pause. Verbally withdrawing consent may be difficult as the test requires items to be placed within the mouth and nose. Some individuals may feel more comfortable approaching the test if they know that they have a method of stopping it. You may wish to incorporate a method into a Social Story if you are using one, or provide a written reminder to the individual of how they can withdraw their consent.

Possible methods of withdrawing consent:

- Raising their hand
- Moving their head back
- Providing the individual with a "stop" card.
- If a person may not be able to use the above methods, an accompanying person who
 knows the individual well can communicate on their behalf if they feel that the test is
 causing distress.