



Giving 'informed consent' to Covid-19 testing

If someone is showing Covid-19 symptoms, testing is recommended in order to confirm this. *Testing needs to be consented to.* Consent can be provided verbally, but may also be assumed if a person turns up for testing and goes ahead with the swab procedure.

It's important to understand that a child, young person or adult who is autistic *may agree, go along with, or refuse something without understanding it.* It is important to realise the reasons for this, so the person can be supported in the best way. For example, someone may give consent to something because they want to 'say the right thing', or may turn up for testing because they have been told to, without actually understanding what will happen, or why.

The law on consent to medical procedures

There are strict laws around consenting to medical treatment. These are based on key factors such as age and capacity (ability) to understand what is involved and make an informed decision.

Generally speaking, parents or guardians can consent to medical treatment for a child under age 16. However, if the child is able to understand what is involved and make the decision themselves then this is far preferable.

Even where parents or guardians are legally allowed to consent on behalf of a child, young person or adult, it's important that this individual has as much knowledge as possible of what testing involves, and the opportunity to refuse it.

Factors to consider

To give 'informed consent' to being tested, one needs to know *what is involved, why, and possible consequences of consenting or not consenting* (see our other [Test and Protect resources](#)).

In terms of Covid-19 testing, the person, where possible, should be supported to understand:

- The procedure and anything else that may be involved (e.g. travel to get there; who will do the test, what they will look like i.e. wearing PPE; being swabbed in the throat and deep into the nostrils; any 'adjustments' that might make the whole process easier)
- The alternatives (a home testing kit, if available; refusing to give consent)
- Any consequences of getting, or not getting, tested (e.g. needing to self-isolate if tested positive or if they refuse testing)
- The support they'll be given if feeling unwell with symptoms

- Information on how their nose/throat may feel after the test, and what can be done to ease this (prior discussion with a medical professional may help to identify this, taking into consideration any sensitivities they have)
- Information on what will happen after the test (e.g. going straight home if they travelled to a testing station; consequences of testing positive or negative; reassurance around getting support for symptoms)
- That they can refuse the test at any point, even if they initially consented to it

Even if the test has already started, this may in fact be the first point at which an autistic person starts to actually understand what it involves. *This may therefore be the point at which they refuse it.* If this is the case, *they should not be made to continue with the test.* If there are concerns that they may refuse at this point, it would be helpful to discuss this when arranging the test and on arrival for testing.

Strategies that may help a person to understand what testing involves:

- Their favoured communication supports, in line with their understanding and desire for knowledge (e.g. photos, pictures, videos, actual objects used in testing; Talking Mats; Social Stories™; picture boards/schedules; written information; flow charts clearly showing options and consequences; information on ‘Flattening the Curve’ (see Covid-19 ‘glossary’) and how testing helps this; scientific/medical information on Covid-19 and testing)
- Some of our other resources on getting tested (which can be personalised)
- Role modelling what testing involves
- Requesting a home testing kit and showing/explaining/trying it out

We hope that this information helps your situation. Please also see [Test and Protect: how the Autism Support Team can help you.](#)

Further reading

You can find out more about informed consent here:

[Medical Protection: Consent – Children and young people – Scotland](#)

[General Medical Council: Making decisions](#)

You can find out more about ‘mental capacity’ here:

[Scottish Government: Chapter 2: About the Adults with Incapacity \(Scotland\) Act 2000](#)