



Health

Having a blood test

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We know from enquiries to our Helpline that some children and adults who have Down's syndrome struggle with blood tests.

Needle phobia is common in the general population, so it stands to reason that people who have Down's syndrome should experience it too, particularly if they find it harder to understand why they need to go through the procedure and/or they have been put off by having a bad experience in the past.

A parent who called our Helpline neatly summed up the issue when she said:

'If you were not sure what was going on and someone tried to stick a needle in your arm, how would you feel?'

We have put together some tips that may help children and adults have a better experience of blood tests. None of the tips and ideas here are new; they are from various sources including parents and health professionals. They have worked for some children and adults used in various combinations.

Health professionals have a duty under the Equality Act to put reasonable adjustments in place to make sure services are accessible to people who have learning disabilities. This duty applies to having a blood test.

The tips on this page are examples of reasonable adjustments that can be put in place.

Preparation

People struggle with the new and unfamiliar.

Familiarising a person with what is going to happen can help to reduce anxiety and prepare them for a blood test. The amount of preparation needed will be different from person to person; sometimes there is a fine line between preparing a person to allay their worries and unintentionally creating anxiety because the forthcoming procedure is being blown out of proportion.

There are tools that people have found useful in helping someone to prepare for a blood test; these include social stories, easy read information, photo books or films.

Others may have their fears allayed by a trip to the doctor or hospital prior to a blood test.

A man who has Down's syndrome needed to go the hospital for the first time to give a blood sample.

His support worker talked to him about what was going to happen and then she arranged for him to have a trial visit to the hospital and to meet the doctor, the person who was going to take his blood sample. Whilst they were at the hospital they took some photos of the building.

When they got home, they made a story book using the photos as a reminder for the man about what to expect when he went to give a blood sample. They also used one of the photos on his visual timetable.

Some hospitals have uploaded films to YouTube explaining what happens during a blood test. There is a link to an example below.

For younger children it may help to rehearse what will happen with their favourite doll or teddy bear. You can bring the toy along to your child's appointment so that they can go through the procedure first. This may provide your child with reassurance.

Rewards

Rewards can work wonders.

Remember to include rewards for getting through the procedure in any social stories, picture books or visual timetables that you use with the person who is having a blood test. Heaps of praise during and after the test will help. If in doubt, resort to a bit of bribery.

Finding the right location

For many people, an unfamiliar and noisy clinical environment can be overwhelming even if they have had a prior visit. Blood tests do not always have to happen in a clinical environment. Some families arrange for a community nurse to do the test at home, at school or at the local children's centre.

Find out if there are alternative settings where a person can the test. We heard of a consultant who did a blood test for an adult who has Down's syndrome in his hospital office because it didn't look like a clinical setting and was therefore less daunting.

Who should I ask to do the blood test?

Although all staff qualified to do blood tests should be able to manage their patient who has Down's syndrome sensitively and calmly, some parents and support workers have found they have had a better experience with particular professionals (e.g. a phlebotomist, a senior nurse or a learning disability nurse).

Finger Prick Test

In some instances, it is possible to have a finger prick blood test instead of a blood sample being taken from a vein. Ask your health professional about this.

Positioning and distractions

Positioning and distractions can make the process easier for children and adults. The right position can help people:

- feel safe and secure
- Make it easier to distract them (e.g. if they are looking at you rather than at the person about to do the test)
- Can reduce movement to make it easier for the test to happen

Providing a distraction during the test may help reduce anxiety. Here are some suggestions (what helps will vary from person to person depending on their interests):

- iPad
- Favourite toy or game
- Mobile phone
- Headphones
- Music
- An activity book involving having to find objects
- Singing
- Have a chat about something the person is passionate about

Medication

Local anaesthetics (e.g. creams such as 'Emla' cream) can numb the skin and reduce pain before the test. Ethyl chloride is an alternative to anaesthetic cream; it acts as local pain relief when sprayed onto the skin. It has no anaesthetic properties; it works as a vapo-coolant. A thin film of liquid is sprayed onto the skin, which makes the skin cold and less sensitive as the liquid evaporates.

Who can help?

Some families arrange for the Community Nurse to visit their child at school to carry out a desensitisation programme. Other parents have found the services of a play worker or play therapist useful.

Talk to your local hospital or GP about this. A play worker can visit your child at home and go through the process of giving a blood sample with them.

Your local Community Learning Disability Team (CLDT) can be a good source of advice. CLDTs usually have clinical psychologists and Learning Disability Nurses who can work with adults with learning disabilities around needle phobia.

Can a blood test be combined with another procedure to make it less stressful?

If a person is having an operation, ask the anaesthetist at the pre-op session about the possibility of taking a blood sample whilst the patient is anaesthetised.

A final note

These tips may help someone you support to find it easier to have a blood test.

They are not a magic wand that can be waved with instant success. For some people, just getting them to a point where they feel comfortable with the setting and staff, where blood may eventually be taken, can be a lengthy process in itself. This is before you even reach the stage of the person being happy to undergo the full procedure, if ever.

Realistically speaking, we know there are going to be some children and adults who will always struggle with blood tests whatever measures are put in place to help them.

Further information and advice

If you have any questions about health issues, you can call DSA's Helpline (Tel: 0333 1212 300) or email using info@downs-syndrome.org.uk.

If an information officer is unable to answer your question, they can make a referral to the medical adviser at the UK Down Syndrome Medical Interest Group (DSMIG). Please note DSMIG can provide general advice about health issues but they are not able to comment on individual test results. DSMIG are happy to take enquiries from health professionals but they will not take direct enquiries from families or supporters.

Resources and useful organisations

Social stories (DSA)

This resource tells you how to write your own social story – you could write a social story about blood tests for the person you support.

[link tbc]

Blood tests for people with learning disabilities – making reasonable adjustments – guidance (Public Health England)

<https://www.gov.uk/government/publications/blood-tests-and-people-with-learning-disabilities/blood-tests-for-people-with-learning-disabilities-making-reasonable-adjustments-guidance>

Getting a blood test – social story (oneplaceforspecialneeds.com)

This is an example of a social story about having a blood test.

http://www.oneplaceforspecialneeds.com/main/library_blood_test.html

Having A Blood Test - Learning Disabilities Version (Derby Teaching Hospitals NHS Foundation Trust)

An example of a film for people who have learning disabilities about having a blood test.

<https://www.youtube.com/watch?v=0AVkU9Hs7VM>