Some inherited conditions develop in adult life and are untreatable. Some adults who are at risk of developing such an illness choose to have a test; others prefer not to know so do not to have a test. Because of this, healthy children are not offered tests for these conditions. We believe that decisions about testing in these circumstances should only be made in adult life by the person who is at risk, after a discussion of their own views and feelings.

Sadly, there are other untreatable conditions that begin in childhood, when a healthy child is too young to make a decision about pre-symptomatic testing. In these cases, although a genetic test may not help a child directly, it may allow the child’s family to plan ahead and begin to come to terms with their illness. In this situation, we would ask to see the child’s parents in the genetics department before testing is performed. This is so that we can help them make the decision that is best for them, and to help prepare them for the possibility of a distressing result.

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Healthy people who may carry genetic disorders, where the concern is purely for their future children, should have a chance to discuss the possible outcomes of being tested before they make a decision about having the test.

In the case of a young child, they are not in a position to be able to have that discussion and make that type of careful decision. However, many teenagers can understand about testing and decide for themselves.

Help for parents and children
We understand how worried parents must feel when they know that their child may suffer from a genetic disease, may develop an inherited illness in the future, or may carry a genetic condition that could be passed on to future generations. It can also be very difficult to know how or when to talk to a child about any of these situations. Clinical genetics departments can offer help and support to parents and families.

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Genetic testing of children
This leaflet gives information about why your child might have genetic testing, what the tests are, and possible outcomes.
What is a genetic test?
A genetic test is a special kind of test, usually done from a blood sample, which can detect an altered gene or chromosome pattern.

What are genes and chromosomes?
Genes are the unique set of ‘instructions’ that make each of us individual. There are many thousands of different genes, each carrying a different instruction. Genes affect how we look and the way each cell, or building block, of the body work. If a gene is altered it can cause a genetic disease or condition.

We have two copies of each gene. One copy is inherited from each of our parents. When we have children we pass on only one copy of each of our genes.

String of genes are tightly packaged into structures called chromosomes. Each chromosome has thousands of genes.

Are there different types of genetic tests?
Yes, they fall into three main groups:
- diagnostic tests
- pre-symptomatic (or predictive) tests
- carrier tests

Diagnostic tests
Diagnostic genetic tests try to find the cause of your medical problem. If the underlying cause can be found, a suitable treatment for the symptoms of the illness may be possible.

Pre-symptomatic (predictive) tests
A pre-symptomatic genetic test is one that is performed on a person who is currently healthy but is known to be at risk of developing a particular inherited illness sometime in the future (one of their parents may be have a condition that can be passed on to their children)

Carrier test
Many of us "carry" an altered gene or chromosome pattern that. Although it is harmless to us, it can cause problems in our children, who inherit some of our genes and chromosomes. A genetic carrier test is one that can identify a healthy "carrier" whose children could be affected with particular genetic conditions.

Should a child have a carrier test?
It does not matter at what age a person has a genetic test, as the result will always be the same. Many genetic tests are not done straight away as they can have difficult, long-term consequences for the person being tested. This is why many parents, doctors and other health professionals have strong reservations about testing children.

When a genetic test on a child is being considered, it is helpful for professionals and parents to ask themselves three important questions:
- Is the test in the child's best interests?
- Could the test do the child more harm than good?
- Is it possible to wait until the child is old enough to decide for themselves whether or not to have the genetic test?

A diagnostic genetic test
If the result of a diagnostic test shows a child to have a serious genetic illness, it can be upsetting for the whole family. An accurate diagnosis is often in a child's best interests. They may be able to be helped by a particular treatment plan and other unnecessary tests may be avoided.

A diagnostic test is often better for a child than not having it. Parents and doctors will often need to decide which tests may be helpful on behalf of a child who is not old enough to make a decision of their own.

A pre-symptomatic genetic test
Having a pre-symptomatic test is not always in the child's best interests. It can depend on the illness that is suspected. In this situation, the most important question is ‘can anything be done to prevent the child developing the condition?’

Some inherited illnesses, such as certain cancer syndromes, require lots of screening. In these cases healthy children who may have the altered gene that causes this condition, can benefit from a genetic test. If they do not have the altered gene, their risk of that illness is reduced, so more screening may not be necessary. If they do have the altered gene, then they know that special regular check-ups are needed. In these cases it is often possible to involve the child in the decision about genetic testing.
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Sadly, there are other untreatable conditions that begin in childhood, when a healthy child is too young to make a decision about pre-symptomatic testing. In these cases, although a genetic test may not help a child directly, it may allow the child’s family to plan ahead and begin to come to terms with their illness. In this situation, we would ask to see the child’s parents in the genetics department before testing is performed. This is so that we can help them make the decision that is best for them, and to help prepare them for the possibility of a distressing result.

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In the case of a young child, they are not in a position to be able to have that discussion and make that type of careful decision. However, many teenagers can understand about testing and decide for themselves.

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We understand how worried parents must feel when they know that their child may suffer from a genetic disease, may develop an inherited illness in the future, or may carry a genetic condition that could be passed on to future generations. It can also be very difficult to know how or when to talk to a child about any of these situations. Clinical genetics departments can offer help and support to parents and families.

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