

Children and raised cholesterol

If you suspect your child might have inherited high cholesterol then it is important that you ask your doctor to check their cholesterol level and to refer them onto a lipid clinic if necessary. This can be a worrying time for parents. Below are some answers to the questions parents most commonly ask.

Q. If I have Familial Hypercholesterolaemia (FH) will my child have it as well?

FH is a genetic disorder that affects 1 in 500 people. It is an autosomal dominant disorder, which means that if you or your partner has the disorder, then your child has a fifty/fifty chance of inheriting it. This means that on average one in two children would be expected to be affected, although sometimes none of the children will inherit the disorder. If you and your partner do not have the disorder then your child will not have it either (unless of course the child is adopted).

Q. At what age can my child be tested?

HEART UK recommends that children from affected families should be tested before the age of ten, but should not normally be tested before the age of two years.

Will my child have to be tested again if the result is normal for his or her age?

During his or her early years your child should not require testing again if the test result is normal. Your child may need testing again in early adulthood if familial combined hyperlipidaemia (FCH) is suspected because the lipid abnormalities in this case only present later in life. Also, it may be a good idea to have occasional checks on cholesterol levels in later life, especially if changes in risk for developing heart disease occur. This could include smoking or developing high blood pressure for instance.

Q. Where should my child be cared for?

Affected children and possibly affected children should be referred for specialist hospital follow-up, ideally in a family/child or adolescent friendly setting.

Q. Do we need to have a genetic diagnosis to be absolutely sure?

Genetic diagnosis may become more important as different methods of treating the disorder are explored. Genetic testing can be performed at specialist centres, but it is expensive and in some areas of the UK it is not routinely available. It involves one affected family member having a blood sample taken to identify the specific genetic alteration. Once the defect has been identified, other family members need only supply a sample taken from a swab of the inside of the mouth. This sample provides enough information to determine whether the genetic defect is there or not.

However, if the result is negative this does not mean that your child will have no chance of developing cardiovascular disease (CVD) in the future. This is because CVD is caused by a multitude of risk factors. If, for example, your child smokes and has diabetes but has a negative test or is not diagnosed with FH, he or she is still at risk from CVD because of these other risk factors.

Q. Will my children's children inherit the disorder?

If your child has not inherited the problem then your grandchildren will not either. However, if your child does have FH then their children will have a 50/50 chance of inheriting the disorder.

Q. What if he/she doesn't want the test?

It is important to know whether your child is affected or not. It is often possible in specialist clinics to make the diagnosis with a finger prick test if your child is particularly frightened by the prospect of a needle and syringe.

Q. What if my GP won't test my child?

Most GPs are sympathetic to parents' concerns. Usually taking along information about the condition and information (such as this leaflet, or even a copy of the NICE guidelines) can help GPs decide to test your child or refer you to a specialist centre for testing. The HEART UK helpline can offer you specific advice about approaching your GP.

Q. What is the treatment for FH?

Diet is the cornerstone of treatment for this age group. A healthy diet is encouraged from as early as two years of age. This should include a variety of foods from all food groups, including lean meats, low fat dairy products, fish, nuts, legumes, cereals, fruit and vegetables. See our comprehensive diet guide for further information. However, care must be taken to ensure that the diet provides sufficient energy and other nutrients to help maintain normal healthy growth and development. Ideally parents should be referred to a registered dietitian experienced in lipid management.

Foods fortified with plant sterols and stanols are safe, effective and palatable and can be used under supervision for children who have FH. They can help reduce LDL cholesterol by 10-15% as part of a healthy balanced diet which is low in saturated fat. Your doctor or dietitian may therefore recommend their use as part of a cholesterol-lowering diet for your child, but you should seek advice before using them.

General healthy lifestyle options should be encouraged such as discouraging smoking and being physically active above and beyond what is offered at school.

Q. What are resins?

One drug that has traditionally been used to help children to lower their cholesterol is called a resin, sometimes called a bile acid sequestrant. This works by binding with excess cholesterol as it passes through the gut. The resin plus excess cholesterol is then excreted in the stools.

Some of these resins are not particularly palatable, they can cause gastro-intestinal side effects such as loose stools and excessive wind.

Q. What are statins?

Later on, usually after puberty, statin drug therapy may be required for older children especially if the risk of cardiovascular disease in the family is high. Statin therapy is less often indicated in girls than boys since coronary risk in early adulthood is much lower in women. Later in adulthood drug treatment will almost invariably be required in people who have been diagnosed with FH and many with FCH.

Q. How do they work?

Most (90%) cholesterol is made in the liver. Statins work by inhibiting a key enzyme that is necessary in this production process.

Q. What are the side effects of these drugs?

Clinical trials in adults indicate that serious side effects are very rare and statins are safe and well tolerated. The minor side effects can include headaches and tummy upsets, loose stools and constipation. However, should your child develop general "flu like" muscle aches and pains then it is important to report these to the doctor. It may be necessary to stop the medication and possibly select an alternative tablet at a later date.

Parents should be aware that there is less information available on the safety and use of some medicines, such as statins, in children. Your hospital specialist should discuss this with you.

Pregnancy should be avoided whilst taking statins and appropriate contraceptive therapy recommended.

Q. Will he or she always have to take them?

Yes. It is important to realise that stopping taking a statin results in the amount of cholesterol in the blood going back up to its previous levels. It is possible that in the future gene therapy or something similar may be available.