Looking after children with congenital heart disease:
40 Questions and Answers

The information in this section was kindly provided by the British Heart Foundation and the Children's Heart Federation. All of the factsheets mentioned below can be found on their website.

The term 'congenital heart disease' covers a wide range of heart conditions and defects. If you have a very specific question about your child and cannot find the answer here, call the Children’s Heart Federation Helpline. If they cannot give you the answer they will be able to suggest where to go for advice.

1. I've been referred to the paediatric cardiology unit for a scan because there may be something wrong with my baby's heart. What will happen when I am there?

At the Fetal or Paediatric Cardiology Centre a thorough scan will be made of the heart. This is a specialist heart scan and so it will not look at the rest of the baby, and your usual ante-natal unit will organise other ultrasound scans.

If you are someone who likes the support of other people, and your partner can’t make it, try and take a relative or friend with you. If all is well, it is someone to celebrate the good news with. If not, you may find it helpful to talk it over straight away with a person to whom you and the baby are important.

2. I'm pregnant and have been told that my baby will have a heart defect. What will happen when my baby is born?

Most women have a normal delivery (rather than a Caesarean) but you will need to talk to your doctor about this. You may need to arrange to have the delivery near a paediatric unit, in case your baby needs to be taken there soon after the birth. There may be several doctors and nurses in the delivery room with you. Also, remember that if your baby's heart condition is severe and he needs to be in intensive care, you may not be able to spend very much time holding him and being close to him at the beginning.

3. Why wasn't my baby's heart condition detected when I was having heart scans during pregnancy?

Not all conditions can be detected. Most scans show only the four chambers of the heart.

4. I have heard that, in some babies, heart conditions are not noticed at birth. How can I be sure that my baby doesn't have anything wrong with his heart?

If there is a severe blockage of blood to the lungs, your baby would show signs of having a heart condition within hours of birth. These are: going off feeds or having difficulty feeding, being pale, sweaty or breathless, having a swollen tummy or puffy eyes, lethargy and grunting, and poor urine output.

However, sometimes a heart condition is not noticed until sometime later. If there is a problem with the blood flow - for example a narrowing or blockage, or if the patent ductus has not closed properly, the baby may gradually start to show signs of having a heart condition, and may also go off
feeds and be sleepy.

If your baby has symptoms that could be caused by a heart disorder, ask your GP for advice. If your GP is not satisfied that all is well, he or she should refer you to a paediatrician, and then on to a paediatric cardiologist if there is any sign of a heart problem.

5. How will congenital heart disease affect my child’s development? Will she be able to go to a mainstream school?

Babies with heart conditions may be slower to learn to sit up and to walk, but their mental development is the same as other children of the same age. Most children with congenital heart disease go on to mainstream nursery and schools. In a very small number of those children who need surgery, there may be some neurological impairment (damage to the brain) following the surgery.

6. How will my son’s heart condition affect his ability to do PE at school, and other sports?

As far as possible, parents are advised that their child should not be treated differently from others. You may be worried about how much these children should be allowed to do in the way of exercise. In most cases children with heart conditions can be allowed to limit their own activity without restraint from an adult, they usually know their own limitations, but you should be advised if this is not the case.

However children who are in danger from blood clots who are taking Warfarin or other blood thinning medicines will not be able to take part in contact sports or sports where they would become physically embroiled with others, such as basketball, hockey, judo, rugby and football.

Children with congenital heart conditions, which have not been corrected, are likely to tire more quickly than other children, and will need to be allowed to stop when they feel like it.

In cold weather, heart children may become breathless more quickly, and because they cannot run around for long periods to keep warm, they may need to be given the opportunity to stay in a warm place during break and lunch periods.

Some children will be taking medicine to help their bodies get rid of excess fluid; they will probably need more frequent and possibly urgent trips to the toilet.

7. Does my daughter need to be on a special diet because she has congenital heart disease?

Children with congenital heart disease are generally encouraged to get extra calories either from formula (for babies), or in drinks or at mealtimes. Your daughter may need to go on a special diet if she starts to lose weight, becomes difficult to feed, is putting on too much fluid, has just had surgery that means she has to go on a fat-free diet, or if she has a syndrome with dietary implications.

8. What is a cardiac catheterisation and what is it for?

Cardiac catheterisation is a very effective way to diagnose heart abnormalities. It is also used to treat many heart defects which in the past would have needed surgery, such as closing holes or stretching narrowed valves, or closing off extra blood vessels.

If your child needs to have cardiac catheterisation, he will be admitted to hospital the day before the
test and will usually need to stay for one or two nights. If you can, stay overnight with him so that he
sees a familiar face when he wakes up. Remember to ask the hospital in advance so that a bed or
other arrangements can be made for you.

The test is done in the cardiac department. Shortly before your child goes there for the test, he will
be given either a general anaesthetic (so that he is completely asleep), or a sedative (to make him
sleepy), and also a local anaesthetic at the top of the leg. In either case, your child will not feel any
pain during the test.

Your child will be linked to an ECG machine so that the doctors can monitor his heart rhythm during
the test. A catheter (a fine, hollow tube) is then inserted into a vein in his right groin, either through
a special needle or a small incision (cut). The child may feel a slight pressure as the catheter is
inserted. The catheter is gently guided through the vein until it reaches the heart. Its journey can be
seen on a special television screen. Samples of blood are taken from the heart to measure the
amount of oxygen in the blood and to check the pressure in each of the four heart chambers.

During the cardiac catheterisation test, the doctor will also do an angiogram. This means injecting a
dye through the catheter, and taking an X-ray to see how the blood flows through the heart. This
test shows up any abnormalities in the structure of the heart or in its network of veins and arteries.

The cardiac catheterisation test usually lasts one to two hours. If your child has had a local
anaesthetic he may wake up during the test. But because of the sedative, he will still be drowsy and
won't feel any pain. Some older children who wake up during the test enjoy seeing the catheter on
the television screen. They may also like chatting to the nurse who will be sitting with them all the
time. If for any reason a child does get upset during the test, the doctor will usually give him another
sedative, through the catheter, to send him back to sleep. Children who have a general anaesthetic
will be completely asleep while they are having the test.

When all the tests have been done and the catheter has been removed, the nurse will take your
child back to the ward. Most children can go home the next day and get back to their normal
routine. Try to encourage your child to talk about what he liked or didn't like about being in hospital
and any worries or fears he had.

It often takes a while for the hospital to analyse the results of the tests and decide on the treatment
your child needs. As soon as the decision is made, the doctor will explain everything to you in detail
and answer any questions you might have. Don't be afraid to ask any questions.

The risk of cardiac catheterisation is very small. The risk varies depending on the type of heart defect
the child has. It is slightly greater in babies who are very blue and breathless and who have complex
abnormalities.

9. My son has an atrioventricular septal defect. Will he be able to travel by plane, and can we take
him up to high altitudes?

The answer is yes to both questions although if traveling by plane you may need to make a few plans
in advance. Try to plan your trip abroad so that your anxieties can take a back seat for a while. There
are a few tips below, but for more detailed information see the Children's Heart Federation leaflet
'Travelling abroad with your heart child.

- Always check that your child is fit to travel. Ask your GP (if your child is generally well) or
  your paediatric cardiology centre (if your child is still frequently treated or monitored) for
advice. You may also need to take a letter from your GP or Cardiologist saying that your child is fit to travel.

- Secure insurance before you buy the tickets. Make sure that it will cover the cost of bringing both you and your child back to the home hospital. For travel in Europe take an E111 card which will allow you to recoup all the money spent on treatment.
- Make sure you have the appropriate medicines and know how to store them. You may need to carry a prescription to prove that they have been prescribed by a doctor. It is a good idea to carry two supplies (keep them separate) of any essential drug since many travellers have problems with lost luggage. Carry medicines in your hand luggage so that you can monitor how they are being stored.
- Ask your cardiologist for the nearest paediatric centre to your destination and learn how to say that your child has a heart condition in the local language. Write the words down so that you don’t forget them!
- If your child is on Warfarin remember that changes in the weather, diet and lifestyle can affect the INR reading so you may want to test your child more frequently while on holiday.
- Pacemakers may set off alarms when going through security, so carry the child’s pacemaker card.
- If your child’s diet is likely to change, try and do it slowly. Take a concentrated bottled fruit juice and make it up with bottled water instead of giving fizzy drinks. It is important for any child not to go short of drinks.
- Smaller children may need to eat little and often. Buying snack food in a foreign currency can be seriously expensive - carry a large supply of acceptable biscuits
- Be careful with exposure to the sun, always use a high factor sunscreen and remember that scar tissue burns very easily.

10. Our daughter has had open heart surgery. Will her scar fade when she is older? Should I put anything on it to help it fade?

disguised with make-up. Some pharmacies now sell a dressing that helps the scar fade. Ask your GP for more information.

11. What sort of circumstances lead to children needing to have a heart transplant?

A heart transplant may be given as a last resort, if the heart can no longer take further surgery or the muscle is not pumping effectively enough to maintain circulation and life. Support groups like the [Children’s Heart Federation](https://www.childrensheartfederation.org.uk) and [GUCH](https://www.guch.org.uk) (Grown Up Congenital Heart Patients’ Association) can offer more information on this.

12. Will congenital heart disease affect my child’s ability to get life insurance in later life?

When your child grows up he or she may find that, because of their heart disease, insurance companies either turn them down or ask them to pay very high premiums. The best advice is to shop around - insurance companies vary greatly in whom they accept for insurance and the terms they offer. The [British Heart Foundation](https://www.bhf.org.uk) can give you a list of insurance companies who are sympathetic to people with heart conditions. [GUCH](https://www.guch.org.uk) (Grown Up Congenital Heart Patients’ Association) can give advice on the types of life insurance available and provide details of companies that may consider life insurance for people in ‘high risk’ categories.

13. Our son has to have a 24-hour electrocardiogram. What will this involve?

An electrocardiogram is a recording of the electrical impulses from the heart. Small patches, set in sticky plaster, are put on the arms, legs and chest and connected to a recording machine.
patches, which are called 'electrodes', are connected to wires which lead to an ECG recorder. This recorder picks up the electrical signals produced by each heartbeat. A few beats from each set of electrodes are recorded onto paper.

A 24-hour electrocardiogram involves continuously recording an electrocardiogram (ECG) over 24 hours. The recording is usually done as an outpatient. Your child will have to make two visits to the hospital: once to have the recorder fitted and once to return it. Small patches (electrodes), set in sticky plaster, are put on the front of the chest. Wires are attached to these and are taped down. The wires lead to a small portable tape recorder, similar to a personal stereo, which your child wears on a belt round his waist. The whole system is very comfortable, quiet and relatively unobtrusive. Your son will be able to do all his normal daily activities except having a bath or shower.

14. My daughter has congenital heart disease. Will she be able to have children of her own? And what are the chances of her children having a heart defect?

Generally speaking, if your daughter is symptom-free she should be able to manage a pregnancy. However, there are some types of congenital heart conditions where pregnancy poses certain risks or may not be advised. Before she considers pregnancy she will need to talk to her cardiologist about it. He or she will probably suggest that she has a series of tests to find out how well her heart is working. She will then need to visit an obstetrician (a doctor specialising in pregnancy).

During pregnancy the circulating blood volume can increase to one and a half times its normal volume. This means extra work for the heart so a woman with congenital heart disease may have to rest more than the average pregnant woman. It is important that she has frequent antenatal and cardiac check-ups.

A normal labour and delivery are thought to be safest for most women with a heart defect. A Caesarean section is advised only if there are other problems, in the same way as with other pregnant women.

A small number of women may be advised to have their babies in a pregnancy unit adjacent to their cardiac centre, because of the need for careful heart monitoring at the time of delivery.

For women who have a heart defect, there is a 2% to 5% chance that her baby may have a similar defect. (This means that, of babies born to women with a defect, between 2 and 5 in every 100 will have a similar defect.) If her partner also has a heart defect, the risk is obviously greater. At about 16-20 weeks of pregnancy, a special ultrasound test called a foetal echocardiogram may be done, to check on the baby’s heart. If the baby has a severe defect, there is the possibility of terminating the pregnancy. This is something that the woman and her partner would need to talk about beforehand.

15. My daughter had an artificial valve and conduit fitted when she was five weeks old. How long do conduits and valves last for?

They usually need replacing after about five years. The younger the child was when he or she had the first operation, then the more replacements will be needed as the child grows up.

16. What is a shunt and what does it do?

A shunt is a piece of narrow tubing about 4mm in width. It helps the flow of the blood from the aorta to the rest of the body.
17. My 18 month old daughter needs to have surgery to close her atrial septal defect. What risks are there that she might die or suffer a stroke?

The risks are very low. Obviously it will depend on your child’s condition. Your surgeon will discuss your child’s risk and outcomes with you before you give your consent to the operation. It is very important that you feel that you have understood what the surgeon has told you. If you are unsure, ask him or her to go over it again.

18. My son will need to take Warfarin after his next operation. What will this involve on a daily basis and how will it affect what he can do?

Warfarin is an anticoagulant; it will thin the blood and stop blood clots from forming. It will be used if your child has an artificial heart valve and it is sometimes given to children who have shunts, or who may have other problems which could cause clots to form.

Your child will need to take Warfarin every day and he/she will need regular blood tests to check that the dose is correct. Children on this drug should carry a card with them detailing the dose and result of the latest blood test, so that they receive the correct treatment in an emergency. Any medicines containing aspirin should be avoided since it is also an anticoagulant.

Children taking Warfarin are more likely to bleed and bruise so contact sports will need to be avoided.

For more information on warfarin, see the Children’s Heart Federation leaflets Growing up with warfarin and Medicines for heart children and the British Heart Foundation booklet Children on anticoagulants.

19. My two week old baby is going to be in hospital for a while, having surgery. I want to keep breastfeeding her. Will I be able do this?

Many mothers of heart children find it difficult to breast feed. We have found it hard to find mothers to give us any tips, but a lot of mothers opt to express milk and give it by bottle or mixed with food. If you find that you are producing far more milk than the baby needs, don’t worry, keep expressing and put it in the freezer for future use. It will keep for up to three months quite safely and will be invaluable when times get stressful and the milk is scarce.

20. The National Childbirth Trust (NCT) and La Leche League are very helpful and can lend equipment such as breast pumps (electric too), as well as providing practical and emotional support.

For more information on this, see the Children’s Heart Federation leaflet Feeding for children with heart problems.

21. Our daughter is going into hospital to have heart surgery. Where will we be able to stay?

Some hospitals can provide accommodation where parents can stay while their child is in intensive care. Other children can visit and may be able to stay in the accommodation too.

22. Can we ask for help with the cost of travel to the specialist hospital, and our living expenses while our child is in hospital? Who should we speak to about this?

Your social worker, or the hospital social worker, can give you advice on this. See also the Children’s
Heart Federation leaflet *Disability Living Allowance*.

**23. We are planning to go on holiday abroad with our son who has a heart defect. Are there any extra preparations we should make?**

Try to plan your trip abroad so that your anxieties can take a back seat for a while. There are a few tips below, but for more detailed information see the Children’s Heart Federation leaflet *Planning a holiday with your heart child*.

**Arrange with the travel agent**
- In some cases cardiologists advise that the child may need oxygen when flying. You may want your travel agent to sort this out with the airline.
- Make sure refrigeration is available if you need it for medication, both on the airplane and at your hotel.
- Remember to ask these questions: How long will it take you to get back to the airport? Where is the nearest English-speaking doctor? In the event of needing to use your insurance policy, will the travel operator be able to help?
- Call the airline you are travelling with if you would like your family transported to the plane, rather than having to walk to the departure gate.

**Doctors and Specialists**
- Always check that your child is fit to travel. Ask your GP (if your child is generally well) or your paediatric cardiology centre (if your child is still frequently treated or monitored) for advice. You may also need to take a letter from your GP or Cardiologist saying that your child is fit to travel.
- Secure insurance before you buy the tickets. Make sure that it will cover the cost of bringing both you and your child back to the home hospital. For travel in Europe take an E111 card which will allow you to recoup all the money spent on treatment.
- Ask your cardiologist for the nearest paediatric centre to your destination and learn how to say that your child has a heart condition in the local language. Write the words down so that you don’t forget them!

**Medicines**
- Make sure you have the appropriate medicines and know how to store them. You may need to carry a prescription to prove that they have been prescribed by a doctor. It is a good idea to carry two supplies (keep them separate) of any essential drug since many travellers have problems with lost luggage. Carry medicines in your hand luggage so that you can monitor how they are being stored.
- If your child is on Warfarin remember that changes in the weather, diet and lifestyle can affect the INR reading so you may want to test your child more frequently while on holiday.

**At the airport**
- Pacemakers may set off alarms when going through security, so carry the child’s pacemaker card and warn the security guard.
- If your child’s diet is likely to change, try and do it slowly. Take a concentrated bottled fruit juice and make it up with bottled water instead of giving fizzy drinks. It is important for any child not to go short of drinks.
- Smaller children may need to eat little and often. Buying snack food in a foreign currency can be seriously expensive - carry a large supply of acceptable biscuits.
- Be careful with exposure to the sun, always use a high factor sunscreen and remember that scar tissue burns very easily.

**24. What impact will having a pacemaker have on my child’s life?**
The heart has its own natural pacemaker, the sino-atrial node which regulates the beating of the heart. However if it is damaged or if your child suffers from a slow heart beat for some or all of the time (bradycardia) an artificial pacemaker can be permanently implanted. This is a small battery and tiny computer which is usually placed in the chest wall or abdomen, just under the skin.

The pacemaker will regulate your child’s heartbeat Most pacemakers given to children will be able to sense when the child’s heart beat needs to be faster- for example when the child is running around. They can also be adjusted without the need for surgery during routine checks. However your child will probably need to use a pacemaker for the rest of his or her life. When a pacemaker is fitted you will be given a card to show you’re your child has had a pacemaker fitted. This will show the correct heart rate for the pacemaker and can be used as proof that your child has a pacemaker for airport security etc.

Ask your cardiologist if there are any restrictions placed on your child by his or her heart condition. If all else is well the pacemaker should free the child to be as active as any other although the child should avoid sports and activities, which may cause the site of the implant to be knocked, such as boxing, bungee-jumping, dodgems or rugby.

The pacemaker manufacturer’s booklet should normally explain what types of appliances may interfere with the pacemaker function. There are very few of these, most everyday electrical items do not interfere with modern pacemakers. This includes microwave ovens, drills and office and light shop equipment.

Here is a list of some devices to watch out for:

- Pacemakers will set off some types of alarm, such as those used in airports. To avoid embarrassment, make sure that security is aware that your child has a pacemaker.
- Shop and library detectors may cause a slight interference, so the child should not stand in the detector or lean against it, just simply walk through.
- Heavy or power-generating equipment such as arc welders, and powerful magnets used in some medical devices may cause problems.
- Mention the pacemaker to your dentist or doctor if they are going to use to a treatment using an electrical or magnetic implement.
- Mobile phones can cause a problem, so if your child has to use one, use it on the side of the body away from the pacemaker.
- Theme parks sometimes stop children from using some rides. Write or call before you visit and ask if there are any restrictions.

For information on this, see the Children’s Heart Federation leaflet If your child needs a pacemaker

25. How long will my child's pacemaker last for?

It is usually several years before a pacemaker needs to be replaced and all being well, batteries are designed to work for a number of years. Your child will have regular checks to see that the pacemaker is working properly (called a box check). As a child gets bigger, the wires from the battery to the heart may need to be replaced with longer ones. Otherwise, normally only the battery part will need to be replaced.

26. How long can a transplant last for?

Several years. The length of time is improving due to the ongoing improvement of drugs to prevent the body from rejecting the new heart.
27. If a child needs a heart transplant, does he or she have to be given a child’s heart?

Not always. The chest cavity of a child with congenital heart disease may be larger than the average child’s, so there is room for a larger heart.

28. What are the signs of heart failure?

Going off feeds or having difficulty feeding, being pale, sweaty or breathless, having a swollen tummy or puffy eyes, lethargy and grunting, and poor urine output.

29. My son has supraventricular tachycardia (SVT) and I’ve been told to check his pulse on a regular basis. How often should I be doing it? Are there any particular situations when it is important to check it?

Medication usually controls SVT, but your doctor has suggested that you check your son's pulse as a way telling if he has an SVT attack coming on. You should check the pulse if there are any signs of an SVT attack. Older children can usually tell you if they are having an attack. If a baby goes off his feeds this can be a sign of an attack coming on. Look for signs daily. Bathtime and bedtime are good times to check the pulse.

For more information on SVT see the Children’s Heart Federation leaflet SVT and your child.

30. My child has supraventricular tachycardia (SVT). What should I do if she has an attack?

A very fast heart rate is called a tachycardia. In children the most common kind of tachycardia is Supraventricular Tachycardia - SVT for short.

The most common symptom that people seem to notice in babies is that they can see a blood vessel in the neck twitching. Most children will be pale and breathe faster. Toddlers may be irritable and then tired. Children who can talk might say they have a funny or sore feeling in their chest, or tummy if they haven't quite got the difference sorted out yet.

An attack can last for seconds or hours - but any feeling of weakness or illness should go as soon as the heart rhythm is back to normal. Many children are remarkably well during these attacks, although some have discomfort and weakness.

For information on this, see the Children’s Heart Federation leaflet SVT and your child.

31. The medicine my baby needs had to be made up specially in the hospital. Will I be able to get the medicines he needs from my local chemist?

Most hospital pharmacists liaise with local chemists after your child has been discharged from hospital. You will need to give your local pharmacist several days' notice for further prescriptions.

32. Can my baby have his immunisations?

It is especially important that children with heart conditions avoid potentially serious diseases, so make sure that your child has all the routine immunisations, in consultation with your GP or cardiologist. If your baby has a history of convulsions, your doctor may advise against having the whooping cough immunisation. And he may not be able to have immunisations if he is about to have surgery or has a problem with his immune system.
33. My baby is having problems feeding and taking his medication and I’m finding it difficult to cope at home. Where can I get help from?

Many heart babies are difficult to feed, but there are no clear reasons why. Make sure you share the worry and responsibility. Let other people (husbands, grannies, neighbours, friends etc) help you feed the baby even though you may feel that you do it best. You may well do it best, but having a break from feeding, even if it is only once a day, makes all the difference to the terrible stress and worry. Don’t even ask how it went! A nurse at your paediatric cardiac unit may also be able to help.

Remember, you are not alone!

Contact the Children’s Heart Federation and read their excellent leaflet Feeding for children with heart problems.

34. Why do I need to take extra care with my child's teeth? What do I need to do?

Dental disease or its treatment can cause a disease of the heart called Infective Endocarditis. This is an infection of the inner lining of the heart caused by bacteria in the blood stream.

Remember to tell the dentist that your child has a heart condition. This is important because children with heart conditions need to take antibiotics before they have dental treatment such as having a tooth out, or having a deep filling.

For more information on this, see the leaflet What have teeth got to do with the heart? from the Children’s Heart Federation.

35. Our child is oxygen-dependent. Where can I get small size cylinders so that we can go out for the day?

Ask your GP or your respiratory nurse specialist to prescribe lightweight cylinders.

36. Is there any financial support or government allowances available to help us to care for our child at home? You may be able to get Disability Living Allowance, or funds from charities to help with things like extra bedding and holidays. Ask your social worker or the hospital social worker. See also the Children’s Heart Federation leaflets Disability Living Allowance and Family support grants.

37. What causes congenital heart disease?

In most cases, the cause of heart defects is not known.

The heart is formed between the sixth and twelfth weeks of pregnancy - often before the mother realises that she is pregnant - and it is at this time that the defects happen. There are some things that may increase the risk of having a baby with heart conditions. These are:

- Having rubella (German measles), diabetes or a viral infection during pregnancy.
- Drinking too much alcohol during pregnancy.
- Smoking during pregnancy.
- Taking certain medicines during pregnancy.

Down’s syndrome accounts for 1 in every 20 cases of congenital heart disease.

As more research is done, it becomes clear that some heart defects are genetic (which means that
they can be passed on from a parent to a child through the genes).

38. What are the chances of my partner and I having another child with a heart problem?

Most paediatric cardiac units have links with genetic departments. Ask your cardiologist to refer you to one.

39. I’m frightened that my grandchild is going to die but I don’t want to talk to my son about my worries. Is there anyone I can talk to about my concerns?

You can call the Children’s Heart Federation Helpline on 0 808 808 5000. They can offer you advice and perhaps put you in touch with a local support group.

40. My grandchild has recently been diagnosed with a heart condition. What can I do to support my daughter and her husband?

The Children’s Heart Federation provides a helpline for all those with a concern or interest in heart children, and we often get calls from grandparents who want to understand how they can best help. Their first problem is that they don’t understand the heart condition. Their second is they need to know how they can be of help to their grandchild’s family.

One in 125 children is born with some kind of heart defect; most of these do not need treatment or can be corrected so that the heart works properly from early childhood.

You may have strong memories of children who died as a result of heart problems. This may mean that you have unnecessary fears for your grandchild, and these are making it difficult for you to talk to your family.

We can help you to understand about heart conditions that children are born with, and how most of these disorders are treated. And nowadays over 95% of children who need open heart surgery survive.

My daughter won’t talk to me

We often hear that family relationships deteriorate when a child is born with a heart problem. Worry about the heart child can make the parent a difficult and selfish person. For your son or daughter, taking on the fears of their own parents as well as their in-laws can be very hard, and hearing their outdated advice can be even harder.

“I caught my daughter feeding Josh cream” said one worried grandmother “and I know that cream is bad for the heart and much too rich for babies anyway. So I told her, and all I got back was ‘You don’t understand’”.

Josh’s mum is trying to increase his weight, so he will be bigger and stronger before he has heart surgery. The dietician may have advised her to feed Josh a high calorie diet - lots of butter and cream on everything!

Being a good grandparent

Please forgive parents, who are short with you, hang-up the phone before you’ve finished speaking, and won’t confirm arrangements in time.
Uncertainty and emotional turmoil strain relationships at a time when everyone's priorities change. Your son or daughter may want to protect you and support you, but just may not have the emotional energy to do it.

'I discovered that my daughter was desperate and did not think I cared - I had made the mistake of thinking that they were coping well...'

Offer help

If it is turned down the first time offer again. You may be urgently needed if a baby is taken into hospital, to run the household for a period of time.

Some other areas you may be able to help with are babysitting, getting other children to school, or someone to work, collecting washing, cooking, checking post and making sure bills are paid.

From my experience the parents cannot ask for help, you have to continuously offer help and be prepared to do ANYTHING.

Visiting the doctor

Your son or daughter may want you to be with them while talking to a cardiologist, as two lots of ears are sometimes better than one.

And if they do not want you at the consultation - well, just getting to out-patient appointments can be hard. Make it clear that you are prepared to park the car, sit in the waiting area with the buggy and the outdoor clothes and the changing bag, so parents can see the doctor unencumbered.

Other help

If you are not close enough to offer this kind of help, stay in touch by short telephone calls; leave time free when you may be able to help, and especially keep an offer of financial help available if you can.

A child with a health problem can be very expensive in terms of travel to and from hospital, affording other domestic help and can damage long-term career opportunities too.

Listen

The parents of children with heart defects often become quite expert in their knowledge and their ability to deal with problems that come up. Take the opportunity to learn from your children and when they want to talk, listen.

For parents of heart children it is a great luxury to have someone for whom you, rather than your child, are a priority, to pour out all the resentments and fears.

I send cards, sometimes flowers to celebrate every small triumph - like when she took more than a few mils of milk, the day she didn't vomit..... And the day she sat up was champagne!

Other grandchildren
The brothers and sisters of heart children can often find themselves overlooked by relatives anxious to keep abreast of the poorly child’s progress. Parents can find it hard not to make their heart child the centre of their attention. Grandparents can play a valuable part in giving other children extra time, perhaps freeing up a parent to attend a school play, or taking a child on a shopping trip.

Ongoing disability

Some children have a severe heart problem, or have a number of health problems. This may need your ongoing support and understanding. Although you yourself may not be able to offer care for a child with behavioural problems, for example, or who needs to be physically moved, your support for the rest of the family is doubly important.

Perhaps the hardest thing to remember is that it is the parents of the child who are the authority on their family, and when you go home they still need to carry on. You can only offer help; you cannot insist that it is accepted. Do not be too sensitive to rejection of either your advice or your help. Make it clear when and how you are available, and that your affection for the family is steadfast.

Help for you

We can provide you with information about heart defects - just call the helpline number 0808 808 5000.

Other grandparents - there are grandparents who are involved with a heart child who would be happy to talk to you.

Support groups - many support groups for families of children with heart disorders would welcome your involvement. There are always areas in which you can help - fundraising, children’s parties, committees, organizing, cooking, publishing, dressing up as Father Christmas - these are just a few of the roles that grandparents play.

And thank you ...

Often on the ward we see grandparents sitting with children while parents take an hour or two to sleep, or work, or see to other members of the family. And off the ward, at fundraising events or social occasions, again it is often grandparents on the stall, baking the cakes, selling the tickets.

“When our son was periodically very ill it was his grandma who rescued us from having to look after the other children, brought delicacies into hospital for Mum and Dad as well as making the fruit juice jellies which were the patient’s staple diet.

She has always been a source of strength and love, even at those benighted times when we were anguished and surly - we acknowledge what she did for us at much sacrifice to her own comfort.”

This information comes from the Children's Heart Federation leaflet How to be a grandparent to a heart child.

Last reviewed April 2010.