



Oxford University Hospitals
NHS Foundation Trust

CONGENITAL HEART DISEASE

**Information for
parents and carers**



This booklet has been written to provide additional information for families who have a child who has been diagnosed with a heart condition.

Our services

The Southampton and Oxford Cardiology service provides specialist treatment for children with congenital and acquired heart disease. We care for children across a wide area.

Our network team includes consultant cardiologists (specialist heart doctors), surgeons, nurses, dietitians and psychologists. We work closely with other services to make sure we provide the best care for your child.

Congenital Heart Disease (CHD)

About 8 in every 1,000 children is born with some form of congenital heart disease (CHD). In some children this is very mild and never requires treatment. However, for others the problems can be much more serious and may require complex heart surgery (sometimes several operations). These children will need to be followed up by a heart specialist for the rest of their lives. For most children, the severity of their heart condition is somewhere between the two.

What causes CHD?

We don't know all the answers to this question, but we do know that there are some things which increase the chance of having a baby with CHD. If one of the parents or a previous child was born with a heart abnormality, then the risk of another child being born with a heart problem increases to around 3-6%.

Where there is no such family history, the risk of a child being born with CHD is about 1%.

Some serious illnesses in the mother (e.g. diabetes) and some drugs taken in pregnancy (including some taken to control epilepsy) can also put the risk up slightly.

Some forms of CHD are seen in children with genetic abnormalities (e.g. Down's syndrome).

Parents often ask if there was something that they did or did not do during pregnancy which caused the heart condition. The answer to this is usually "no". Unfortunately it is something that just happens, in the majority of cases. We do not yet have an answer for 'why?'.

Can CHD be diagnosed before birth?

The baby's heart is completely formed early in pregnancy. By 19-20 weeks the heart is about 2cm in size and big enough to be examined carefully using ultrasound (at the same stage as the whole baby is examined at the anomaly scan).

As equipment has become more advanced it is now possible to bring forward this examination. It can sometimes be done as early as 14-16 weeks (repeated at 20-22 weeks).

Not all heart problems can be ruled out at this time, partly because the baby's circulation is different before birth. However, it should be possible to diagnose the most serious abnormalities of the heart at this stage of the pregnancy.

This special scan of the heart (a fetal cardiac scan) is available to parents who are at an increased risk of having a baby with CHD.

What the Children's Cardiac Nurse Specialist service can offer:

Experienced Children's Cardiac Nurse Specialists are there to provide continued support and information to families and carers upon diagnosis of a heart condition.

The nurse specialists can:

- Help your child to understand their heart condition and how this might affect their lifestyle as they get older.
- Provide verbal and written information about your child's cardiac condition, tests and treatment. They can also offer information about appropriate support groups, and identify other places you can find further information.
- Provide general information about hospital services, facilities, etc. They can also provide specific information about admission to hospital, and procedures/surgery that your child may need.
- If your child is in hospital they will continue to provide support and information about treatment, and be there to discuss any worries or concerns you may have. They will help ward staff prepare you and your child for discharge home.

After your child has left hospital

- The nurse specialists will continue to provide information, advice and support. They are there to act as a resource for your health visitor, children's community nurse and school nurse.
- They can provide details of and carry out referrals to other non-medical professionals who may be helpful to you. This may either be within the hospital or the community, for example the dietitian, children's community nurse or psychologist.

Signs and symptoms to look out for

Your cardiologist will discuss with you any specific signs that you should look out for, before and after surgery. However, if your child develops any of the symptoms below you should contact the Cardiac Nurse Specialists for advice. If you have 'open door access' at your local hospital, ask for your child to be reviewed.

Contact us if your child:

- is more breathless than usual or has difficulty breathing
- is sweeter than usual (cool and clammy)
- has increased difficulty feeding
- looks 'dusky' or 'bluer' than usual
- has episodes of being 'floppy' or looking more pale than usual
- experiences sudden, unexplained fainting
- has funny feelings/palpitations in their chest
- is vomiting up medication
- has increasing tiredness or a lack of energy.

How to contact us

Children's Cardiac Nurse Specialists

Tel: **01865 234 985**

(9.00am to 5.00pm, Monday to Friday)

There is an answerphone available, which will provide details of when the nurse specialists are available and also alternative telephone numbers to contact if they are not available.

Alternatively, if your call is urgent, please call the Oxford Hospital's switchboard.

Tel: **0300 304 7777** and ask for Bleep **4170**

Email: **orh-tr.ccnsoxford@nhs.net**

If your child is due to have treatment in Southampton, you may wish to contact their Children's Cardiac Nurse Specialist team for information about the unit there.

Tel: **023 8120 4659**

What to do if you are concerned about your child

Call 999 and ask for an ambulance if your child:

- has a sudden collapse and is unresponsive
- has a prolonged change in skin colour, becomes more blue/grey than usual or their skin is cool to touch or waxy looking
- develops persistent noisy breathing, is struggling to breathe, or is 'grunting'
- is choking.

If your child has new symptoms that you are concerned about, please call the Children's Cardiac Nurse Specialists.

Outside of hours call **Bellhouse-Drayson Ward**.

Tel: **01865 231 247** or **01865 231 237**

Ask the nurses to discuss the symptoms with the paediatric cardiology consultant on call.

If you are advised to see another health professional, please take a copy of your child's most recent discharge or clinic letter with you.

Precautions

- If your child has diarrhoea and/or vomiting and is unable to keep down any medications they may be taking, contact their GP or Cardiac Nurse Specialist for advice. This is particularly important if they are taking diuretics or captopril.
- If your child has a cyanotic 'blue' heart condition, it is very important that they don't become dehydrated. This is because their blood is thicker than usual and the haemoglobin (Hb) level is higher.

If you think your child is dehydrated, contact their GP for advice as soon as possible. Take care when your child is out in the sun/hot weather. Encourage them to drink plenty of fluids, to avoid dehydration.

- A balanced diet with plenty of iron is also recommended, particularly for children with cyanotic heart conditions.

Information about medication

Storage

All medicine should be stored safely at home, out of the reach of young children or in a locked cupboard.

Any special instructions, such as the need to keep it in a fridge, will be printed on the label.

Re-ordering

The hospital will provide you with enough medicine for at least the first two weeks at home. Before this runs out you will need to see your child's GP to arrange further prescriptions. We will send a letter to your GP, telling them what medicines your child is now taking.

Contact your local pharmacy as soon as possible, to make sure they stock the medicine. You can do this before you get the repeat prescription. Some pharmacies need to order certain medicines, and this may take several days or even weeks. If you use the same pharmacy regularly, they should be able to arrange a repeat prescription service for you.

Be aware that some pharmacies may supply a **different strength** of the medicine than the one supplied by the hospital. Please check each new prescription and supply carefully. If your pharmacy has difficulty supplying your child's medicine or the strength they require, ask them to telephone the pharmacy at the John Radcliffe Hospital for advice/ordering details.

Giving your child medicine

Older children may take liquid medicine off a spoon. Babies can be given medicine using an oral syringe; the hospital will supply this. Squirt the medicine slowly into the corner of your baby's mouth, a little at a time. Do not mix medicines in bottles of milk/juice as if your baby does not finish it, it will be difficult to calculate the amount given.

What to do if your child vomits or spits out the medicine

Give your child their medicine before feeds/meals, unless the instructions on the bottle say not to. This is less likely to make your child sick.

If your child is frequently spitting out or vomiting their medicines, please contact the Children's Cardiac Nurse Specialists for advice. Some medicines work very quickly, so it can be less harmful for your child to miss a dose than have too much medicine from being given a 'replacement' dose.

What to do if you forget a dose

This depends on how often the medicine is being given and how long it is before the next dose:

- If a medicine is given twice a day and you forget to give the evening dose until a couple of hours later that is fine. (Do remember, if the medicine is a diuretic it will make your child pass urine, which may result in late night trips to the toilet.) If you remember after this time, miss that dose and wait for the next one.
- If the medicine is given three times a day and you forget a dose, but realise a few hours before the next one, just miss the forgotten dose and carry on as usual.

If in doubt, call the Children's Cardiac Nurse Specialists for advice.

Over the counter medicines

Ask your local pharmacist for advice about which over the counter medicines are safe to take at the same time as their current medications.

Financial assistance/benefits

Bringing your child for hospital appointments or for a hospital admission may cause you financial stress.

Disability Living Allowance (DLA) for children

If your child is under 16 and requires more care than a child their age would normally need (such as nasogastric feeding, oxygen, etc.), you may be eligible to claim this allowance. DLA is granted depending on the care needs of your child, not on their heart condition or syndrome. It is important that you fill in the application form with as many details as you can.

Please ask the Cardiac Nurse Specialist or your children's community nurse for further information.

The Children's Heart Federation (CHF) also provides a useful leaflet explaining this allowance.

Website www.chfed.org.uk

Little Hearts Matter have examples of completed DLA applications for children with single ventricle conditions.

Website: www.lhm.org.uk

You can apply online via the GOV.UK website:
www.gov.uk/disability-living-allowance-children

Alternatively, you can contact the DLA helpline and ask for a DLA claim pack for a child.

Tel: 0800 121 4600

It is helpful to get advice when completing the application form. Your health visitor, children's Community nurse, Cardiac Nurse Specialist or social worker should be able to help you.

Travelling expenses

If you are on a low income or certain benefits you may be able to claim travelling expenses. Ask at the reception desk in the Outpatients department when you come for your child's appointment, or on the ward if your child is being admitted to hospital.

Travelling with your child

If you are planning a holiday with your child there are some things that you should consider before you book:

- Temperature – will your child cope with very hot or cold weather?
- Transport – will your child cope with long journeys; can they fly? Short haul or long haul? Will they require oxygen?
- What are the medical facilities like where you are going?

All children have different requirements and these may change over time. If you have any concerns or need advice about travelling with your child, please contact your child's consultant or the Cardiac Nurse Specialists.

It is helpful to take a copy of your child's most recent clinic letter with you, in case your child needs to see a doctor while you're away. It should contain a summary of your child's treatment and their current medication.

Insurance

It is important that your child is fully insured and you provide the insurance company with all the relevant details of your child's heart condition.

In Europe it is helpful to have a European Health Insurance Card (EHIC), which entitles you to free or reduced cost emergency treatment. You can apply for one at the Post Office, by telephone or online.

Website: www.gov.uk/european-health-insurance-card

Your insurance company may ask for a letter from your child's consultant, to confirm that their condition is stable or they are fit to fly.

If you have any problems getting travel insurance, please contact the Cardiac Nurse Specialists for advice.

The British Heart Foundation (BHF) have information about travel insurance on their website:

www.bhf.org.uk/informationsupport/support/practical-support/travel-insurance

Medicines

Make sure you take an adequate supply of all of your child's medicines with you. You may need to have a fridge available to store some medicines or INR testing strips. If you are carrying bottles of liquid in your hand luggage, you should consider the current airline requirements about transporting liquids. Carry a copy of your child's most recent clinic letter with you, to show as evidence for the medication your child needs to take.

If you are taking an INR monitoring machine, you should carry this equipment in your hand luggage. You may need a supporting letter from the consultant, Cardiac Nurse Specialist or GP for this.

Other things to consider when travelling:

Long-haul flights – Make sure your child has a good fluid intake, particularly if they are cyanosed (this is because their blood is thicker than normal and more likely to clot).

Hot climate – A good fluid intake is important, particularly if your child is cyanosed or is on diuretics, as they will be more likely to become dehydrated in hot conditions. Also remember that scar tissue may be sunburnt more easily.

There is a useful leaflet produced by the Children's Heart Federation called 'Planning a holiday with your heart child', which has more details on things to consider when travelling. This is available on their website:

www.chfed.org.uk

Infective endocarditis

Infective endocarditis is a rare but serious condition in which bacteria can settle on the lining of the heart (sometimes including a heart valve) and cause an infection.

It is more likely to occur if the lining of the heart, the endocardium, is rough. This can be where there is scarring from surgery or where there is turbulent blood flow (e.g. through a narrow valve). This rough surface makes it easier for the bacteria to attach.

What causes infective endocarditis?

Infective endocarditis is caused by certain types of bacteria or other organisms, which get into the bloodstream in large numbers. Once in the heart, they attach to an area of endocardium which is rough and an infection develops.

Preventing infective endocarditis

Although it isn't possible to stop all bacteria getting into the bloodstream there are a number of things that can be done to reduce the risk of getting endocarditis:

- **Good oral hygiene**

Problems such as gum disease and tooth decay can cause infective endocarditis; therefore it is important that your child cleans their teeth and mouth, ideally twice a day, using fluoride toothpaste and visits the dentist for regular check-ups (every 6 months).

- **Body piercing and tattoos**

Your child should avoid having body piercings and tattoos, as these have a high risk of infection.

- **Infections on the skin**

Antibiotics are recommended for infected cuts/grazes (not ones that are healing normally), infected eczema, infections around finger and toenails, or chicken pox spots that become septic.

Previously, people at risk of infective endocarditis were offered antibiotics before certain dental and medical procedures. In March 2008 the National Institute for Health and Care Excellence (NICE) introduced new guidelines. The research surrounding endocarditis has shown that taking antibiotics to prevent endocarditis in these circumstances is not necessary.

Following the introduction of these guidelines it is recommended that antibiotics are only given for these procedures if there is an active infection present in the area. There are some exceptions to this; for example if your child has had a mechanical heart valve implanted or has had previous endocarditis.

It is important that any medical, nursing or dental personnel treating your child are aware that they are at increased risk of infective endocarditis.

Symptoms of infective endocarditis

Early symptoms may be flu-like, a high temperature, tiredness, shivering and night sweats, breathlessness, weight loss and joint pain. If these symptoms continue for longer than a week take your child to see their GP or contact your child's Cardiac Nurse Specialist. It is important to get early diagnosis and treatment for this condition.

Treatment of infective endocarditis

Infective endocarditis is usually treated successfully with a long course of intravenous antibiotics in hospital (usually 6 weeks). However, surgery may be needed if the infection does not respond to treatment and a heart valve becomes damaged.

Dental care

What have teeth got to do with the heart?

It is important that children with even a minor heart abnormality look after their teeth and visit the dentist regularly. This can help to prevent endocarditis, which can be caused by bacteria getting into the bloodstream from an area of dental decay. Good dental hygiene is highly recommended.

Avoiding dental disease

Children should be taught to clean their teeth thoroughly, twice a day, with fluoride toothpaste.

Many medicines contain a large amount of sugar, which is bad for gums and teeth. Ask your doctor or pharmacist if a sugar-free formula is available. Your child should brush their teeth after medicine given at bedtime, including sugar-free medicine..

Tell the dentist that your child has a congenital heart defect.

Advice leaflets about dental care for children with heart conditions are available from:

The Children's Heart Federation

Website: chfed.org.uk

Heartline Association

Website: www.heartline.org.uk

Support groups

British Heart Federation (BHF)

Provides useful information and fact sheets for parents who have a child with a heart condition, as well as information for teenagers and adults.

Customer Line: 0300 330 3322

Support line: 0300 330 3311

Website: www.bhf.org.uk

Children's Heart Federation (CHF)

Provides support and information for families, with a telephone helpline for parents, teachers and health professionals. Fact sheets are available on feeding, travelling abroad, benefits and Disability Living Allowance, etc.

Freephone Helpline: 0300 561 0065

Website: www.chfed.org.uk

Contact

A resource for families of children with specific conditions and rare disorders. Provides information about support groups and resources throughout the UK.

Freephone Helpline: 0808 808 3555

Website: www.cafamily.org.uk

Down's Heart Group

Written information, website and support for families of children with Down's syndrome and congenital heart disease.

Telephone: 0300 102 1644

Website: www.dhg.org.uk

The Somerville Foundation

Provides support for young people and adults with congenital heart disease. Provides fact sheets and information about employment, insurance, etc. Organises social events.

Patient helpline: 0800 854 759 (Answerphone only at weekend)

Website: www.thesf.org.uk

HeartLine

For children with heart conditions and their families. They can supply the 'Heart Children' book for families.

Email: intouch@heartline.org.uk

Website: www.heartline.org.uk

Little Hearts Matter

Offers information and support for families of children diagnosed with a single ventricle condition.

Telephone: 0121 455 8982

Website: www.lhm.org.uk

Max Appeal

Supporting families affected by DiGeorge syndrome, 22q11.2 deletion and velocardiofacial syndrome (VCFS).

Telephone: 0300 999 2211

Website: www.maxappeal.org.uk

Cardiomyopathy UK

Written information, advice and support for children and adults with cardiomyopathy.

Telephone: 0800 018 1024

Website: www.cardiomyopathy.org

Families of Ocean Ward

Parent support group for families who have been treated on Ocean Ward, in Southampton Hospital. Offers emotional support and some financial support for families of children referred to Southampton.

Email: info@oceanward.co.uk

Website: www.oceanward.co.uk

Also via Facebook

There are other specialist support groups for children with Turner syndrome, Noonan syndrome, Marfan syndrome and others. If you would like more information, please ask the Cardiac Nurse Specialists.

Useful websites

Aboutkidshealth

www.aboutkidshealth.ca

Website with information for parents and children. From the Hospital for Sick Children, Toronto.

American Heart Association

www.heart.org

Contains information about heart defects.

Birmingham Children's Hospital

www.bwc.nhs.uk

Contains general information, how to get there, parking, etc.

Cardiac Risk in the Young

www.c-r-y.org.uk

Raises the awareness of cardiac risk and offers support to families who have lost a family member through sudden death.

Cincinnati Children's Hospital

www.cincinnatichildrens.org

Excellent website about heart defects.

Children's Hospital Boston

www.childrenshospital.org

Information about heart defects.

Children's Hospital of Philadelphia

www.chop.edu

Excellent information about most congenital heart conditions.

Congenital Heart Disease Website

www.nicor4.nicor.org.uk

Website providing information about surgical and catheter procedures from all units across the UK. Shows survival rates for the most common procedures.

Cove Point Foundation

www.pted.org

Congenital Heart Disease information for children and adults from Helen B Taussig, Children's Heart Center, Johns Hopkins University.

Great Ormond Street Hospital for Sick Children (GOSH)

www.gosh.nhs.uk

Contains general information, details relating to accommodation, parking, how to get there, etc. Also a variety of fact sheets for parents.

Website has links to other sites relating to health and illness for young people.

Southampton General Hospital

www.oceanward.co.uk

www.uhs.nhs.uk/ourservices/childhealth/childrenscongenitalcardiacservices

Information for parents and children about the ward in Southampton.

For children and young people

BHF Children and Young People

www.bhf.org.uk

BHF site providing information, games, chat and events aimed at children and young people.

Little Hearts Matter – Youth Zone

www.lhm.org/uk/zipperzone

Space dedicated to children and young people with a single ventricle condition and their siblings. Here you can share and read stories, discover information about your heart, get lifestyle tips and much more.

The Somerville Foundation

www.thesf.org.uk

Support for young people and adults with congenital heart disease.

Second opinions

We have always endeavoured to keep up to date and to present full information to children and families about the condition being dealt with and treatment options.

If you would like to discuss your child's treatment with another cardiologist (a second opinion) we would encourage you to ask their child's cardiologist for this. (You are entitled to this as your child is an NHS patient). This can be with a consultant in Oxford or at another Children's Cardiac Centre.

Useful phone numbers

If you have any questions or concerns then please call us:

Your child's consultant cardiologist is:

Consultants' secretary:

Oxford Children's Hospital

Children's Cardiac Nurse Specialists: **01865 234 985**

Bellhouse-Drayson Ward: **01865 231 247** or
01865 231 237

Oxford University Hospitals Switchboard: **0300 304 7777**

Southampton General Hospital

Children's Cardiac Nurse Specialists: **023 8120 4659**

E1 Ocean Ward: **023 8120 6470**

Great Ormond Street Hospital, London

Children's Cardiac Nurse Specialists: **0207 405 9200**
ext 5774

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.



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