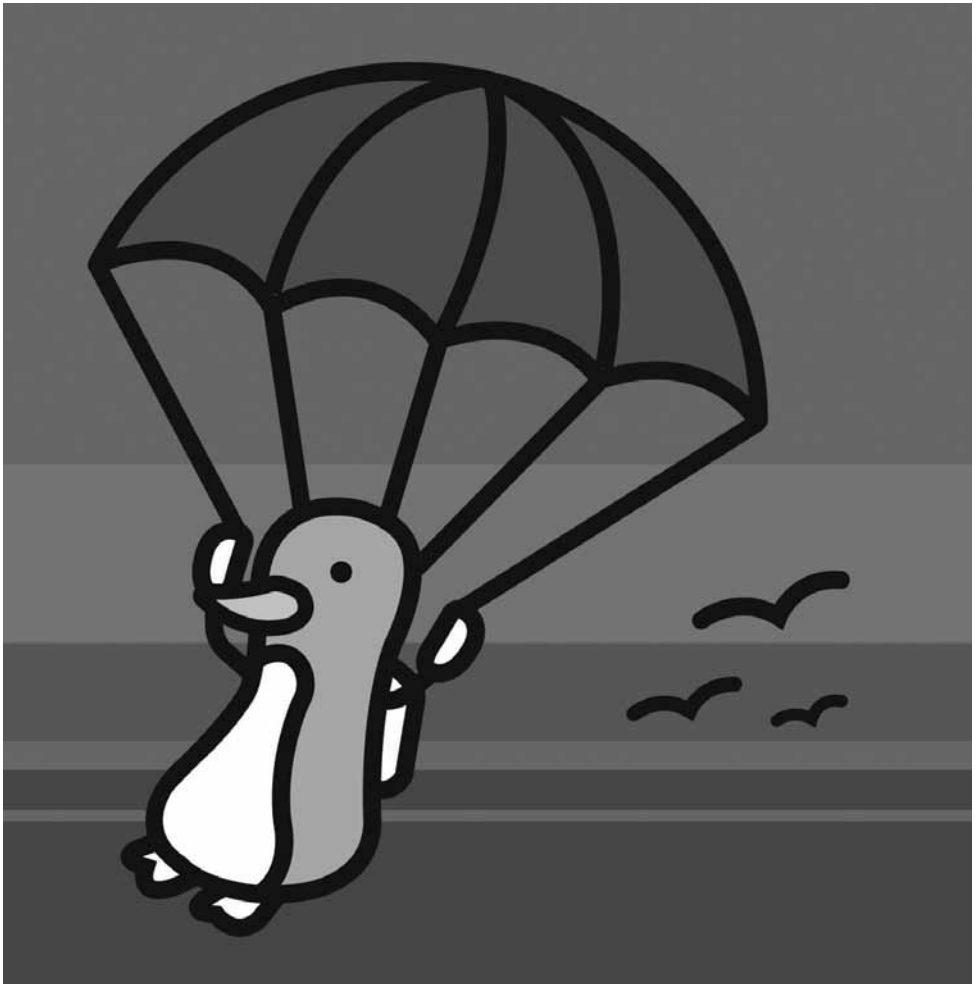


Congenital Heart Disease

General Information for parents



General information for parents

This leaflet is to provide additional information for families who have a child with congenital heart disease (CHD).

Congenital Heart Disease (CHD)

About 1 in every 100 children is born with some form of congenital heart disease (CHD). In some 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% (or 94-97% chance of being born with a normal heart). Where there is no such family history the risk of a child being born with CHD is 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 2cms 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 and in some cases it can 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. But 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.

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 is likely to 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 there.

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 should clean their teeth and mouth, ideally twice a day, using fluoride toothpaste and go to 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.

Until recently people at risk of infective endocarditis were offered antibiotics before certain dental and medical procedures. In March 2008 NICE (National Institute of Clinical Excellence) introduced new guidelines; they have looked at research about endocarditis which 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.

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

Symptoms of infective endocarditis

Early symptoms may be flu-like, fever, tiredness, shivering and night sweats, breathlessness, weight loss and joint pain. If these symptoms continue for longer than a week then you should take your child to see their GP or contact the hospital. It is important to get early diagnosis and treatment for this condition.

Treatment of infective endocarditis

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

What have teeth got to do with the heart?

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

Avoiding dental disease

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

If the water in your area is not supplemented with fluoride then fluoride drops may be advisable. Ask your dentist where you can get these, if necessary.

Avoid sugary foods and drinks between meals. Sweets are best given after a meal.

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.

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

Advice leaflets regarding dental care for children with heart conditions are available free of charge from:

- The Children's Heart Federation – telephone 0808 808 5000
- Heartline Association – telephone 01276 707 636

What the children's cardiac nurse specialist service can offer:

Experienced children's cardiac nurses are there to provide continued support and information to families and carers upon diagnosis of a heart defect.

Advice/information

On diagnosis, they will provide verbal and written information about your cardiac condition, tests and treatment. They can also offer information regarding appropriate support groups, and identify other places you can find further information.

Pre-admission

The children's cardiac nurse specialists can provide general information regarding hospital services, facilities etc. They can also provide specific information about admission to hospital, and the procedure/surgery to be undertaken.

During your hospital stay

They will continue to provide support and information regarding 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 discharge from hospital

The nurse specialists will continue to provide information, advice and support once your child is back at home. They are there to act as a resource for your community team, health visitor, children's community nurse and school nurse.

Referral to other professionals

The nurse specialists will also be able to provide details and carry out referrals to other non-medical professionals who may be helpful to you. This can either be within the Children's Heart Service or the community team, i.e. social worker, dietitian, children's community nurses.

Contact details

The children's cardiac nurse specialists are:

Kathy Lurcook and Georgie Stepney

Telephone number: **01865 234 985** (answerphone available)

The answerphone will provide details of when the specialist nurses are available and also alternative telephone numbers to contact if they are not available.

Alternatively, if your call is urgent please ring: **01865 741 166** – ask for Bleep **4170**

Support groups:

British Heart Federation (BHF)

Provides useful information and fact sheets for parents who have a child with a heart condition; also information for teenagers and adults.

Greater London House
180 Hampstead Road
London NW1 7AW

Telephone: 0207 554 0000

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.

Level One
2-4 Great Eastern Street
London EC2A 3NW

Freephone Helpline Telephone: 0808 808 5000

Website: www.chfed.org.uk

Contact a Family

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

209-211 City Road
London EC 1V 1JN

Telephone: 0207 608 8700

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.

PO Box 4260
Dunstable
Beds LU6 2ZT

Telephone: 0844 288 4800

Website: www.dhg.org.uk

The Somerville Foundation (previously GUCH)

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

Saracens House
25 St. Margarets Green
Ipswich IP4 2BN

Patient helpline: 0800 854 759 Answerphone only at weekend

Website: www.thesf.org.uk

HeartLine

For children with heart conditions and their families. Provides information packs for families and can put parents in touch with other parents whose child has a heart condition. They can supply the "Heart Children" book for families.

HeartLine Association
32, Little Heath
London SE7 8HU

Telephone: 03300 22 44 66
Website: www.heartline.org.uk

Little Hearts Matter

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

11 Greenfield Crescent
Edgbaston
Birmingham B15 3AU
Telephone: 0121 455 8982
Website: www.lhm.org.uk

Max Appeal

Supporting families affected by DiGeorge syndrome, 22q11.2 deletion and Velo Cardio Facial Syndrome (VCFS).

Freepost Max Appeal
15 Meriden Avenue
Wollaston
Stourbridge
West Midlands DY8 4QN
Freephone Telephone: 0800 389 1049
Website: www.maxappeal.org.uk

The Cardiomyopathy Association

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

Unit 10 Chiltern Court
Asheridge Road
Chesham
Bucks HP5 2PX

Telephone: 0800 018 1024

Website: www.cardiomyopathy.org

Young Hearts

Local parents support group for families who are managed by the Children's Hospital, Oxford. Provides telephone advice, organises social events for families and may be able to provide some financial support for families.

PO Box 602
Abingdon
Oxon OX14 2XQ

Telephone: 0845 4673052

Website: www.younghearts.co.uk

There are other specialist support groups for children with Turner's Syndrome, Noonan's Syndrome, Marfan's Syndrome and others. If you would like more information please ask the cardiac nurse specialists.

Useful websites

Aboutkidshealth

www.aboutkidshealth.ca/en

Excellent 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.bch.org.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 of heart defects.

Children's Hospital Boston

www.childrenshospital.org

Information about heart defects.

Children's Hospital of Philadelphia

www.chop.edu/service/cardiac-center/heart-conditions

Excellent information about most congenital heart conditions.

Congenital Heart Disease Website

www.ccad.org.uk/congenital

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

Congenital Heart Information Network (USA)

www.tchin.org

International organisation which provides information, support and resources to families of children with CHD, acquired heart disease and adults with CHD. Has links to other relevant websites.

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.

DiPEX – Personal experiences of health and illness

www.healthtalkonline.org/heart_disease/Congenital_Heart_Disease

UK website where families share their experiences of having a child with CHD.

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.

Heart Children Translations

www.hearttranslations.co.uk

Heart Children book translation site. Languages available Urdu, Punjabi, Bengali, Hindi, Gujarati, Arabic, Italian and Somali.

Royal Children's Hospital, Melbourne, Australia

www.rch.org.au/cardiology/parent_info/parent_information

Excellent website for information on many heart defects.

Rush Children's Heart Centre, Chicago, USA

www.rush.edu/rumc/HealthInformation

Excellent website with factsheets and diagrams.

Southampton General Hospital

www.oceanward.co.uk

Information for parents and children about the ward in Southampton.

For Children:

cBHF

www.bhf.org.uk/cBHF

Great games, activities and information for children.

Children First

www.gosh.nhs.uk/children

Excellent fun website divided into age appropriate sections which allows children to explore at their own pace

For Teenagers

Meet@TeenHeart

www.yheart.net

BHF site providing information, games, chat and events aimed at teenagers.

The Somerville Foundation

Previously Grown-up Congenital Heart Patients Association (GUCH)

www.thesf.org.uk

Support for young people and adults with congenital heart disease.

Useful phone numbers

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

Children's cardiac nurse specialists: **01865 234 985**

Bellhouse-Drayson ward: **01865 231 247/8**

John Radcliffe Hospital: **01865 741 166**

If you need an interpreter or need a document in another language, large print, Braille or audio version, please call **01865 221473** or email **PALSJR@ouh.nhs.uk**

Kathy Lurcook & Georgie Stepney
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www.ouh.nhs.uk