

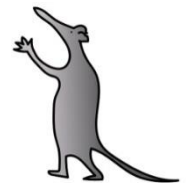
Cardiac Department
Cardiac Catheterisation

Information for parents and carers

Introduction

You have recently been informed that your child requires a cardiac catheter. The information in this booklet aims to answer any questions you may have about the procedure and will cover the following main areas: -

- What is a cardiac catheterisation?
- Where will the catheterisation be performed?
- Admission for catheterisation
- Going home after cardiac catheterisation



Should you have any questions about any of the information in this booklet or about the admission please contact the Cardiac Liaison Nurses on 0151-252-5291.

What is a cardiac catheterisation?

In children a cardiac catheterisation is performed using a general anaesthetic and x-ray. This means that your child will be asleep throughout the procedure. During the procedure a fine narrow tube is inserted into the blood vessels normally in the groin area, at the top of your child's leg. Very occasionally the blood vessels in the arm or the side of the neck may be used. The tube is then passed gently into the heart via the blood vessels. The doctor will move the catheter around and measure the pressures in different parts of the heart and take blood samples if necessary.

A special dye is injected through the catheter into the heart (this can be filmed and viewed at a later date). All this information gives the team a more detailed picture of your child's heart. When the procedure is over, the catheter is taken out and a pressure bandage is put over the entry site (at the top of your child's leg) to help stop any bleeding.

Another test, known as a trans-oesophageal echocardiogram (T.O.E.) can be done at the same time as the catheter. A TOE involves a probe (a tube) being passed down the back of the throat. This allows the cardiologist to get some very clear pictures of your child's heart from a different angle and can be very helpful in getting a more detailed picture of your child's heart condition. If your child is having a TOE the cardiologist will discuss this with you during consent.

The results of the cardiac catheter are usually available straight away. The consultant will see you the same day to explain the results and answer any of your questions. It may be that the Cardiologist needs to discuss your child with other members of the team, for example the surgeons and therefore you may be given more information at a later date. You will be told this on the day of the catheter if this is the case.

There are three types of Cardiac Catheters:

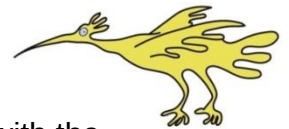
Diagnostic Cardiac Catheter - To obtain more information, confirm a diagnosis or help the team decide appropriate timing for your child to have their heart operation.

Interventional Cardiac Catheter - To stretch ("balloon") narrow valves or vessels, close a hole or a vessel using a device. This can be done instead of heart surgery in some but not all cases.

Electrophysiology Study and Ablation - This is to diagnose heart rhythm problems and destroy (ablate) abnormal or irregular heart rhythm tissue. Using an electrode catheter the doctor locates the abnormal rhythm and radio frequency or freezing energy is used to destroy the areas causing the problem.

Information about your child's procedure

The outcome of cardiac catheter procedures are kept on a database to provide the Department of Health with figures on how many and what type of catheters are done each year and the outcomes of the procedures. This information is used to make certain that each centre gives care of the highest standard. The doctor who asks you for your consent to do the procedure will discuss with you how the information is shared. All the information is available for the public at www.ccad.org.uk/congenital



Possible complications of any catheter procedure

It is important that you discuss the specific risks of the procedure for your child with the Cardiologist before the procedure and that you understand both the risks and the benefits.

Complications that can occur during and/or after the procedure include, but are not restricted to:

Bleeding from the blood vessel – This usually responds to pressure being applied over the puncture site (the point on the body where the catheter was inserted). Blood vessels in children are small and cardiac catheterisation can cause blood clots to form and block blood flow. This is seen more commonly in babies and is usually only temporary. This is why your child's dressing will be checked regularly once they are back on the ward.

Blood vessel blockage – Your child may need a blood thinning drug (heparin) to be given via a drip if this occurs. If this fails to work then a clot busting drug (alteplase) is given through a drip. This is why you will see the nurses checking the blood supply in the feet by feeling for a pulse. Your child's discharge may be delayed if this happens.

Abnormal heart rhythms - (heartbeat too fast or too slow). These are quite common while the catheter is moving through the heart. Usually moving the catheter is all that is needed to resolve the problem. On rare occasions medication, an electric shock or a temporary pacemaker may be needed to stabilise the rhythm. Once your child is back on the ward they will be connected to an E.C.G monitor so that their heart rhythm can be monitored.

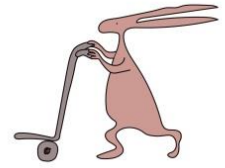
Damage to the heart structures – This is very rare. The doctor may use a needle to aspirate (remove) blood from around the heart and an operation may be needed to repair the damage.

Side effects of the anaesthetic – these involve being very drowsy, vomiting, high temperature or chest infection following the procedure.

If the Cardiologist needs to do something unexpected they will seek your consent first. In case of an emergency we do not need to seek your consent but you would be informed of any treatment as soon as possible. It is very important that you remain within the ward during the time your child is having their catheter so that you can be contacted straight away.

The risk of death or serious complication is extremely low although the risk may be slightly increased in: -

- newborn or very young infants
- patients with high blood pressure in their lungs
- patients with bleeding or clotting disorders
- patients who are very blue (cyanosed)
- patients whose heart function is poor



Where will the catheter be performed?

All catheters are performed at Alder Hey Children's NHS Foundation Trust. Your child will normally be admitted on the day of the procedure. Some patients will be day cases, others may stay overnight - your Cardiologist or one of the Cardiac Nurse Specialists will discuss this with you.

Where will my child be nursed after the catheter procedure?

Your child will be nursed on Ward 1C, however occasionally, children may need to be nursed in the Critical Care Unit.

Who will perform the procedure?

Cardiac catheterisation is performed by consultant Cardiologist who specialises in this field. This may/may not be the cardiologist you see regularly in clinic.

Specialist Registrars are also involved in performing procedures under supervision.

EP studies and RF Ablations are performed by the heart rhythm specialists (Dr Todd, Dr Hall) who are based at Liverpool Heart and Chest Hospital.

Organising the Cardiac Catheter Admission date

Please ensure that the details we have about you and your child are correct and update the hospital if you change your telephone number.

We need a daytime contact telephone number in case we can bring you in at short notice. If you have call barring we need a different day time contact number..

At this stage it is important that you tell us about any of the following problems as the procedure may need to be postponed.

- **Dental issues:** It is very important that your child does not have any outstanding dental treatment. Problems with children's gums or teeth can be a major source of infection and bugs entering the blood stream. In children with heart disease this can lead onto a serious infection with the heart called Endocarditis. The catheter procedure may be postponed if your child is found to have dental decay or require any fillings.
- Your child has recently had their immunisations within two weeks of the planned procedure date.
- Your child is unwell with infection or has a cold or flu like symptoms.
- Your child has been in contact with any infectious diseases recently, for example chicken pox or measles.

Pre-admission Clinic

After your child has been added to the list for cardiac catheter you will be contacted via letter to arrange a visit to the Pre-admission Clinic held in the Cardiac Outpatient (2.2) at Alder Hey. This clinic appointment usually lasts about one and a half to two hours. The cardiac procedure would normally take place the week or two after this clinic.

At the clinic we will check height, weight, oxygen saturations and blood pressure. We will also check two swabs (nose and groin area) for MRSA. Your child may also have an ECG and echo.

You will be seen by one of the cardiac team to ensure that your child is well and can go ahead for the procedure and one of the Cardiac Nurse Specialists to discuss the procedure. For girls over the age of 12 we will ask about her periods and the possibility of her being pregnant. We do not routinely check any bloods at this clinic but will take blood samples during the catheter procedure to check kidney function, iron levels and a blood group. If your child is having a valve implantation then we will ask for a blood test.

Medication Advice

If your child is on a medicine called Warfarin you will need to discuss when to stop it with the Cardiac Specialist Nurses. Your child should start taking their Warfarin again once they are awake after the procedure.

If your child is waiting for an RF Ablation and is on an anti-arrhythmic medicine please discuss with the Cardiologist's Secretary when your child needs to stop taking their medication before admission.

All other medication should continue to be given unless you are given specific instructions by our hospital team.

Getting to Alder Hey and what to bring with you

There is a map of the Alder Hey site on our website. Please note: The post code for Sat. Nav is L14 5AB

It is expected that you make your own way to and from the hospital. If you are on particular benefits you may be able to have your travel costs reimbursed-you need to bring any relevant documentation and receipts as proof.

Car parking is available. The cost is £2.00 per visit.

Your child will be wearing a theatre gown going to and returning from the catheter room. They can change into loose clothes if they are going home the same day, or pyjamas/nighties if staying overnight. Please also bring slippers, a dressing gown if you have one and some toiletries. Please bring nappies for your baby/child.

Patients can bring hand held electronic games or other small items, such as books, games to use before and after the procedure.

We would recommend you bring an overnight bag for your child and one parent in case you need to stay. Bring nightwear, slippers and toiletries. You do not need to bring linen or towels.

Admission on the day of procedure to ward 1C

Morning cases will be asked to come in at 7am or 7.30 am and the afternoon cases at 10am or 11.00 am. The Cardiac Nurse specialist will tell you what time you need to come in.

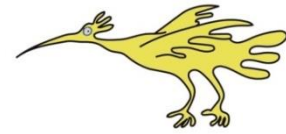
Children must have a bath or shower and a hair wash before admission, including clean nails and arrive for their catheter in clean clothes. This is to minimise wound infections. Long hair must be tied back, but make sure there is no metal in the bobble. For older children, the groin area where the catheter will be inserted may need to be shaved.

It is important that your child has an empty stomach before having an anaesthetic. You will be given clear instructions about when your child needs to stop eating and drinking before the procedure. This is called being "nil by mouth" and these instructions must be followed. It is also important that children do not chew gum or suck sweets whilst they are "nil by mouth".

One parent/carer will be able to accompany their child to theatre and be able to stay until their child is asleep. A nurse will then escort you back to the ward. Following the procedure a parent/carer can go with the nurse to the recovery area in theatre to collect your child. If your child needs to stay on the ward overnight then ONE parent/carer can be accommodated at the bedside. Other parents/carers should make arrangements to sleep at home or book in at a hotel. We have details of local accommodation if required.

Discharge advice following cardiac catheter

Please ask the ward staff any questions before you leave



Caring for the wound site

The puncture site is quite small and does not need stitches. It should heal within a few days. The area around the site may become slightly discoloured and bruised and can be covered by a small plaster to keep the site clean but this is not essential.

Your child can have a bath or shower every day but should avoid having long hot baths for the first three days.

Pain relief

There may be some discomfort or pain for a few days after the procedure particularly if your child has a bruise. Loose clothing can help to reduce discomfort around the puncture site. Also your child can be given Paracetamol but do not exceed the dose recommended for your child's age.

Medication

Continue with the same medication as before the procedure unless your Cardiologist advises otherwise.

You may be asked to start giving your child a new medicine. If this is the case you will be given a supply before you go home from hospital. Make sure you understand why your child needs it, how to give it and how long to give it for. Your GP will provide repeat prescriptions.

Return to normal activities

Your child may be tired for a day or so but should be able to resume most activities, including going to school, within a couple of days unless advised otherwise by your Cardiologist. They should avoid cycling and sports for a week.

Immunisations

Your child can restart any immunisation programme about one week after the procedure, unless the cardiologist tells you otherwise.

When to contact the ward for advice

It is very important to contact the ward immediately if any of the following occur:

- There is bleeding from the puncture site.
- The wound site becomes red, swollen and painful.
- The leg becomes discoloured, appears swollen or feels colder than the other leg.
- Your child complains of 'pins and needles' in the leg.
- Persistent high temperature (particularly if they have had a device inserted)

However if you are concerned about your child's colour, breathing or there is excessive bleeding from the catheter site please call 999 and ask for an ambulance. They will take you to the nearest A&E department for assessment.

Follow-up appointments

Your child's follow up will be arranged following discharge – you should receive a letter asking you to make an appointment, if your follow up is at Alder Hey. Otherwise you will be sent an appointment in the post by your local hospital. If you are unsure about the plans for your child's follow up or don't have Cardiac appointment please contact the Cardiac Secretaries

For more information or support before or after the procedure:

Alder Hey Children's NHS Foundation Trust Switchboard: 0151-228-4811

Cardiac Nurse Specialists 0151 252 5291 Monday to Friday 8.00am to 5.00pm

Ward 1C 0151 228 4811 Select blue option ext. 4156 or 2740

Cardiac Secretaries 0151 252 5710, 0151 252 5173, 0151 252 5711, 0151 252 5633

Organisations / parent groups you may find helpful

Children's Heart Association (this is our local parent support group)

23 Hesketh Drive

Heswall

Wirral CH60 5SP

01706 213632

website: www.heartchild.info

email: information@heartchild

British Heart Foundation

Greater London House

180 Hampstead Road

London NW1 7AW

020 7544 000 or 0300 330 3311

Website: www.bhf.org.uk

Children's Heart Federation

Level One,

2-4 Great Eastern Street

London EC2A 3NW

0808 808 5000

www.childrens-heart-fed.org.uk



Max Appeal (for children affected by Di-George syndrome)

13 Meriden Avenue

Wollaston

Stourbridge DY8 4QN

01384 821 227

01562 710 708

Website: www.maxappeal.org.uk

e-mail: maxappeal@cableinet.co.uk

Grown Up Congenital Heart Patient's Association (GUCH)

Saracen's House

25 St Margarets Green

Ipswich IP4 2BN

0800 854 759

website: www.guch.org.uk

email: admin@guch.org.uk

Little Hearts Matter
(for children/babies with single ventricle anatomy-who will be having Fontan surgery)
75 Harborne Road, 4th floor
Edgbaston
Birmingham
B15 3BU0121 455 8982
website: www.lhm.org.uk email: info@lhm.org.uk

Downs Heart Group
17 Cantilupe Close
Eaton Bray
Dunstable LU6 2EA
01525 220379
website: www.down-heart.downsnet.org email: downsheartgroup@msn.com

Arrhythmia Alliance (for patients with arrhythmias)
PO Box 3697
Stratford upon Avon
Warwickshire CV37 8YL
01789-450787
website: www.arrhythmiaalliance.org.uk e-mail: info@arrythmiaalliance.org.uk

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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