

Paediatric Cardiac Nurse Specialist Team
Cardiac Surgery Discharge Advice

Information for parents and carers

Introduction

The Paediatric Cardiac Nurse Specialist Team and Ward 1C Staff are here to help you to prepare for your child's discharge home. Your child will only be discharged home when the Cardiac Team feel that they are fit to do so. We hope you find the following information useful.

Before you go home you will be advised of the timescale for your post-operative clinic review, this is usually around a week after you go home. The surgical team aim to give you a discharge file which includes a copy of your operation notes prior to you going home. You will also get a copy of the ward discharge letter.

The cardiac nurse specialist team aim to call you a few days after you go home to assess how things are and ensure you have been given an out-patient appointment date and time. Please contact the cardiac nurse specialist team's advice line on 0151 252 5291 if you have any concerns and questions. The advice line will most likely go to voicemail, please leave a message and we aim to return your call that day whenever possible.

There is a new initiative from NHS England involving an online patient experience survey for Congenital Heart Disease which was rolled out in February 2018. It is an on-going survey that parents / children and patients over 16 can fill in at each admission or each clinic appointment, its take approximately 5 minutes to complete either after the clinic appointment or following discharge from an inpatient admission. The website is www.chdpatientsurvey.co.uk

Alder Hey has also introduced a concept called Alder Play for our young patients. This is an app which uses gaming and augmented reality to help to distract patients having procedures in hospital. Children can choose their own avatar which will help them to understand their hospital visit before they arrive. The avatar helps them to collect "rewards" following procedures which leads to access to new content. The Alder Play app is available for iPhone and Android via your app store.

The journey home

Where possible, your child should not travel home by public transport. If you don't have your own transport please arrange for someone to pick you up. Your baby/child will need to sit in their car seat or use a seatbelt as usual. If you have a long way to go it may be beneficial for your child to stop for breaks. Please ask the ward on admission with regard to applying for a 10 day or 30 day car park pass, otherwise you will be charged at the daily parking rate for the duration of your stay.

What to expect when you go home

- Your child may take between four to six weeks to fully recover after their heart surgery. If your child has had a Fontan procedure they may take longer to recover.
- Your child may not seem quite themselves. They may have physical issues to deal with such as tiredness, pain, stiffness and have sleeping difficulties. They may have loss of appetite.

- Babies may tire easily when feeding. It may help to wind them frequently. Your baby should achieve a minimum of 100mls/kg/day i.e. if your baby is 3.5kg they should be taking a minimum of 350mls in a 24 hour period. Ideally your baby will be taking approximately 120-150mls/kg/day. The expected fluid volumes will be explained to you prior to discharge.
- Current World Health Organisation guidelines (Reference 1) say that you should not wean until your baby is around six months old. However, early weaning, at 17 weeks old, to solids may be recommended by the Cardiac Team.
- If your child has continuing feeding issues, please contact the Paediatric Cardiac Nurse Specialists. Your child may be referred to a Dietician, a Speech and Language Therapist (SALT) or to the Cardiac Feeding Clinic at Alder Hey.
- Your child may behave differently. They may be irritable, clingy, have nightmares or wet the bed. With time and patience things should gradually improve. If they do not, then please contact the Paediatric Cardiac Nurse Specialists.

Resuming normal activities



- Your child will probably know their limitations and should be allowed to rest.
- If your child has had a sternotomy, you should avoid lifting them under their arms for six weeks after surgery whilst the sternum (breastbone) heals. When lifting your child you should scoop them under their head and bottom.
- If your child is of school or nursery age, they may be able to return to school within three – four weeks. You should check with the Cardiologist when you come to clinic for your child's post-operative check. Half days at nursery or school may be best for them at first.
- Your child should not take part in physical sports / activity for 6 weeks after surgery to avoid injury to the surgical site. This includes PE at school, cycling, horse riding, swimming and trampolining.
- It is important that your child keeps to their immunisation schedule. Immunisations, including the flu jab, should not be given two weeks before surgery or cardiac catheterisation and four weeks after cardiac surgery. If your child is on the Waiting List for further cardiac surgery and is due immunisations, please contact the Paediatric Cardiac Nurse Specialist Team. Please ask your child's Paediatrician for specific advice if your child has a compromised immune system e.g. 22q deletion (DiGeorge Syndrome), asplenia or is on steroids.
- Children on Warfarin therapy should be given their immunisations subcutaneously rather than intramuscularly.

Medication

- Your child may go home on some medication; if this is the case you will be given 14 days' supply of these medicines. Your child's medication will be reviewed by the Cardiologist at their post-operation clinic check. Further information about your child's medications can be obtained from www.medicinesforchildren.org.uk, your local pharmacist or via the Cardiac Nurse Specialists.
- If your child needs the medication for more than 14 days, your GP will need to prescribe these. We will give you a copy of the discharge letter to take to your GP practice; this will contain information regarding your child's operation and any medications they are on. The medicine may not be routinely stocked in your local pharmacy, so you may need to give them plenty of notice when you need a new prescription. Please contact the Paediatric Cardiac Nurse Specialists if you experience any difficulties. Some drugs can be difficult to obtain from local pharmacies e.g. Spironolactone and Sildenafil.

- It is important to check the strength of the medicine dispensed by your GP as it may differ from the medicine given to you at Alder Hey or Manchester Children's Hospital. If you are unsure, please speak to your local pharmacist.
- Before your child is discharged, nursing staff or a pharmacist at Alder Hey will explain how to give your child their medication. It is important when you are at home that you check the dose and the time it is to be given; it may help to keep a record of which medications are due and note when they have been given.
- Medication should be given at regular intervals, as prescribed. It is usually best to give babies their medicines before their feed to reduce the risk of vomiting. If your child does vomit after their medicine, do not repeat the dose as it is difficult to say how much of the medicine has been absorbed. Give your child the next dose of medicine at the normal time.
- If your child is on medication and has vomiting or diarrhoea for more than 24 hours, contact your GP or the Paediatric Cardiac Nurse Specialists for advice, especially if they are on Furosemide, Warfarin or Aspirin.
- It is advisable not to put medicine in your child's bottle or drinks. If your child does not finish their drink, the full dose of the medication will not have been given.
- Most medicines are available in a liquid form and can be given in the required small amounts, by spoon or in an oral syringe supplied by a pharmacy. If the medicine is in a liquid form and is not sugar free, please encourage your child to have a drink of water afterwards, as this may help to prevent tooth decay.
- If you have been advised by the Speech and Language Therapist to only give your child thickened feeds, oral medications should also be thickened. Do not put medicine in the thickened milk as this may cause the milk's consistency to change.
- Pain Relief: Your child may experience some discomfort or pain during the first few days following discharge. Your child can be given Paracetamol (Calpol). Ibuprofen should be avoided for the first seven days following cardiac surgery. Do not exceed the recommended dose of medicine for your child.
- If your child is constipated following cardiac surgery, they may need medication e.g. lactulose; please contact your GP.
- Please keep all medicines and tablets out of reach of children. Lock them away securely. If the medication needs to be stored in the fridge you may need to put a lock on the fridge door. Ensure the correct storage by checking the label on the bottle.
- If your baby / child is on Warfarin, their INR's and Warfarin dosing will be arranged by the Paediatric Cardiac Nurse Specialists. You will be given a "Yellow Book" and your child's treatment will be discussed with you before they are discharged home.

Wound Care

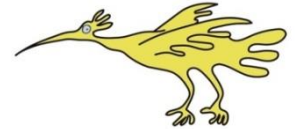
- Your child's wound should heal within four weeks. The wound should look pink around the edges. It is normal for the wound to be a little itchy.
- If there are signs of infection including redness, swelling, and discharge of any kind, fever or pain you should contact the Cardiac Surgical Team at Alder Hey.

They can be contacted on 0151- 282-4515, Monday-Friday 9am-5pm.

Out of hours, please contact the Cardiac Surgical Registrar via Alder Hey Switchboard on 0151-228-4811.

- Your child may have drain site sutures (stitches). These need to be removed 10 days after the drains were removed. We can arrange for a Community Paediatric Nurse to remove the sutures at home, or if this date coincides with your outpatient appointment it can be done here at Alder Hey.
- If your child has sutures in place, the sutures should be kept dry.
- Your baby / child can have a bath when you go home but their wound should not be immersed in the water until it has fully healed. The wound can be splashed with plain water and patted dry. Creams and lotions should not be used until the wound is fully healed. Bio-Oil may be used once the wound has healed.

Long Term Issues



Scar management

Your child's scar, once healed, should be protected with sunblock when exposed to the sun, both in the UK and abroad.

If you need any advice regarding your child's scar, please contact the Paediatric Cardiac Nurse Specialists.

Dental Care and Endocarditis

It is important for your child to continue good dental care after surgery. The general advice of brushing teeth twice a day with a fluoride containing toothpaste is usually sufficient. Your child should have six monthly routine check-ups by their dentist. You should let your dentist know that your child has a heart condition. If your child has dental caries (cavities) and needs further cardiac surgery or a cardiac catheter, the procedure would be delayed until dental treatment is carried out.

NICE guidelines (2008) (Reference 2) state that antibiotic prophylaxis is no longer required prior to dental work in children with a congenital heart disorder. If this is not the case with your child, your Cardiologist will let you know.

Piercing and Endocarditis

Avoid any body piercing as these carry a high risk of infection. Piercings in or around the mouth are very risky. You should check with your child's cardiologist if they are happy for your child to have their ears pierced.

Tattoos and Endocarditis

Once your child reaches 18 they may decide to have a tattoo. Tattoos should be avoided as they also carry a high risk of infection.

If your child has a cyanotic heart condition

If your child has a heart condition which causes them to be cyanosed (blue) make sure they receive extra fluids during hot weather. If the weather is particularly cold ensure your child is well wrapped up and is not outdoors for prolonged periods.

Physical Exercise

Unless you have been told otherwise, your child can resume physical exercise six weeks after surgery.

If your child has a complex heart defect, there may be restrictions on their ability to do competitive sports, but they should be able to take part in some physical activity. Please ask your Paediatric Cardiac Nurse Specialist if you are unsure.

Travel

- It is advisable for your child not to travel by aeroplane for six weeks following Cardio-Pulmonary Bypass (open heart surgery).
- If your child has a complex heart defect, you may need a “Fit to fly” letter. Please contact your Paediatric Cardiac Nurse Specialist Team before you book your holiday if you are unsure.
- It is very important that you have adequate travel insurance when travelling abroad as well as a European Health Insurance Card (EHIC) if travelling within Europe. You must declare your child’s heart condition. A comprehensive list of travel insurance companies is available on the Little Heart Matters website if your child has a single ventricle condition otherwise you can find information on the British Heart Foundation (BHF) and Children’s Heart Federation websites. You may need to contact the insurance companies by phone rather than apply online. (References 3, 4 and 5)
- Please take your child’s surgical file with you when you go away in case of illness; this file will be given to you prior to discharge.
- If you need to take more than 100mls of liquid or refrigerated medicines, you will need to contact the airline to find out if they need any documentation regarding the medications.

When to contact the Cardiology Centre for Advice

It is very important to contact us if any of the following occur as you may need to go to your child’s Cardiology Centre for medical review:

- Shortness of breath, a change in colour, or unusually sweaty.
- Not eating as well as they normally do, or persisting vomiting.
- Sudden unexpected change in behaviour, e.g. unduly irritable, quiet or restless.
- Redness and/or swelling of the wound site and discharge of any kind fever or pain. Please contact the surgical team at Alder Hey if there is a wound problem.



There is a **very rare** risk of infection after open heart cardiac surgery with a bacteria called Mycobacterium chimera. This may be very slow to develop, usually within two years of surgery but occasionally longer. This infection would cause some of the symptoms above. If concerned, please contact us on the details below.

Remember that you know your child best. If you are worried about anything we are here to help. Just telephone:

- Alder Hey’s Paediatric Cardiac Nurse Specialist Team
Monday-Friday 0800-1600 0151 252 5291
(Please leave a message on the answering machine)
- Ward 1C, Alder Hey,
(out of office hours, weekends and bank holidays) on 0151 252 5740

Patients who have a Manchester Cardiologist can contact:

- Manchester Children’s Hospital’s Paediatric Specialist
Nurse Cardiology Service 0161 701 0664 / 0665
- Ward 85,
Manchester Children’s Hospital 0161 701 8500 / 8501

The following link is for information about resuscitation training, if you would like to learn more please click below:

<https://www.treasurehuntadventurepacks.com/offers/T6tkKUwU>

References

1. World Health Organisation (WHO) (2001): **Global Strategy for Infant and Young Child Feeding.**
2. NICE Guidelines (CG64) Published date: March 2008, last updated: September 2015
Prophylaxis against infective endocarditis: antimicrobial prophylaxis against infective endocarditis in adults and children undergoing interventional procedures.
3. www.lhm.org.uk
4. www.bhf.org.uk
5. www.chfed.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.

Alder Hey Children's NHS Foundation Trust
Alder Hey
Eaton Road
Liverpool
L12 2AP

Tel: 0151 228 4811
www.alderhey.nhs.uk

