

E1 Ocean Ward Going Home Information



for children and
parents



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Getting home



This booklet has been written to help you prepare for taking your child home following a stay in hospital.

We hope you find this booklet useful. It mainly explains about care following surgery, but much of the information will be useful if your child has been in hospital for any other reason.

We always try to arrange for the children to be ready to go home in the morning.

If you are travelling home by car remember that your child will need a booster car seat or seat belts as usual and if your journey is a long one take frequent breaks.

Unfortunately the hospital cannot routinely provide transport home.

You will be given a discharge letter when your child leaves hospital. Copies of this letter are sent to your GP and any other doctors involved in your child's care.

At home

When you go home it is quite usual for your child to experience some unsettled periods, for example, waking at night and generally being more 'clingy'. Teenagers may also experience some difficulties and need a lot of reassurance.

These symptoms should soon settle but if they do not, please contact your GP for advice.

When you get home it is important to settle into your daily routine as soon as possible and not plan too much for the first weeks.

Wound care



The wound should be kept clean and dry to help healing. Your child will be able to shower or bathe normally, although you should avoid long soaks for the first four weeks. The wound should then be patted dry. The stitches in your child's wound will dissolve and therefore do not need to be removed. The scar may form scabs, which fall off, and eventually the scar will fade. Protect the wound from direct sunlight as this can hinder healing and make the scar more noticeable.

Should your child suffer any discomfort once at home you can give Calpol, Disprol or Paracetamol, but read the instructions on the bottle carefully, and do not exceed the recommended dose.



Please do not put any oil or moisturiser on the wound site. Please contact your GP if you notice any of the following at the wound site:

- redness
- swelling
- oozing or weeping of fluid from the wound site or
- separation of the wound edge

If your GP is not available, please contact the Liaison Nurse, E1, or your local hospital.

Chest drain sutures are removed five days after the drain has come out. If your child is discharged before this it is usually possible for the children's community nurse or GP to do this for you. We will make these arrangements.

Your child's wounds will heal in time. It is important that he or she does not scratch or pick at their scar to prevent an infection or skin problems.

Activity



Your child's body will need to heal while at home and it may be some time before he or she can return to a normal routine.

Your child's sleep pattern might change after the different routine in hospital, but it will return to normal over time.

You might also find that your other children are being more demanding. This can be related to the increased amount of time you have needed to spend looking after their brother or sister. If you have any questions or concerns, please contact your health visitor or GP, or discuss with the liaison nurses.

Babies and toddlers (0 - 2 years)

Your baby or toddler will not remember the experience of heart surgery. If you have any concerns about their recovery, please contact the liaison nurse or the ward staff.

Toddlers can be quite unsettled or clingy in the first few weeks at home. This can be related to their experience in hospital and the change of environment.

Young Children (2 - 9 years)

Your child should recover three to six weeks after the operation. During the first two weeks, it is important that your child avoids rough play, as much as possible, to allow the breastbone time to heal.

Contact games and certain sports should be avoided for up to six to eight weeks. Please speak with your doctor and physiotherapist for more information.





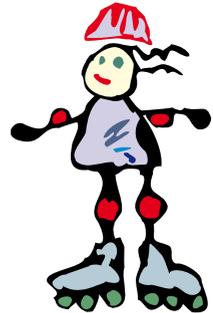
Teenagers and young adults (10 years old and over)

In this age group, recovery from surgery will vary and might take between two to three months.

Your son or daughter has been through major surgery and it is not uncommon for him or her to feel sad or moody. It is good for them to talk about their experiences and we can put you in touch with other parents and children who have been through a similar experience. For more information about support groups, please see page 15.

When can my child go back to school?

Your child can help decide, with members of the cardiology team, when to return to school and how much activity he or she can manage. Usually, your child can return to school six weeks after operation, but may need to start with a half-day or just specific lessons.



It is a good idea to meet with your child's teacher to discuss your child's needs. If the school needs more information or advice, please speak to the liaison nurse.

Medicines



Your child's medication

Your child might need to take medication for some time after going home and the hospital pharmacy will give you at least one or two weeks supply of medicines. You will need to renew the prescription with your GP as soon as possible.

It is important that your child continues to take the medication until the cardiologists tell you to stop. If your child does not take the medication, it can slow their recovery or he or she might need to return to hospital.

We will explain when and how to give the medication before you go home. Many people do not understand the instructions straight away so please do not hesitate to ask us questions.

Your child's medication might need to be measured in an oral syringe. You will be given some syringes with the medication before you go home, but you will need to get a further supply from your local pharmacist or GP.

If your local pharmacist has problems supplying your medication, please ask them to phone the hospital 02380 777222 and ask to speak with a Paediatric Pharmacist.

Sugar-free medication

Please ask your pharmacist to give you sugar-free medicines or those with the least amount of sugar, especially if the medicine is to be used for a long period of time - this will help to prevent problems with your child's teeth.





Storing medication at home

Please keep all medication out of your child's reach. The ideal place is in a locked cupboard.

Please check the label on the medicine container for storage instructions - some medicines need to be kept in the fridge or in a cool, dark place. If medicines need to be stored in a fridge, you might consider getting a lock on your fridge.

Please ask your pharmacist to supply the medicines with childproof lids.

It is important to follow the instructions on the medicine container, as the amount to be given can vary. Different strengths of preparations are available and when you renew your prescription you might not get the same strength.

Please double check with your pharmacist the dose to give each time you renew the prescription.

If you are at all worried please ring the Liaison Nurses or E1 Ward numbers on the back page of this booklet.



Dental hygiene



Good dental hygiene is important for all children, but it is essential for children who have had heart surgery to help prevent endocarditis (an infection in the heart).

Your child might need to have antibiotics before certain dental treatments, to prevent an infection. You will be given an antibiotic guidance card before you go home. If you do not have one, please speak to your nurse.

It is important that your child has regular dental checks, once they reach two years of age, for advice on caring for their teeth and preventing dental problems. For more information, please ask your nurse for a copy of our leaflet, Dental Advice For Children With Heart Disease.

Brushing Teeth

Brushing your child's teeth is very important to prevent tooth decay and infections. A dentist or hygienist can show you how to do this properly. You can start to brush your child's teeth from the time they start to appear. All children should brush first thing in the morning and last thing at night, using a small, soft toothbrush with a small, pea-sized quantity of fluoride toothpaste. Parents should help with brushing up to the age of seven.



Immunisations



Unless there is a specific reason we recommend that your child should be fully immunised. Their immunisations programme can start, or be continued four weeks after surgery.

Please ask the liaison nurse for specific advice on immunisations if your child has no spleen, DiGeorge's Syndrome or 22q chromosome deletion. Children on Warfarin therapy should be given their immunisations just under the skin rather than intramuscularly.

Follow up after discharge

Most children are seen back at the Southampton hospital within one week of discharge. However, if you live a long way from Southampton it may be possible to make an appointment to see one of our doctors at a clinic held at your local hospital.

Children's Cardiac Liaison

The two liaison nurses are children's cardiac nurses who have considerable experience in caring for children with heart conditions.

They are a link for families between the hospital and home and liaise with health visitors, community nurses, teachers and school nurses.

The liaison team run a help line for parents and children, Monday - Friday, 9am - 5pm. If they cannot answer your concerns they can speak to the ward doctor or your child's consultant and ring you back.



Worrying symptoms

Worrying symptoms in babies

Increasing breathlessness

- Increasing blueness
- Poor feeding/sweating with feeds
- Poor weight gain
- Increasing lethargy or irritability
- Puffy face or dry nappies
- Unexplained fevers



Worrying symptoms in children

- Increased tiredness with physical activity
- Poor weight gain
- Fevers
- Pain
- Unexplained concerns

What if my child is unwell at home?

There might be times when your child feels unwell. This could be something related to his or her heart condition or it could be an unrelated illness or infection. Regardless of the problem, there will always be someone available to help you.

If you want some general advice about your child's health, please contact your GP health visitor, Liaison Nurses or E1 Ward.



If you think the problem is related to your child's heart condition, please contact:

- your GP
- the liaison nurses - Monday to Friday 9am to 5pm; or
- E1 Ward - Monday to Friday 5pm to 9am, weekends and bank holidays.

Contact numbers can be found on the back of this booklet.

If the problem is not related to your child's heart condition, please:

- contact your GP, health visitor or NHS Direct on: 0845 4647 or
- go to Accident & Emergency department at your local hospital - the local hospital will contact the cardiologists at Southampton if necessary, for advice.

Dial 999 immediately and ask for an ambulance if your child:

- **has a sudden collapse and is unresponsive; or**
- **your child becomes suddenly unwell.**

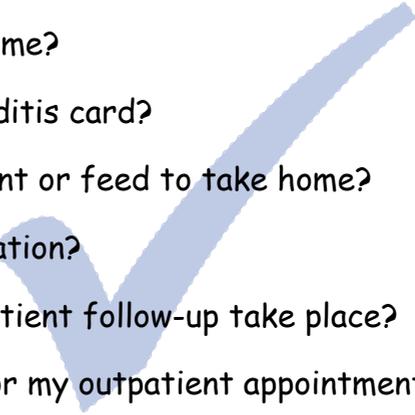
These are uncommon, but it is important to know what to do if they happen.

Please take your child's discharge letter with you.

It contains important information that will be helpful for the local hospital.

Discharge check list for parents

It may be helpful to complete this checklist, to make sure you have all the information you require before going home.

- Does the hospital have up to date address and telephone numbers?
 - What arrangements have I made for going home?
 - What is my understanding of my child's heart condition and long term plan?
 - Who is my child's heart doctor?
 - When should stitches be removed?
 - Has my community team been contacted?
 - Do I understand my child's medicines and how to give them?
 - Do I understand what my child can and cannot do?
 - How will I care for the wound?
 - What symptoms should worry me?
 - Have I got my child's endocarditis card?
 - Do I need any special equipment or feed to take home?
 - Do I need any further information?
 - Where and when will my outpatient follow-up take place?
 - Do I require an interpreter for my outpatient appointment?
- 

Useful websites



Ask Noah About Congenital Heart Defects

www.natural-treatment.net/heart/congenital-heart-defects.php

American Heart Association

www.americanheart.org

Cincinnati Children's Hospital

www.cincinnatichildrens.org

DIPEX.org

www.dipex.org

www.arrhythmiaalliance.org.uk

Hospital for Sick Children Toronto

www.sickkids.on.ca/childphysiology

MedlinePlus: Arrhythmias

www.nlm.nih.gov/medlineplus/ency/article/001101.htm

Melbourne Children's Hospital Australia

www.rch.org.au/rch/index.cfm?doc-id=1495

PediHeart Website

www.pediheart.org

Rush Children's Heart Centre

www.rchc.rush.edu

Variety Children's Heart Circle

www.rchc.ca

We recommend that you use a search engine to help you find these sites.

Please note that the accuracy of information provided by these sites cannot be guaranteed and that the information provided on a certain condition may not all be of relevance to a specific individual.

Support Groups



Wessex Children's Heart Circle

A local family support group which provides support and help for families. The Heart Circle supports the ward with many projects. Newsletter and website.

Children's Heart Federation

National organisation that provides support and information for families. Newsletter and website. **Tel: Help Line 0808 808 5000**

Little Hearts Matter

National support group for families with children with single ventricle conditions. Newsletters, information booklet and website. **Tel: Help Line 0121 456 4521**

Downs Heart Group

National group with local contacts providing support and information for families. Newsletter and website. **Tel: 01525 220379**

Grown Up Congenital Heart (GUCH)

National group for adult and teenagers providing families with support and information. Newsletter, website and social events. **Tel: Help Line 0800 854 759**

Max Appeal

Support group for families with children affected by DiGeorge Syndrome and 22q deletion. Information leaflets, website and newsletter. **Tel: 01384 821227**

Heartline

National support group with a message board which enables parents to talk to each other. Newsletter, information booklet, website. **Tel: 01276 707636**

There are lots of support groups which are linked to individual medical conditions. If you would like information on a support group please contact the Cardiac Liaison. **Tel: Help Line 023 8079 4659**



Contact Details

E1 Ocean Ward
Southampton General Hospital
Tremona Road
Southampton
SO16 6YD
Tel: 023 8079 6470

Cardiac Liaison Nurses Tel: 023 8079 4659
To Bleep Liaison Nurses Tel: 02380 777222,
Enter Bleep: 2478



For a translation of this document,
an interpreter or a version in



please contact Access to Communication

☎ 023 8079 4688