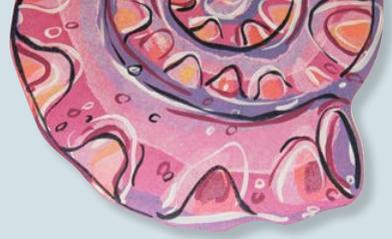


Going home from E1 Ocean ward

Information for patients, parents and guardians





Welcome

This booklet has been written to help you and your family prepare for your child to go home following their stay in hospital. We hope you find it useful. Some of the information is related to care following heart surgery, but a lot of the information will be useful if your child has been in hospital for any other reason.

If you have any questions about anything covered in this booklet, speak to the children’s cardiac nurse specialist (CCNS) team. As we help to prepare you and your child in the days before going home, your child’s nurse will help you complete the discharge checklist on page 13.

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Children's cardiac nurse specialist team (CCNS)

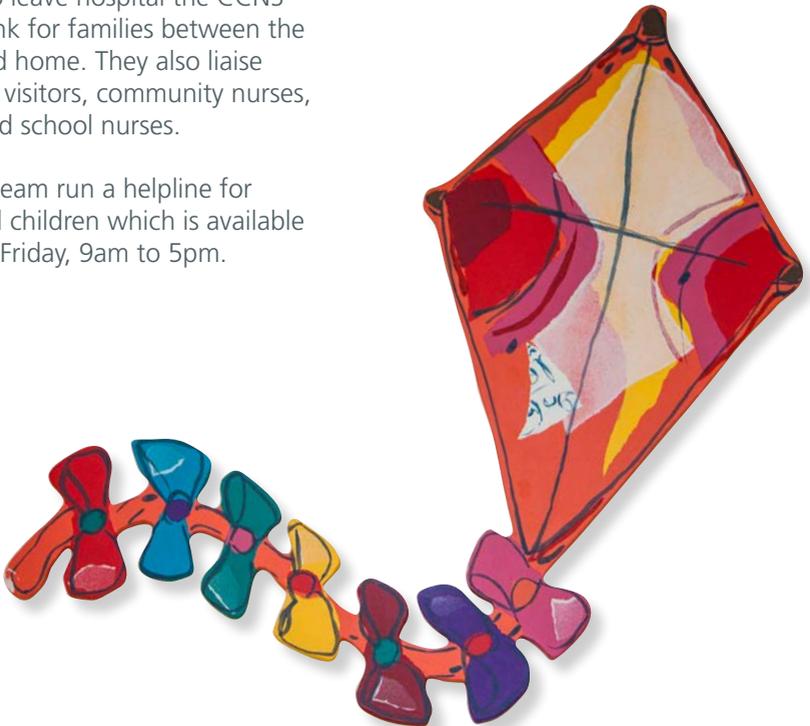
Your child's CCNS will be involved in helping you and your child prepare to go home from hospital.

CCNS are children's cardiac nurses who are experienced in caring for children with heart conditions. When children are ready to leave hospital the CCNS provide a link for families between the hospital and home. They also liaise with health visitors, community nurses, teachers and school nurses.

The CCNS team run a helpline for parents and children which is available Monday to Friday, 9am to 5pm.

If your concerns or questions cannot be answered immediately, the CCNS can speak to the ward doctor or your child's consultant and ring you back.

**Contact the children's cardiac nurse specialists (CCNS) on:
023 8120 4659**



Getting home

We may be able to send you home before 11am if your child has no outstanding investigations and doesn't require any medications. If your child does require medication to take home or any additional investigations, there may be a delay while we complete these. The nurse looking after your child will be able to give you an estimated time of departure on the day.

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

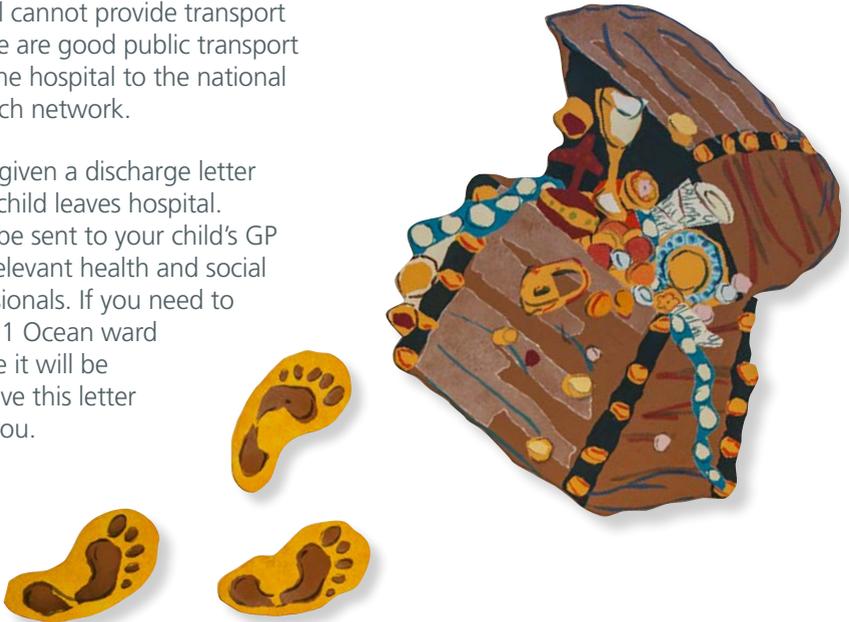
The hospital cannot provide transport home. There are good public transport links from the hospital to the national rail and coach network.

You will be given a discharge letter when your child leaves hospital. Copies will be sent to your child's GP and other relevant health and social care professionals. If you need to telephone E1 Ocean ward in the future it will be useful to have this letter in front of you.

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 child's GP for advice.

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



Recovery

Babies and toddlers (0-2 years)

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

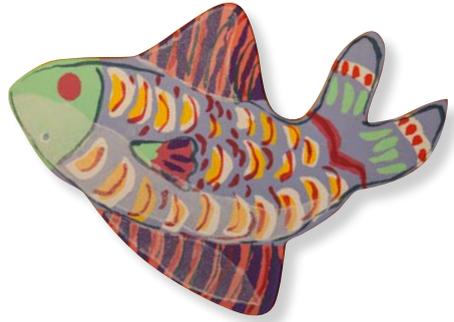
Toddlers can be quite unsettled or clingy in the first few weeks at home, this can be related to their experience in hospital and the change of environment.

For six weeks after surgery remember to avoid lifting your child under the arms to allow their chest to heal.

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

Young children (2-9 years)

Your child should recover four to six weeks after surgery. During the first two weeks, it's important that they avoid rough play as much as possible, to allow the chest bone to heal.



Teenagers and young adults (10 years old and over)

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

Your son or daughter has had major surgery and may feel sad or moody afterwards – this is not uncommon.

It is good for them to talk about what has happened to them and we can put you in touch with other parents and children who have been through a similar experience.

Swimming

Once the wound has healed, your child can visit the swimming pool and play in the water. Your child should avoid using swimming strokes for 12 weeks after their operation.

Activity

Initially on return home it is important to let your child recover from surgery. A little physical activity is important however, for example a gentle daily walk. They can become more active as the weeks go by. You may find that your child's energy levels vary. One day they might feel fine, the next day completely exhausted. This is just their body's way of saying they need more time to recover.

Contact games and certain sports may need to be avoided for up to 12 weeks after surgery. This can be discussed during your child's discharge and at their first follow-up appointment in clinic.

When can my child go back to school?

Children can usually return to school six weeks after surgery, but may need to start with half days or just specific lessons. Some children may be ready to return to school after four weeks. Please discuss this at your child's first clinic appointment.

It's 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 CCNS.



Your child's medication

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

If your local pharmacist has problems supplying your child's medication, please ask them to call the **hospital patient discharge helpline on 023 8120 6907**.

It's important that your child continues to take the medication until the cardiologists (specialist heart doctors) 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.

Before your child leaves hospital, we will explain when and how to give them their medication, and you'll have the opportunity to practice. Many people do not understand the instructions straight away so please do not hesitate to ask if you have any questions. Please talk to your nurse about how to choose safe, family-friendly medication times.

Your child's medication might need to be measured in an oral syringe. We will teach you how to do this before your child goes home, and you'll be given some syringes with the medication. For further supplies please speak to your pharmacist or GP.

It's safe to give vitamins, iron supplements, Bonjela, Infacol or Calpol (paracetamol) if your child has a heart condition. Please discuss with your pharmacist or GP before giving any other medicines as they may affect your child's regular heart medication.

If your child immediately spits out the full dose of their medication please repeat the dose. If your child should vomit after taking their medication please seek medical advice before repeating the dose.



Storing medication at home

Keep all medications out of reach of children. The ideal place is in a cool, dry, lockable cupboard.

Check the label on the medicine container for storage instructions, as some medicines need to be kept in the fridge or in a cool, dark location. If medicines need to be stored chilled, you might consider getting a lock on your fridge.

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

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

If medicines are no longer needed or have passed their expiry date they should be returned to your local pharmacy.

If you are at all worried please telephone the CCNS or E1 Ocean ward using the numbers on the back of this booklet.

Dental hygiene

Good dental hygiene and regular dental check-ups are important for all children, but are essential for children who have had heart surgery to help prevent endocarditis (an infection in the heart). Some children may need to have antibiotics before certain dental or surgical treatments to prevent infection. This is because they are at increased risk of infective endocarditis. Your child's consultant will discuss this with you before they are discharged or at their first clinic appointment.

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 around seven.

After your child goes home

Follow-up appointment

If your child has had heart surgery, you will receive a follow-up appointment within 7 to 10 days of leaving hospital. If you have not received an appointment, please contact the CCNS team.

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. If your child has no spleen, a condition called DiGeorge's syndrome or 22q chromosome deletion, please ask their CCNS for specific advice on immunisations. Children on warfarin therapy should be given their immunisation just under the skin rather than into their muscle (intramuscularly).



If your child is unwell or you are concerned about anything

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, NHS 111 or health visitor. If you feel your child is very unwell, please go to your nearest emergency department. They will contact us if they have concerns about your child's heart condition.

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

- Children's cardiac nurse specialists (CCNS) (Monday to Friday, 9am to 5pm) or
- E1 Ocean ward (Monday to Friday, 5pm to 9am, plus weekends and bank holidays)

You'll find contact numbers on the back of this booklet.

Dial 999 immediately and ask for an ambulance if:

- Your child has a sudden collapse and is unresponsive
- Your child becomes suddenly unwell

These emergency situations are uncommon, but it's important to know what to do if they happen.

Symptoms requiring urgent medical advice

If you see any of the following symptoms, please contact us immediately:

Babies

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

Children

- Increased tiredness with physical activity
- Poor weight gain
- Fevers
- Pain
- Or if you have any unexplained concerns

Please take your child's discharge letter with you when visiting other health professionals. It contains important information that will be helpful.



Wound care

The wound should be kept clean and dry to help healing. Your child will be able to shower or bathe normally, although they should avoid long soaks for the first four weeks. The wound should then be patted dry (not rubbed). The stitches in the 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 affect healing and make the scar more noticeable. Please do not put any oils or moisturiser on the wound site until it has completely healed.

Should your child experience any discomfort once at home you can give them paracetamol (Calpol), but read the instructions on the bottle carefully, and do not exceed the recommended dose. You may wish to discuss other forms of pain relief with your GP or pharmacist.

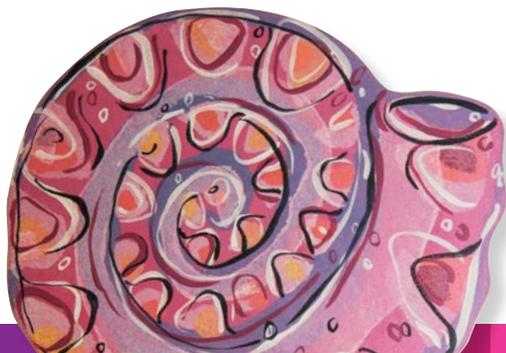
Please contact E1 ward or the CCNS if you notice any of the following at the wound site:

- Redness
- Swelling
- Oozing, weeping or fluid from the wound
- Separation of the wound edges

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 nurses or GP to do this for you. We will make these arrangements.

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

The stitch at the top of your child's wound may start to come through the skin. This may cause some irritation. If you are concerned, please call the CCNS team for advice.



Discharge checklist

Before your child goes home from hospital, please consider the following points to help ensure you are prepared. If you are unclear about anything or require more information, speak to your child's nurse.

I know/understand:

Parent's initials

my child's condition/treatment	_____
who my child's heart doctor is	_____
when and where my child's next appointment is	_____
how to care for my child's wound	_____
the risks of infective endocarditis	_____
who to contact if I'm concerned about anything	_____
what the symptoms I should be concerned about are	_____
what my child's expected saturation range is (if applicable)	_____
my child's feeding plan	_____
my child's medicines and how to give them (including family-friendly times, repeat prescriptions)	_____
what activity/exercise my child can do in the first few weeks	_____
what exercise my child can do in the longer term	_____
when my child can have immunisations	_____

If you would like to receive basic life support training, please speak to the nurse looking after your child who can assist you in arranging this.

If your child is 12 years or over, please speak to our CCNS team if you would like information about the transition process to the adult service.

Useful websites and support groups

Families of Ocean ward

A registered charity formed by volunteers – the majority of whom have children who have received treatment on E1 Ocean ward. The website provides support and information for parents and children with heart conditions and organises fundraising events.

www.oceanward.co.uk

British Heart Foundation (BHF)

The BHF website provides useful information about heart conditions, diagnosis and treatment. It also offers support for families and children and offers advice about preparing your child for a hospital stay. See the website for details of the helpline and publications.

www.bhf.org.uk

Little Hearts Matter (LHM)

LHM is a charity offering support and information for children and their families when a child only has half a heart (children with a single ventricle circulation). The website features parents' and children's experiences and includes a helpline, information and publications about feeding issues, travel advice, exercise and school information.

www.lhm.org.uk

Children's Heart Federation

A charity providing information, education and support for families and children with heart conditions. It also offers a helpline and online publications and factsheets.

www.chfed.org.uk



Arrhythmia Alliance

Provides support and information for children and adults affected by heart arrhythmias and their families. It has downloadable child-friendly information about many aspects of treatment including information about ICD's and pacemakers.

www.arrhythmiaalliance.org.uk

Medicines for Children

The Medicines for Children website is developed in partnership by the Royal College of Paediatrics and Child Health (RCPCH), Neonatal and Paediatric Pharmacists (NPPG) and WellChild. It provides useful information about medications used in children's medical care.

www.medicinesforchildren.org.uk

Down's Heart Group

A charity offering support for non-medical people in the UK with good quality information about the heart conditions associated with Down's Syndrome and other related topics.

www.dhg.org.uk

Max Appeal

Max Appeal is a registered charity supporting families affected by genetic disorders DiGeorge syndrome and 22q11 deletion.

See website for helpline, information, publications and fundraising.

www.maxappeal.org.uk

The Somerville Foundation

This registered charity aims to support and work with teenagers and young adults born with a heart condition (congenital), providing practical and emotional support, and enabling them to take control of their lives and manage their own condition. See the website for information, support, advice and details of their helpline.

www.thesf.org.uk



We greatly value your feedback, as it helps to improve the services we provide. We would like to hear your thoughts about the quality of the hospital and the care you received during your recent experience. We would appreciate any feedback you can provide.

We are committed to making improvements across our services and understanding your recent experience is a vital step in this process.

Please let us know how we are doing by completing the congenital heart disease patient experience survey online at: **www.chdpatientsurvey.co.uk**

E1 Ocean ward
Southampton Children's Hospital
Tremona Road
Southampton
SO16 6YD

E1 Ocean ward: **023 8120 6470**
Children's cardiac nurse specialists (CCNS): **023 8120 4659**
Patient discharge helpline: **023 8120 6907**
Children's dietitian: **023 8120 4588**

Web: **www.uhs.nhs.uk/childrenshospital**

If you need a translation of this document, an interpreter or a version in large print, Braille or on audiotape, please telephone **023 8120 4688** for help.