

# Going home from E1 Ocean ward

Information for young people, families and carers



# Contents

Welcome ..... 3

Children’s cardiac nurse specialist team (CCNS) ..... 4

Leaving hospital and transport home ..... 5

Discharge letter ..... 5

Recovery ..... 6

Activity ..... 7

Going back to school or college .....7

Medicines ..... 8

Dental hygiene .....10

Follow-up appointment .....11

If you are unwell or concerned about anything .....12

Symptoms requiring urgent medical advice .....13

Wound care .....14

Discharge checklist .....16

My Medical Record .....17

Useful websites and support .....18

Mental and emotional health support ..... 21

Contact the children’s cardiac nurse specialist (CCNS) team ..... 22

# Welcome

This booklet has been written to help you and your family prepare for you to go home following your stay in hospital. We hope you find it useful.

Some of this information is related to care following heart surgery, but a lot of the information will be useful if you have been in hospital for any other reason.

As we help to prepare you and your family in the days before going home, your ward nurse will help you to complete the discharge checklist on page 16.

If you have any questions about anything covered in this booklet, please speak to the children's cardiac nurse specialist (CCNS) team.



## Children's cardiac nurse specialist team (CCNS)

The CCNS team, along with the ward staff, will be involved in helping you prepare to go home from hospital.

CCNS are children's cardiac nurses who are experienced in caring for children and young adults with heart conditions.

When you are ready to leave hospital, the CCNS team provide a link for families between the hospital and home. They also liaise with community nurses, teachers, colleges and school nurses.

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

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

You can contact the CCNS team on: **023 8120 4659**.

## Leaving hospital and transport home

On the day you leave hospital (your day of discharge), it may be possible for you go home in the morning if you do not have any outstanding investigations and don't require any medications to take home with you.

- If you do need medication to take home or any additional investigations, there may be a delay while we complete these. The nurse looking after you will be able to give you an estimated time of discharge on the day.
- If you are travelling home by car, remember to use the seat belt. It is safe to travel with the seat belt across your wound, which should be cushioned adequately by your clothing. If your journey is long, your family should plan to take frequent breaks.
- The hospital cannot provide transport home. However, there are good public transport links from the hospital to the national rail and coach networks.
- If you have any questions or concerns about travelling home safely, please speak to us.

## Discharge letter

- You will be given a discharge letter when you leave the hospital. Copies will be sent to your GP and other relevant health and social care professionals.
- If you or your family need to phone the CCNS or the ward in future, it would be useful to have this letter with you.



## Recovery

The time taken to recover from surgery is different for each person. You will need to arrange for some time off school or college after you leave hospital to continue your recovery. When you feel well enough, there may be the option of joining lessons online. Please discuss this with your teachers.

- It is very common to feel sad, worried, or anxious after your procedure. Major surgery is often a life-changing event, requiring a time of adjustment. It can be helpful to talk to your loved ones about how you are feeling. Keeping in touch with friends can also help support your positive mental health and wellbeing.
- When you go home you may find that you experience some periods of feeling unsettled. You may find your sleep is disturbed and that you are generally feeling more emotional. You may find you need more support from your family and friends than usual. These symptoms are very common after surgery and should soon settle, but if you find that they don't, please contact your GP for advice.
- Our psychological support services and youth workers, who specialise in working with young people living with a cardiac condition, are available to support you, should you feel this would be helpful. Please visit the following website for further information: **[www.congenitalheartnetwork.org.uk](http://www.congenitalheartnetwork.org.uk)**

## Information for parents and carers

Teenagers and young adults may take longer to recover from surgery than younger children. It's important to take the time to sit with your young person, to listen and provide reassurance.

## Activity

- It's important to give yourself time to recover. However, light physical activity, such as gentle walking, is important. Gradually increase your activity as you feel able. You may find your energy levels vary; one day you might feel fine, the next day completely exhausted. This is just your body's way of saying that you need a bit more time to recover.
- Once your wound has healed, you can visit the swimming pool, but you should not perform actual swimming strokes for 12 weeks after your operation.
- Contact games, such as rugby, and certain sports may need to be avoided for up to 12 weeks after surgery. This can be discussed at discharge and your first follow-up appointment.
- If you're planning to return to the gym or start a new exercise programme, it's best to wait at least 12 weeks after your operation. This can be discussed at discharge. Start with light exercise and gradually increase as you feel able. Aim to keep activity at a light to moderate level. If you'd like more advice or support, speak to your cardiologist or specialist nurse who can refer you to a physiotherapist for personalised guidance.

## Returning to school or college

- You can usually return to school or college six weeks after surgery, but you may need to start with half days or just certain lessons to begin with. Please discuss this at your first clinic appointment.
- It's a good idea for you and your parents/carers to meet with your teacher to discuss your needs. You may also be able to get a key for the lift or other help with accessibility
- If your school or college needs more information, contact the CCNS team for advice.



## Your medicines

You may need to take medication for some time after going home. The hospital pharmacy will provide a new supply of medicine but you will need to renew the prescription with your GP as soon as possible, as they may need time to order it in.

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

### How long will I take my medicines for?

It is important you continue to take your medication until your cardiologists (specialist heart doctors) tell you to stop. If you do not take the medication it can slow your recovery, or you may need to return to hospital.

Before you leave hospital, we will go through all your medications, explaining what they are, how they help you and when and how to take them. You will have the opportunity to practise this. 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.

### Strength and dosage

It's important to follow the instructions on the medicine container, as the amount to give can vary. Different strengths of medicines are available and when you renew your prescription you might not always get the same strength as last time, so always double check the dose to take with your pharmacist each time you get a new prescription.



## Other medicines

Please discuss with your pharmacist or GP before taking any other medications as they may affect your regular heart medication. You can also call the UHS medicines information team on: **023 8120 6907**.

## What to do if you are sick (vomit)

- If you spit out a full dose of medication immediately after taking it, this dose will need to be repeated.
- If you are sick (vomit) after taking your medication, please seek medical advice before repeating the dose.

## Storing medication at home

Please keep all medication stored in a safe place, away from young 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.

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

If you have any questions please telephone the CCNS team 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 everyone but are essential for people who have had heart surgery. This is to help prevent infective endocarditis (I.E.), which is an infection in the heart.

Some people may need to take antibiotics before certain dental or surgical treatments to prevent infection. This is because they are at increased risk of infective endocarditis. This will be discussed with you before you are discharged, or you can ask at any of your clinic appointments.

### Brushing teeth

Brushing your teeth is very important to prevent tooth decay and infections. A dentist or hygienist can show you how to do this properly. You should brush your teeth first thing in the morning and last thing at night. You can ask your dentist for further advice.



# After you go home

## Follow-up appointment

- If you have had heart surgery, you will receive a follow-up appointment within 7-10 days of leaving hospital.

If you have not received an appointment, please contact the CCNS team.

## Immunisations

- Unless there is a specific reason not to, we recommend that you are fully immunised as recommended by national health guidance. Immunisations can be given 4 weeks after surgery.
- If you are on warfarin therapy, you should receive any immunisations just under the skin (subcutaneously) rather than into a muscle (intramuscularly), if possible.
- If you require an injection that needs to be given into the muscle, please contact the CCNS team or ask your doctor for advice.



# If you are unwell or concerned about anything

## What if I am unwell at home?

There might be times in the future when you feel unwell. This could be something related to your 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 or your parents/carers want some general advice about your health, please contact your GP, NHS 111, or school nurse.

If you are very unwell, please go to your nearest emergency department. They will contact us if they have concerns about your heart condition

## If you think the problem is related to your heart condition, please contact:

- **Children's cardiac nurse specialist (CCNS) team** (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.

Please take your discharge letter with you when visiting other health professionals. We suggest taking a photo of this, and any clinic letters, to keep on your phone. It contains important information that will be helpful.

## Symptoms requiring urgent medical advice

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

- Decrease in exercise tolerance
- Shortness of breath or increased work of breathing
- Poor weight gain
- Unexplained fevers
- Pain
- Puffiness around face or ankles
- Any unexplained concerns

## Information for parents or carers

**Dial 999 immediately and ask for an ambulance if your teenager or young adult:**

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

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



## Wound care

Your wound should be kept clean and dry to help it heal. You 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 (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 sunshine as this can affect healing and make the scar more noticeable. Please do not put any oils, moisturisers or makeup on the wound site until it has completely healed.
- Should you experience any discomfort once home, you can take paracetamol, but read the instructions on the bottle/packet 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 team 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

## If you have had a chest drain

- Chest drain sutures are removed 3-5 days after the drain has come out. If you are discharged before this, it is usually possible for the GP practice nurse to do this for you. Please make sure you and your parents/carers are aware of who is arranging this.
- Your wound will heal in time. It's important that you do not pick or scratch at your scar to prevent an infection or skin problems.
- The stitch at the top or bottom of the wound may start to come through the skin. This may cause irritation and may need to be cut flush with the skin. Please contact your CCNS team for further advice.

If you have questions about caring for your wound or have any concerns, please call the CCNS team for advice.



# Discharge checklist

Before you go 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 nurse.

I know/understand:	Patient and parent initials
• My heart condition/what treatment I have had	_____
• Who my heart doctor is	_____
• When and where my next appointment is	_____
• How to care for my wound	_____
• The risks of infective endocarditis	_____
• Who to contact if I'm concerned about anything	_____
• What symptoms I should look out for	_____
• What my expected oxygen saturation range should be (if applicable)	_____
• My medicines and how to give them (including family-friendly times, repeat prescriptions)	_____
• What activities/exercise I can do and when	_____
• What exercise I can do in the longer term	_____
• When I can have immunisations	_____
• How to register for My Medical Record	_____



## Basic life support training

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

## Transitioning to the adult service

Please speak to the CCNS team if you would like information about the transition process to the adult service.

## My medical record

My Medical Record gives you access to information about your healthcare and connects you with your clinical team and other support services.

### How to sign up

Visit [mymedicalrecord.uhs.nhs.uk](https://mymedicalrecord.uhs.nhs.uk) or scan the QR code



If you are having trouble logging in, registering or have any questions about the app, email [mymedicalrecord@uhs.nhs.uk](mailto:mymedicalrecord@uhs.nhs.uk)

## Useful websites and support groups

### **Arrhythmia Alliance**

Charity providing support and information for those affected by heart arrhythmias and their families. It has information about many aspects of treatment including information about ICD's and pacemakers.

Website: [www.arrhythmiaalliance.org.uk](http://www.arrhythmiaalliance.org.uk)

Instagram: @arrhythmia.alliance

### **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 their website for details of the helpline and publications.

Website: [www.bhf.org.uk/](http://www.bhf.org.uk/)

Facebook: [www.facebook.com/bhf/](http://www.facebook.com/bhf/)

Instagram: @the\_bhf

X: @TheBHF

### **Children's Heart Federation**

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

Website: <https://chfed.org.uk/>

Instagram: @chfedinsta

### **Down's Heart Group**

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

Website: [www.dhg.org.uk](http://www.dhg.org.uk)

**Families of Ocean Ward**

A registered charity formed by volunteers, the majority of whom have children/young adults 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.

Website: [www.oceanward.co.uk](http://www.oceanward.co.uk)

Facebook: [www.facebook.com/groups/149209835097519/](https://www.facebook.com/groups/149209835097519/)

**Little Heart Matters (LHM)**

LHM is a charity offering support and information for individuals with a single ventricle circulation and their families. The website features the experiences of parents, children and young adults and includes a helpline, information and publications about feeding issues, travel advice, exercise and school information.

Website: [www.lhm.org.uk](http://www.lhm.org.uk)

Facebook: [www.facebook.com/littleheartsmatter/?locale=en\\_GB](https://www.facebook.com/littleheartsmatter/?locale=en_GB)

Instagram: @Littleheartsmatter

**Max Appeal**

A charity supporting families affected by genetic disorders DiGeorge syndrome and 22q11deletion. See website for helpline, information, publications and fundraising.

Website: [www.maxappeal.org.uk](http://www.maxappeal.org.uk)

Instagram: @maxappeal\_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.

Website: [www.medicinesforchildren.org.uk](http://www.medicinesforchildren.org.uk)

## **The Somerville Foundation**

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

Website: [www.thesf.org.uk](http://www.thesf.org.uk)

## **Wessex Heartbeat**

A registered charity that supports those with congenital heart conditions in the local Wessex area.

Website: [www.heartbeat.co.uk/](http://www.heartbeat.co.uk/)

Facebook: [www.facebook.com/UKHeartbeat/](https://www.facebook.com/UKHeartbeat/)

Instagram: @whbcharity

X: @ukHeartbeat

For further useful information please visit:

[www.congenitalheartnetwork.org.uk](http://www.congenitalheartnetwork.org.uk)

# Mental health and wellbeing support

The contacts listen below can be useful sources of confidential support.

## Young Minds

A national charity that offers information and advice to young people, parents and carers and can direct you to further support.

Website: [www.youngminds.org.uk/](http://www.youngminds.org.uk/)

## Youth Options

A local charity that provides support to children and young people across Hampshire. Offering support for families and individuals.

Website: <https://youthoptions.org.uk/>

## Samaritans

A national charity aimed providing emotional support to anyone in emotional distress.

Website: [www.samaritans.org/](http://www.samaritans.org/)

Telephone: 116 123

## On the ward

If you feel like you would benefit from more support, remember you can also ask to speak to our youth support worker or psychology service at any time. We are all here to support you.





**Southampton  
Hospitals  
Charity**



**University Hospital  
Southampton**  
NHS Foundation Trust

# Join our family of Southampton Hospitals Charity supporters with a monthly donation!

Making a monthly donation is a wonderful way to show your ongoing support to patients and staff at University Hospital Southampton. Even a small amount can make a BIG difference!

**£5**

**could pay for a toy in  
the children's hospital  
waiting area**

**£10**

**could pay for a sensory  
kit to help patients with  
dementia**

**£25**

**could help pay for  
complimentary therapies  
for patients with cancer**



The Direct Debit Guarantee. This guarantee should be retained by the payer.



- This Guarantee is offered by all banks and building societies that accept instructions to pay Direct Debits. If there are any changes to the amount, date or frequency of your Direct Debit Southampton Hospitals Charity will notify you (normally 10 working days) in advance of your account being debited or as otherwise agreed. If you request Southampton Hospitals Charity to collect a payment, confirmation of the amount and date will be given to you at the time of the request.
- If an error is made in the payment of your Direct Debit, by Southampton Hospitals Charity or your bank or building society, you are entitled to a full and immediate refund of the amount paid from your bank or building society. If you receive a refund you are not entitled to, you must pay it back when Southampton Hospitals Charity asks you to.
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**\*Gift Aid Statement** – I am a UK Income or Capital Gains taxpayer. I have read this statement and want Southampton Hospitals Charity to reclaim tax on my donations. I understand that I must pay an amount of Income Tax and/or Capital Gains Tax in the tax year at least equal to the amount of tax that all the charities and Community Amateur Sports Clubs I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify.

# Yes, I would like to support the hospital with a monthly donation to Southampton Hospitals Charity

## 1. My details

Title: \_\_\_\_\_ Forename: \_\_\_\_\_ Surname: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Tel: \_\_\_\_\_ Email: \_\_\_\_\_

Please write your email address above if you'd like to receive updates on how your gift is helping as well as other ways you can help.

## 2. Regular giving

I would like to make a regular monthly gift of: £5 ☐ £10 ☐ £25 ☐ OR my choice of £

monthly by Direct Debit. Please debit my account on the following day of the month: 1st ☐ 15th ☐

## 3. Make my gift worth an extra 25%

If you have not already done so, **please make every pound you give worth an extra 25% to the Charity at no extra cost to you by ticking this Gift Aid declaration.**

*giftaid it*

☐ Yes, I am a UK taxpayer and want to Gift Aid this donation and any donation I make in the future or have made in the past four years to Southampton Hospitals Charity

☐ No, I am not a UK taxpayer

I understand that, if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it is my responsibility to pay any difference. Please notify Southampton Hospitals Charity if you wish to cancel this donation, change your name or home address, or no longer pay sufficient income and/or Capital Gains Tax.

## 4. Instructions to your Bank or Building Society to pay by Direct Debit

Name(s) of Account Holder(s):

Originator's Identification Number:

6 9 1 2 1 3

Charities Aid Foundation, 25 Kings Hill Avenue, Kings Hill, West Malling, Kent ME19 4TA

Account Number:

Sort Code:

Banks and Building Societies may not accept Direct Debit instructions from some types of account.

**Instruction to your Bank or Building Society.** Please pay Charities Aid Foundation re Southampton Hospitals Charity Direct Debits from the account detailed in this Instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this Instruction may remain with Charities Aid Foundation re Southampton Hospitals Charity and, if so, details will be passed electronically to my Bank/Building Society.

Signature(s):

Date:

You can also set-up your monthly donation online via our website – [southamptonhospitalscharity.org/donate](https://southamptonhospitalscharity.org/donate) or by scanning the QR code.



SCAN ME

## 5. What to do now

Please return this form to our Freepost address: Freepost RRUA-CSKX-JUBZ, Southampton Hospitals Charity, Mailpoint 135, Southampton General Hospital, Tremona Road, Southampton, SO16 6YD.

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

**Contact us:**

E1 Ocean Ward: **023 8120 6470**

Children's Cardiac Nurse Specialists (CCNS): **023 8120 4659**

Children's Dietician: **023 8120 4588**

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email **patientsupporthub@uhs.nhs.uk**

For help preparing for your visit, arranging an interpreter or accessing the hospital please visit **[www.uhs.nhs.uk/additionalsupport](http://www.uhs.nhs.uk/additionalsupport)**

**[www.uhs.nhs.uk/childrenshospital](http://www.uhs.nhs.uk/childrenshospital)**

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