

# Welcome to E1 Ocean ward

Information for patients, families and carers



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# Welcome to E1 Ocean ward

E1 Ocean ward cares for babies, children and young people up to the age of 18 with heart or lung problems.

This booklet has been written to help you and your family prepare for your child's stay with us. We hope it will answer some of the initial questions you are likely to have.

We understand that having a child in hospital can be a very stressful time. If you would like more information about anything covered here, would like to visit us or speak to someone before your child's admission, we're here to help.

Please contact one of our children's cardiac nurse specialists (CCNS) via the numbers on the back page of this booklet. They will be happy to answer any questions that you may have or arrange a visit.



# Helping your child prepare

## Communication

We will ensure that you and your child are included in any plans or decisions regarding their treatment. If an interpreter or signer would be of help to you, please ring the ward before your child's admission so that one can be organised for you.

## What to tell your child

Depending on their age and understanding, you should talk to your child in advance about coming into hospital. Tell them as much about the operation as you think they can understand. Books and DVDs about coming into hospital are also widely available. The British Heart Foundation website [www.bhf.org.uk](http://www.bhf.org.uk) contains links to some publications you may find helpful. Feel free to call our CCNS and play specialists if you have any questions about how to help your child prepare.

## What to pack for your child's stay

Pack a bag for your child containing some comfortable clothes, slippers, nightwear and toiletries. We also recommend you bring 'button down the front' pyjamas and baby grows, nappies, favourite toys and activities for in bed, such as colouring, card games, tablets and audiobooks (we have free Wi-Fi on the ward). Make sure you bring any comforters your child likes, however tatty!

## Can I stay with my child on E1 Ocean ward?

We have fold-out beds on the ward where you can sleep next to your child. Other arrangements will be made if your child is in paediatric intensive care (PICU), high care or in the nursery on E1 where there is limited space available.

## Visiting

Please see our website for the most up-to-date information about visiting.

# The members of staff you will meet

You may meet a number of different members of staff during your child's stay. All staff should be wearing an identification badge which clearly states their name and job title. If someone is not wearing one, do not feel embarrassed to ask them who they are and check with your nurse.

## Children's cardiac nurse specialists (CCNS)

Our CCNS are here to support you and your child from their diagnosis through to their transition to our adult services.

Your child's cardiologist (heart doctor) will spend time with you, and explain the diagnosis and necessary treatment.

Many parents feel they would like further explanation and support after a diagnosis. The CCNS team can provide you with written information, diagrams of your child's heart, guidance on websites, and details of how to access local and national support groups. They can also offer advice on a number of matters,

including finances, education, support available in the community and lifestyle changes. You can talk through any concerns that you may have with them.

## Senior ward sister

The ward and nursing care is managed by the senior ward sister and their team. You can speak to any member of the nursing team about your child's stay on the ward.

## Paediatric (children's) nurses

Our paediatric nurses have experience in the care of children with heart conditions.

## Play specialists

Our play specialists encourage play and help prepare children for operations and investigations. Feel free to contact them on the ward before admission to organise a visit and/or to discuss preparing your child for their stay.

## Dietitian

Our dietitian aims to meet all babies and children on the ward, and is available to discuss any eating or feeding problems that your child may be experiencing.

## Child psychologist

Our child psychologist is available to offer support with any emotional or behavioural problems your child may be experiencing in relation to their condition or treatment. If you wish to meet the psychologist, please ask your nurse or the CCNS to contact them for you.

## Nurse practitioner

Nurse practitioners are children's nurses with specialist training to admit, discharge and order investigations and tests required for your child's care.

## Pharmacist

The ward pharmacist visits the ward daily, and is happy to discuss your child's medication with you or to assist you in obtaining ongoing medications from your local pharmacy when your child goes home.

## Physiotherapist

Physiotherapists are available to visit your child after surgery to help encourage mobility and advise on breathing exercises if required.

## Consultants

Each week a consultant will be responsible for the care of all the children on the ward. The team of consultants work closely together and are fully informed regarding each other's patients. Consultants are assisted by a team of doctors (registrars and senior house officers, known as SHOs).

## Consultant cardiac surgeon

A doctor trained in children's heart surgery. You will meet them before your child's operation.

## Consultant paediatric (children's) cardiologists

Doctors trained in children's heart conditions and illness.

## Consultant paediatric (children's) anaesthetist

A doctor trained to monitor and care for children during procedures or operations requiring a general anaesthetic (medicine which puts your child to sleep during surgery).

# Your child's admission

Your child will usually be admitted to the ward the day before their operation.

When you arrive, please press the button on the ward's intercom system. The ward clerk or nursing staff will greet you and take you to your child's bed. Your child's nurse will show you around the ward. The nurse and doctor will discuss the operation with you and a play specialist will be on duty to explain the operation to your child, with the help of picture books.

## Tests your child may have

Your child will have their temperature, pulse and blood pressure taken by the nurse, and any other tests required will be arranged.

These may include the following:

### Echo

An ultrasound scan which shows the structure of the heart and how it is working.

### Chest x-ray (CXR)

A chest x-ray shows the size and position of the heart and how air expands in the lungs.

### ECG

ECG stands for electrocardiogram. This is an electrical tracing of the heart which shows the heart's rhythm and heart rate. Sticky patches will be put on your child's arms, legs and chest, and connected to a recording machine. The test is painless and takes about five minutes.

### Blood test

Your child will have a blood test in order to check their blood group and prepare any blood which may be needed during surgery. Blood can also be taken to test for infections. Topical cream, sometimes called 'magic' cream, will be used to numb the area of skin before the blood is taken. Visit: [www.uhs.nhs.uk/childsbloodtest](http://www.uhs.nhs.uk/childsbloodtest) for more information and a video you may find helpful to watch with your child before their stay in hospital.

## Before the operation

Usually the surgeon will meet you on the ward before the operation to answer any questions you may have. You will then be asked to sign the consent form. The young person may sign themselves if they are 16 to 18 years of age.

You will also meet the consultant anaesthetist who will tell you when your child needs to stop eating and drinking before their surgery. Usually this will be no food for six hours and no drinks for two hours before the operation.

Your child will also be asked to have a wash the night before and the morning of surgery. On one of these occasions, they will need to wash their hair.

Both parents may accompany their child to theatre with the ward nurse. In most circumstances, one parent may then go through into the anaesthetic room. Please discuss this with the anaesthetist.

If your child is having heart surgery, you will have the chance to visit the children's intensive care unit (PICU) to look around before your child's operation.

## After the operation

Your child may be nursed in E1 ward's high care area after their procedure, or after their stay in intensive care. If this is likely, we'll give you the opportunity to have a look around there too before your child has their operation.

## Eating and drinking

After the operation, your child may be restricted on how much they can eat or drink. Babies may not be able to breast and/or bottle feed straight away. Many children are required to have a tube passed into their tummy during the operation to allow the nurses to give them fluids or milk while they rest and recover. If you are breastfeeding, we will support you to re-start feeding and discuss expressing your breast milk if required.

Older children may take a week or so at home before they gain their appetite back, so bringing some of their favourite snacks in can help encourage them to eat.

## Doctors' ward round

The doctors will see your child daily on the ward round. A consultant or registrar and senior house officer (SHO) will discuss your child's progress with you and answer any questions. If you are not here during the ward round, a doctor will be happy to talk to you later. If you wish to arrange a meeting with the ward consultant, speak to a member of nursing staff who can arrange this for you.

# A typical day on E1 Ocean ward

### 7.45am - Day staff arrive

The nurses who have been on duty overnight will report to the day nurses.

### 8 to 11.30am - Breakfast, playroom activities, school and doctors' ward round

Cereal, toast and fruit juice will be available for children and parents.

The nurse caring for your child will be introduced.

Age-related play activities will be offered to your child.

School on G level will open. This will be arranged for your child by a play specialist if appropriate.

Treatments and tests will be carried out, observations will be recorded, medicines will be given, the ward will be cleaned and the bed linen will be changed.

### 12 noon - Lunch

The lunch trolley will arrive and meals will be served to children.

### 5 to 6pm - Dinner

The dinner trolley will arrive and meals will be served to children. Menu cards will be completed for the next day.

### 7.45pm - Night staff arrive

Nurses who have been on duty during the day will report to the night nurses.

### 8pm onwards - Prepare for bed

Lights will be dimmed.

Observations will be recorded and medicines will be given as required throughout the day and night.

### Quiet time

Children and babies require rest and sleep. We would appreciate your understanding in keeping noise levels down during quiet time.



# Facilities for children

## Children's meals

Meals are supplied for children of all ages. If your child needs puréed food or a special diet, please talk to their nurse. Snacks and some pre-packed baby milks are available in the ward kitchen.

## School

If your child goes to school, a teacher will work with them on the ward when appropriate, and if they are well enough, they will be able to go to the hospital school on G level. The hospital teacher will also speak to your child's school. If you have any questions, please talk to our play specialists.

## Playroom

Activities are arranged in the playroom from Monday to Friday and can also be arranged by the bedside if your child is not able to go to the playroom. We can also offer the use of games consoles and tablets, if available.

## Bed area

At each bed there is a bedside cabinet and a comfy chair.

## Washing facilities

As well as showers and a bathroom, we do have a disabled toilet and shower if needed.

## Nursery

If your child is below six months, they may be cared for in the nursery. There are four cots in the nursery. You will not be able to sleep in the nursery with your child. We will discuss alternative sleeping arrangements with you.

## Children's cardiac high care area

When your child comes back from intensive care (PICU), they may be nursed in the E1 high care area. As your child recovers and needs less monitoring, they will be cared for in a general bay. You will not be able to sleep with your child in the high care area.



# Facilities for parents



## Washing facilities

We have a bathroom and showers. All cubicles have an ensuite shower room. Towels can be supplied and we have a hair dryer on the ward.

## Meals and refreshments

Drinks and light snacks are available in the ward kitchen. A fridge/freezer and microwave are available to store and prepare food for you and your child. Please label your food and we ask that everyone helps to keep the kitchen tidy.

## Fire safety

The fire alarms are tested regularly (an intermittent alarm). In the event a real fire is detected, a continuous alarm will sound until the area is made safe. If the fire alarm sounds during your stay, please stay where you are and wait for a member of staff to tell you what is happening and what you need to do.

If you discover a fire, contact a member of staff or go to the nearest break glass point to raise the alarm.

## Accommodation

You will find fold-out beds next to most of the children's beds on the ward. Only one parent can stay with your child on the ward. If your child is in the nursery or high care area, you will be accommodated elsewhere on the ward. Bed sheets and blankets will be provided. Because space is limited, we can only accommodate one parent on the ward. We will aim to arrange additional parent accommodation at Ronald McDonald House, which is located next to the hospital. Arrangements to stay can only be made on the day of admission, so please discuss availability with your child's nurse when you arrive.

**Please do not bring valuables onto the ward.**

## Security and safety

The hospital takes your safety very seriously and there are security guards present 24 hours a day.

## Shops and eating facilities

There are a number of areas in the hospital where you can sit down to eat or buy food to take away. There are a range of shops in the main entrance area, including a pharmacy and a newsagent selling toiletries and other items. Staff on the ward will be able to give you more information about opening times.

## Smoking

Smoking is not permitted inside the hospital or hospital grounds, except in the designated smoking shelters. Ask your nurse for more information.

## Alcohol

Alcohol is not permitted in the hospital.

## Laundry

A washing machine and tumble dryer are available on the ward.

## Post

Post can be delivered to the ward. The address is on the back of this booklet.

## Cash machine

A free cash machine is available on C level, centre block next to children's x-ray and in main reception.

## Shopping

There are shops and food and drink outlets in the main hospital entrance area. Sainsbury's supermarket is a 15 minute walk. Shirley is the closest shopping area which is a 20 minute walk. Southampton city centre is ten minutes away by car. Feel free to ask ward staff for directions.

## Transport

Buses to Sainsbury's, Shirley and Southampton city centre are available from the front of the hospital. Timetables are available online or at the main hospital reception area. A free taxi phone is situated by the main reception area on C level.

## Spiritual care

Our spiritual care team are available 24 hours a day to support you and your family. The chapel and prayer rooms are always open, with services held throughout the week. You don't need to have a particular faith or belief in order to use this service, and visits by representatives of all the major faiths and beliefs can be arranged on request. For more information, ask a member of the ward staff to contact the spiritual care team for you, or telephone: **023 8120 8517**.

## Reclaim travel costs

If you receive certain benefits or are on income support, you can reclaim your travel costs on admission and once your child has been discharged. You will need to take evidence of your financial support to the cashier's office. Your child's nurse or the ward clerk will be able to direct you.

You may find this link helpful:  
**[www.turn2us.org.uk/Benefit-guides/Going-into-Hospital-and-benefits/Help-with-the-cost-of-travel-to-hospital](http://www.turn2us.org.uk/Benefit-guides/Going-into-Hospital-and-benefits/Help-with-the-cost-of-travel-to-hospital)**

## Parking

Our car parks can get very busy and parking on site is limited. We have a main multi-storey car park with disabled parking clearly marked near to the main entrance, and elsewhere around the site. We provide discounted parking for one car per patient. Ask your nurse to fill out a discount form for you to take to the Travelwise office to buy your ticket. Remember to take any short-term tickets you have already paid for, so that these can be taken off the price of your long-stay ticket.

To contact Travelwise, please call: **023 8120 4133** or email: **[travelwise@uhs.nhs.uk](mailto:travelwise@uhs.nhs.uk)**

More information about parking is available on:  
**[www.uhs.nhs.uk/parking](http://www.uhs.nhs.uk/parking)**



# Information for new mothers

## Accommodation

Ward accommodation is available for you. You may be asked to share with another mum. We have a small emergency stock of toiletries on the ward if you have arrived unprepared. If you would like your partner to stay with you, speak to your nurse and we will do our best to provide accommodation for them too.

## Care

Your nurse can arrange for you to visit a midwife at Princess Anne Hospital (PAH) if you have any issues or need your post-natal check up. We can also help to organise an appointment with a local GP if you are from another area.

## Feeding

We can support you to breastfeed on the ward, and can put you in touch with the breastfeeding advice service run by midwives at PAH, arranging for a midwife to visit the ward to support you if required. We can supply bottles and expressing equipment, but you are welcome to bring your own.

If you are breastfeeding, your meals will be provided on the ward for ten days after the birth of your baby. You may select your food choices on a menu card.

## Spiritual care

The spiritual care team are happy to be called at any time. If you wish to discuss a baptism or christening, please ask our nurses.

## Registering birth

Your baby should be registered by six weeks of age. This takes place at the nearest registrar's office to your child's place of birth. A member of staff can provide more information if required.



# Suggestions and comments

Should you have any compliments, comments, concerns or complaints at any time, please do not hesitate to share them with the CCNS, the senior sister, your child's nurse or the nurse in charge that day.

Our patient advice and liaison service (PALS) team are also here for you if you'd like to discuss any aspect of your child's hospital care. You can call them on: **023 8120 6325** (Monday to Friday, 9am to 4pm) or email: **pals@uhs.nhs.uk**

Our 'Raising a concern or complaint' booklet explains the ways in which you can let us know about your experiences in hospital. Ask for a copy or search for 'raising a concern or complaint' on: **www.uhs.nhs.uk**

Your views and opinions are very important to us and help us to continually improve the service we provide. We would be very grateful if you would take the time to complete a short comments form before you leave. You can leave it with the ward clerk or your child's nurse.





# 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 our cardiac ward. The website provides support and information, and organises fundraising events.

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

## Congenital Heart Disease Network (Southampton and Oxford)

There are a number of hospitals within the Thames Valley and Wessex region which form the Thames Valley and Wessex Congenital Heart Disease Network, including Southampton and Oxford hospitals. The website provides useful information about congenital heart disease and how to prepare for your child's cardiac admission.

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

## Children's Heart Federation

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

[www.chfed.org.uk](http://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 ICDs, reveal devices and pacemakers.

[www.arrhythmiaalliance.org.uk](http://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](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), 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](http://www.thesf.org.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**  
Children's dietitian: **023 8120 4588**  
Child psychologist: **023 8120 4657**

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

For a translation of this document, or a version in another format such as easy read, large print, Braille or audio, please telephone **0800 484 0135** or email [patientsupporthub@uhs.nhs.uk](mailto: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)

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