Welcome to E1 Ocean ward
Information for patients, parents and guardians

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.

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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 realise that having a child in hospital can be a very stressful time, so if you require more information about anything covered here, or would like to visit us or speak to someone before your child’s admission, you are very welcome to contact one of the children’s cardiac nurse specialists (CCNS) via the numbers on the back page. 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 contains links to some publications you may find helpful. Feel free to call our CCNS nurses and play specialists if you have any questions about how to prepare your child.

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, favourite toys and activities for in bed, such as portable DVD players (some available on ward), colouring, card games and audiobooks. 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
Your family and friends are welcome to visit at any time of the day.
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 senior nurses are here to support you and your child throughout your stay. They can provide written information and diagrams of your child’s heart, along with details of how to access further information and local and national support groups. Although your child’s cardiologist (heart doctor) will spend time with you explaining the diagnosis and necessary treatment, many parents feel they would like further explanation and support. The CCNS helpline is always available to patients and families. The nurses can offer advice on a number of matters, including financial and education issues, community support and lifestyle advice, and you are welcome to talk through any other concerns that you may have with them.

**Senior ward sister**

The ward and nursing care is managed by the senior ward sister. Feel free to ask to speak to them or the nurse in charge 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**

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 SHO’s).

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
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).

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 can show 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 are put on the 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 and how quickly the blood clots. A ‘magic’ cream is 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 discuss 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.

**Eating and drinking**

After the operation, babies may be restricted on how much they can feed, and may not be able to breast and bottle feed straight away. Many babies are required to have a tube passed into their tummy during the operation which allows the nurses to give them milk while they rest and recover. 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.

**E1 Ocean ward routine**

7.45am - Day staff arrive
The nurses who have been on duty overnight report to the day nurses.

7.45am - Breakfast
Cereal, toast and fruit juice is available for children and parents.

8am - Playroom activities
The nurse caring for your child will be introduced.

9.15 to 11.30am - School
School on G level opens. This will be arranged for your child by a play specialist if appropriate.

9 to 9.30am onwards - Doctors’ ward round
Treatments and tests carried out, observations recorded, medicines given, ward cleaned, bed linen changed.

12 noon - Lunch
Lunch trolley arrives, meals served to children.

2pm - Observations
Observations recorded, medicines given.

2pm to 3pm - Quiet time
Lights dimmed, children are encouraged to rest.

5.30pm - Dinner
Dinner trolley arrives, meals served to children.

6pm - Observations
Observations recorded, medicines given, menu cards completed for next day.

7.45pm - Night staff arrive
Nurses who have been on duty during the day report to the night nurses.

8pm - Prepare for bed
Lights are dimmed.

10pm - Observations
Observations recorded, medicines given.

Observations and administration of medication is sometimes necessary overnight, your nurse will discuss timings with you.
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 pre-packed baby milk 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 organised 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, portable DVD players and computers, if available.

Bed area
At each bed there is a locker and notice board for cards and toys. A sticker chart will be given to help encourage and reward your child.

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. This area has cots and there is always a nurse present.

Children’s cardiac high care
When your child comes back from intensive care (PICU) they may be nursed in the E1 high care area. This area has a greater number of nurses and special equipment to care for your child. As your child gets better they can return to dolphin bay.
Facilities for parents

You will find fold out beds next to most of the children’s beds on E1, meaning one parent can stay 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 and there are storage areas in dolphin bay for luggage. We ask that you avoid bringing valuables onto the ward. Because space is limited we do not always have enough room for both parents to stay on the ward, and may refer you to Meller House, Rotary House or Ronald McDonald House, which are charity-run facilities offering accommodation next to the hospital for relatives. Arrangements to stay in these houses can only be made on the day of admission, so please discuss availability with your child’s nurse when you arrive.

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.

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.
Trolley shop
A volunteer from the League of Friends visits most days with a trolley selling items including newspapers, magazines, drinks and toiletries.

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.

Shopping
There are shops and food and drink outlets in the main hospital entrance area. Sainsbury’s supermarket is a fifteen 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.

Chaplaincy
Our chaplaincy team and a duty chaplain 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 chaplaincy 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.

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. More information about parking is available on: 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. Toiletries can be supplied 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 you both.

Care
Your nurse can arrange for you to visit a midwife at Princess Anne hospital (PAH) if you have any issues or require 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. Our E1 Ocean ward breastfeeding room is well equipped with bottles and expressing equipment. If you are breastfeeding your meals will be provided on the ward for ten days following the birth of your baby. You may select your food choices on a menu card.

Chaplaincy
The chaplains 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 ‘Have your say’ booklet explains the ways in which you can let us know about your experiences in hospital. Ask for a copy or search for ‘have your say’ on: www.uhs.nhs.uk.

Our patient support services team are 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 3pm) or email: patientsupportservices@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 E1 Ocean ward. The website provides support and information 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, Reveal devices 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

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