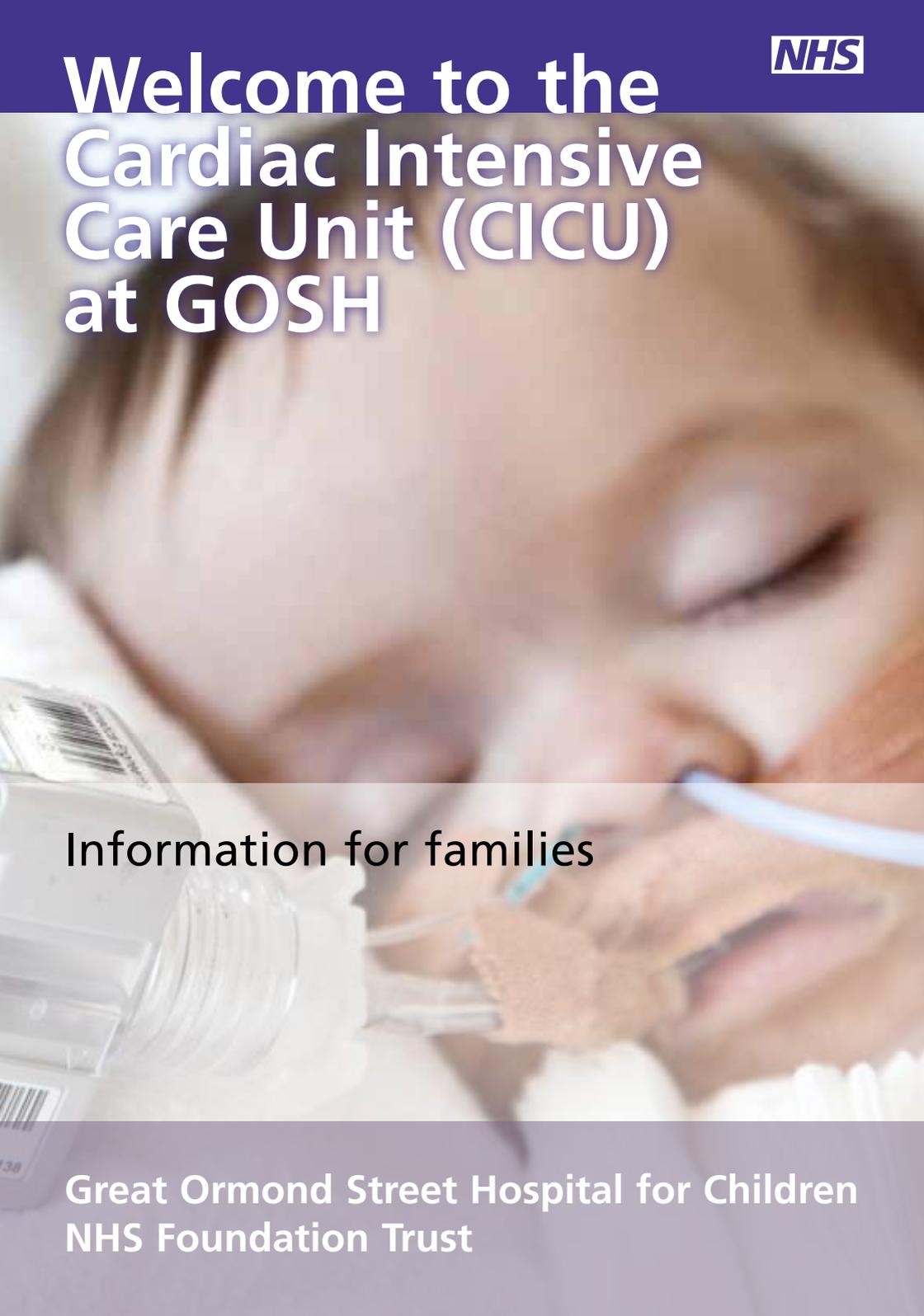


Welcome to the Cardiac Intensive Care Unit (CICU) at GOSH

A close-up photograph of a child's face, likely a patient in the Cardiac Intensive Care Unit. The child's eyes are closed, and they appear to be resting or sleeping. Medical equipment is visible, including a clear plastic container with a white cap and a blue tube connected to the child's mouth. The background is softly blurred, focusing attention on the child's face and the medical care being provided.

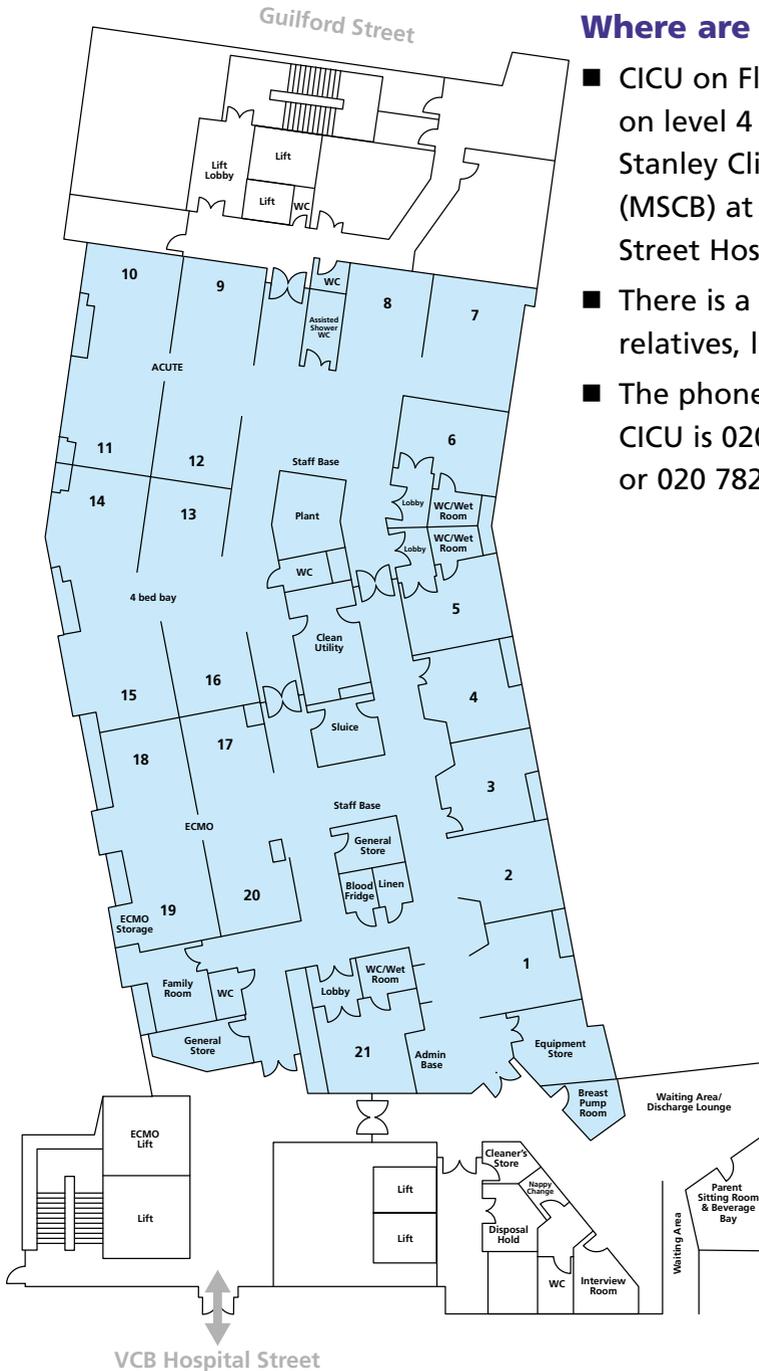
Information for families

Great Ormond Street Hospital for Children
NHS Foundation Trust

The Cardiac Intensive Care Unit (CICU) at Great Ormond Street Hospital (GOSH) is for children up to 18 years old who require intensive care for conditions involving the heart, lungs and airways. The CICU also cares for children on extra-corporeal membrane oxygenation (ECMO – if needed, please ask for a copy of the ECMO leaflet). The unit is staffed 24 hours a day by specially trained intensive care nurses and doctors.



CICU Entrance



Where are we?

- CICU on Flamingo Ward is on level 4 of the Morgan Stanley Clinical Building (MSCB) at Great Ormond Street Hospital.
- There is a lounge area for relatives, located in CICU
- The phone number for CICU is 020 7829 8652 or 020 7829 8828

What we do

- Children with heart or lung problems may sometimes become so sick that they need machines and medicines to help keep them alive. When that happens, they will be admitted to CICU for such treatment.
- More specifically, we are able to monitor closely children who are sick, and if necessary provide support for severe heart and lung failure.
- The treatments include medications that cannot be safely given on a general ward, and use of machines that can take over the work of the lungs, heart and kidneys.
- We also care for children who have had major heart, lung or airway surgery. They require a period of close observation and treatment during the immediate post operative period.



- Each child has different needs and problems, so the amount of treatment and length of stay will vary from child to child. However, we do expect most children to make progress day by day, and our staff will keep you updated as much as possible. Some children have some setbacks along the way, and we will always inform you if there are unexpected problems. If you have any questions concerning your child's progress, please ask one of the team looking after them.

Intensive Care Team

- Your child will be looked after by a large multidisciplinary medical team consisting of specialist intensive care doctors, cardiac surgeons, paediatric cardiologists and specialist nurses.
- Children on ventilators (breathing machines) are nursed on a one-to-one basis by a qualified nurse who may also be supervising a student. Your child's overall care will be co-ordinated by the intensive care consultant on duty for the day. You can ask to speak to a doctor at any time but if the unit is busy an appointment may need to be made for later in the day.
- The team on the unit also includes ventilator technicians, physiotherapists, dieticians, psychologists, pharmacists, chaplains, volunteers and housekeepers.
- Specialist doctors from other disciplines may also be consulted for specific problems.

Ward round on CICU



What will happen to my child?

- **Booked surgery** – Your child will usually have had their operation and come to CICU afterwards. On arrival, the team usually needs some time to settle your child onto CICU and this usually takes around 30 minutes. We need this time to transfer your child, and set up the equipment.

The nurse looking after your child will come to get you from the waiting area and take you to see your child. He or she will update you, answer any questions and can arrange for the doctor to visit you to discuss any further issues with you. The intensivist will come to update you as soon as they are able.

- **Emergency surgery** – On arrival, if your child is admitted to CICU as an emergency, you will be asked to sit in the waiting area while the team assesses and stabilises your child. Sometimes it is not possible to update parents straightaway. This is difficult on a night shift as there are fewer members of

staff on the unit. As soon as a member of the team is able, they will update you.

Reception area on CICU



Medicines

Your child may be put on special medicines to keep them stable or perhaps temporarily still or sedated (asleep).

They will be surrounded by complex machinery and it may seem frightening. However, each machine has a specific purpose and allows us to observe your child constantly without disturbing them. The machines are explained later in this information sheet. Do not be concerned if you do not understand all the machines - your nurse will explain them to you.

You can play with your child and will be as involved as is possible.

We would encourage you to take regular breaks and meals if you are not, as it is important that you remain fit and well.

You may experience a number of emotions. You may feel scared, frightened, confused and/or anxious. This is entirely normal. Please ask us any questions.



Visiting

Before you come into CICU, please call from the entrance to check if you can enter using the wall intercom.

Please wash your hands and take off your coat and hang it up before going to the bedside. There are hooks by the entrance to CICU.

- You may visit at any time except during nursing handover and when procedures are being carried out.
- Ward rounds are done twice a day, between 8.30am to 10.30am and 5pm to 6pm every day. Parents are welcome to stay during ward rounds but will be updated by the Intensive Care team afterwards.
- Please limit the number of visitors to a maximum of two at any one time. We ask that you are present when other visitors arrive to see your child. Your child's siblings are welcome to visit but an adult must be present to supervise them. After 10pm, parents should be the only visitors.
- Anyone with an infection should NOT visit. If in doubt, please ask your child's bedside nurse.



Daily Routines

– admission to the unit

- Your child will still need you while he or she is on the CICU and we want you to help look after him or her as much as possible. It would help us to know about your child's likes and dislikes and personality.
- When your child arrives on the unit, monitors, drips and tubes will be need to be set up. This will take around 30 minutes and then you should be able to come in and see your child.

Daily routines – monitors

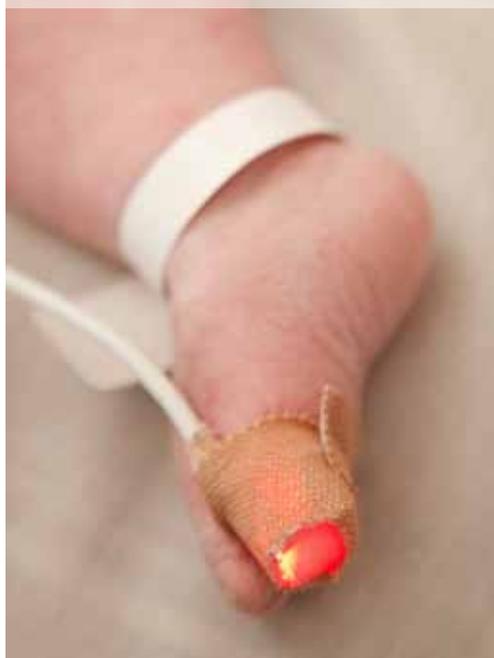
- Your child will be connected to a **monitor**, which looks like a computer screen, which will show your child's heart rate, blood pressure, temperature and oxygen saturation.



Routine Monitoring

- We measure oxygen levels in the blood ('oxygen saturations') using a small light emitting probe on a finger, toe or ear.
- Heart rate is measured using small sticky 'electrodes' (ECG electrodes) attached to the chest and arms
- A temperature probe will be placed through your child's nose or mouth.

Oxygen saturation probe on a foot



Arterial Lines

Blood pressure is measured either with a blood pressure cuff (similar to ones used by your family doctor), or using a small cannula (arterial line) that is placed directly into an artery (usually wrist, groin or upper arm). These arterial lines allow us monitor your child's blood pressure constantly and to take blood samples without needing to use a needle prick for each blood test.

The risks of arterial lines are low, but include:

- Infection – can occur at site of entry into skin.
- Blockage – the line may need to be replaced.
- Occasionally these lines may reduce the amount of blood getting to the hand or leg. If this occurs to a significant degree, the line will need to be removed as soon as possible and very occasionally specialist treatment instituted to improve blood flow (which will be discussed in detail with you, if necessary).



Daily routines – cannulae & central lines

There will be one or more small tubes (**cannulae, central lines**) going into your child's veins to give fluids and drugs. We can sometimes also take some blood samples from the central lines.

Risks are low, but include:

- Infection - at the entry site into the skin, or infection of the blood stream
- Blockage – the line may need to be replaced. Occasionally the vein may become obstructed with a clot and need treatment.
- Leakage – into the tissues. Leakage of certain drugs into the tissues can cause damage, and may require a special procedure to wash them out.



Cardiac output monitors

Occasionally additional monitoring of cardiac output (amount of blood pumped out by the heart) may be required. This will help to monitor and optimise the treatment your child is receiving. We will discuss the risks and benefits of the procedure if the need for this arises.

Daily routines – help with breathing

- If your child needs help with their breathing, a tube (**endotracheal tube, or ET tube**) will be passed through the nose or mouth into their windpipe (trachea). Your child will be anaesthetised for this to avoid any discomfort. There is a small risk with this procedure as for any anaesthetic.



- The tube will be connected to a breathing machine (**ventilator**) and will remain in place until your child can breathe comfortably without it.
- Most children will be placed on a breathing machine on the CICU after heart surgery.
- Occasionally children are not strong enough to breathe on their own after the tube is removed, and might need to go back on the ventilator.



Ventilators

Procedures on the CICU

- During the time your child is in intensive care, various tubes and lines will probably be used to monitor and treat your child's condition (as described above).
- On occasions these tubes will become displaced, fall out or simply need changing. We will always try to discuss this with you, but sometimes this may not be possible as the tubes are needed for essential minute-to-minute monitoring or treatment. In these circumstances we will need to replace them without prior discussion.
- In emergency situations, life saving procedures will always be carried out in the best interests of the child unless specific prior discussion has taken place.
- *When major procedures are performed on CICU we also ask that all parents please leave the unit until the procedure is finished. Notices will be placed on entry doors giving an estimated time for re-entry.*

Daily routines while on a breathing machine

- **Suctioning** – While the breathing tube is in place your child will not be able to cough up secretions ('phlegm') effectively. The nurse and/or physiotherapist will need to clear the secretions by putting in a thinner tube (**suction catheter**) through the breathing tube and applying suction (**suctioning**).
- **Infection** – there is a slightly increased risk of chest infection in children on breathing machines. If this occurs we will treat your child with antibiotics and physiotherapy.

Daily routines – feeding and other matters

- **Feeding:** A **nasogastric tube** will be placed in your child's stomach through their nose. This can be used for draining excess fluid and air from the stomach and for feeding. It can also be used to give medicines.
- **Sedatives:** One of our most important priorities is that your child does not suffer any pain or discomfort whilst on CICU. We will therefore give your child regular and/or continuous doses of sedation and pain relief to make sure they are comfortable. Occasionally children will develop withdrawal symptoms when these sedatives are stopped. This is more common if the sedatives have been used for more than a week. If this occurs, we will then need to wean off the sedation over a number of days.
- **Urinary catheter:** A tube placed in your child's bladder may be needed to closely monitor their urine output.

Daily routines – chest drains and pacing wires

- **Chest drains:** If your child is having surgery, plastic drainage tubes (**chest drains**) will usually be left in your child's chest by the surgeons at the end of the operation to drain blood and air from their chest and to allow the lungs to re-expand. Sometimes these drains may need to be inserted or replaced on the CICU.
- **Pacing wires:** The surgeons may also place small blue wires on your child's heart (**pacing wires**) at the end of the operation which can be used to control your child's heart rate with a pacemaker if necessary.

Other equipment on the unit





Infusion pumps – for infusion of medicine



ECMO machine

Your needs

It is very important that you, the parents, look after yourselves. Your child needs you to be in tip-top condition. Try to take some time out away from the unit, go for a walk, get some rest. Try to eat well and remember to drink plenty, this is particularly important for breast feeding mothers.

Working together

- Children who need to come to intensive care are usually sick, sometimes with complex problems.
- There will be many different teams of specialists involved in your child's care. The intensive care consultant will take overall responsibility for your child's care and co-ordination of their care whilst they remain on the CICU. As your child improves, and transfers to Bear ward, their care will be handed over to the cardiology or surgical teams.
- We make every effort to keep families updated, to be open and honest and involve families in decision making. If there is something you do not understand, or are concerned about, please feel free to ask one of the medical or nursing team members.

Useful information

Psychologists/social workers

There is a team of psychologists who work with the CICU team.

They are here to help provide support to families while on CICU. There is also a social worker linked to the cardiac unit who is available to assist you with any social or financial problems that you might be experiencing due to your child's admission to hospital. You can contact the Psychosocial and Family Services directly on 020 7829 8896.

Accommodation

We offer free accommodation to two carers/parents for the duration of your child's stay on CICU. Please bring in your own towels, soap, and so on. Where possible, we advise you to leave other children with relatives or friends. If this is not possible, we have the use of two houses which are part of the Sick Children's Trust. We can offer free accommodation there, subject to availability. All keys issued for accommodation require a returnable deposit of £10. For

more information about our accommodation, please ask for a copy of our information sheet.

Facilities

There are toilets available in the parents' area.

There are various eating places at GOSH - please see our posters for details. A limited out of hours service is offered in the Peter Pan Cafe. Alternatively, vending machines are available in various locations.

General information about the Cardiothoracic Unit

A separate booklet has details about the layout and running of the Cardiothoracic Unit and other useful information about the local area. Please ask for a copy if you do not have one.

Breast feeding

Breast feeding is actively supported at GOSH. If you need to express breast milk, there is a breast pump room in the reception area of CICU on Flamingo Ward. Whilst you

are in hospital accommodation, a breast pump can be supplied for use in your room, but must please be returned before you go home. If your baby is six months or younger, you are entitled to breast feeding vouchers which can be used in any of the catering facilities at GOSH. The vouchers may be obtained from the Family Accommodation Office and are for £4 per day. Your baby's nurse will assist you with any of the arrangements. There is a Neonatal Nurse Advisor available during the week who will be happy to discuss any of these issues with you.

Midwives

Midwives visit the hospital (Monday, Wednesday and Friday between 1.30pm and 3pm) to care for mothers who have recently had babies. Their clinic is held on the mezzanine floor of the Main Nurses Home, which is on the Guildford Street side of the hospital. Please take your midwifery notes with you when you attend. In an emergency, we can contact the labour ward at University College London Hospital,

which is happy to give advice and arrange urgent consultation.

Research

As a leading centre for children's cardiac services, we are always aiming to improve and advance the care we offer to children under our care. Often this requires research and therefore we may ask to include your child in one of these studies. You are under no obligation to agree to this and our care of your child will not be influenced by your decision.

Telephones

Mobile phones must be switched off in the CICU as they can interfere with medical equipment. For incoming calls, you may use the direct telephone lines on the unit. We do ask that you try to keep incoming calls from relatives to a minimum, as the unit is very busy with many people trying to get through on the phones. We suggest that you nominate one person that you update who can relay information to other friends or relatives.

Improving our service

We are committed to improving patient care and communication with parents. We would therefore welcome any feedback, both positive and negative in this regard. Parents should receive a feedback form which you are encouraged to fill in and return. If you have not received one, please ask one of the members of staff for a copy.

Notes

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Ref: 2012F0293

Compiled by staff on CICU

in collaboration with the Child and Family Information Group

Photography: UCL Medical Illustration

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