Evelina London

Guy's and St Thomas' NHS Foundation Trust

Paediatric Intensive Care Unit (PICU)

showing we care

Contents

Welcome to PICU

Welcome to the Paediatric Intensive Care Unit (PICU) at Evelina London Children's Hospital. On Forest PICU, we look after children needing specialist care. Whether your child's admission was planned or an emergency, we understand you might have lots of emotions.

This booklet will answer some of your questions about your child's stay on PICU. Not all of the information in this booklet will be relevant to your child. If you have any questions, please speak to your bedside nurse.

Admission

Where we are

We know everyone's PICU journey is different. You might have arrived by ambulance with the South Thames Retrieval Service (STRS). You might have come to PICU from an emergency department (A&E) or a ward at Evelina London.

You can get to PICU using St Thomas' Hospital main entrance (following signs for Evelina London Children's Hospital) or the entrance on Lambeth Palace Road, using the 'Big lift'. PICU is on the 2nd floor of Evelina London.

When you arrive at PICU, please ring the buzzer and wait for a staff member to open the doors. When the unit is busy, it can take a few moments to answer the door.

Travel to the hospital

Evelina Hospital is a 15 minute walk from Waterloo and Waterloo East train stations, where you can find trains to the South and the South West. The Bakerloo, Waterloo & City, Northern, and Jubilee lines can all be accessed from Waterloo Underground station.

Westminster Underground station is a 15 minute walk from the hospital, and you can access the Circle and District and Jubilee lines.

Lambeth North Underground station is a 10 minute walk from the hospital, and you can access the Bakerloo line.

The hospital is inside the congestion **and** ultra-low emissions zone (ULEZ). The congestion charge operates from Monday to Friday, 7am to 6pm, and at weekend and Bank holidays 12 midday to 6pm. ULEZ operates 24 hours a day.

To find out more information about travel and charges, please visit **web** www.tfl.gov.uk

Parking

There is limited car parking available at the hospital. If it is an emergency, we can arrange 24 hours of free parking for you. There are daily and weekly parking permits available. Your nurse can help you arrange this.

Accommodation

One of our priorities when you arrive on PICU is to provide you with a room for you to have some rest. We understand that this is a challenging time for you, and we try to make our PICU parent rooms available to all parents.

Availability of the rooms is reviewed each day, and allocated based on the greatest need. The PICU parent rooms are on the 1st floor of Evelina London, and are allocated to you for the first 48 hours of your child's admission. These rooms are cleaned between 11am and 1pm, and you will be asked to leave the room.

If there isn't a room available, we might provide accommodation for you in Gassiot House. This is close to the main entrance of St Thomas' Hospital.

Ronald McDonald House

When your child is admitted, you will be put on the waiting list for a room at Ronald McDonald House. Rooms are allocated according to criteria.

Ronald McDonald House provides free accommodation and support for families with children at Evelina London. They have communal areas, such as kitchens, playrooms, lounges, and laundry facilities. Families can stay at the house free of charge while their child is in hospital.

Day passes are also available to use their facilities. Speak to your bedside nurses to arrange this. To find out more visit
web www.rmhc.org.uk/our-houses/evelina-london-house

Your child’s care on PICU

Who will look after your child

You will meet our large team of specialist staff during your child’s time on PICU. We all work together to care for your child. Evelina London is a teaching hospital, so you might also meet students that work with us.

There is an electronic information screen near the reception desk. You might find this useful in recognising staff looking after your child. There is more information on the team caring for you on page 17.

Caring for your child on PICU

Positive touch is really important for your child. If your child is stable enough, you can help with cares, washes and nappy changes. Please ask your nurse for more information on how you can help with your child’s care.

Your child might look different when they are on PICU, and this can be distressing. Some children look very swollen, or puffy. Although this is upsetting to see, their usual appearance will come back.

As your child might be having different medicines, they might not be aware of exactly what is happening. It is important to continue to reassure them. You can do this by:

- talking to them
- reminding them what is happening
- distracting them
- reading to them
- just simply being there for them

Equipment on PICU

There will be a lot of monitoring and equipment attached to your child. This can be daunting. The staff looking after your child are specially trained to use this equipment and how to respond to any alarms or changes.

There is more information on our equipment on page 21.

Food and drink

When your child is well enough to eat and drink, we can collect meals for them from the kitchens on other wards. PICU does not have a kitchen, as there are only a small number of children that are well enough to eat and drink. You and your child can choose food from a weekly menu. Lunchtime is at 12 midday, and dinner time is at 5pm. If your child would like something specific to eat or drink, or food outside of these mealtimes, we might ask you to get this food from a nearby shop.

PICU environment

Your child might have been admitted to hospital before. If this is the case, we know PICU can feel very different and be overwhelming. Procedures need to take place throughout the day, so the unit can be very noisy.

Specialist doctors and health professionals might visit your child’s bedside during their ward round. This might look intimidating at first, but everyone is here to keep your child safe, and keep you up to date with your child’s care.

Visiting your child

We know that you can comfort your child in a way that we cannot. We work as part of a team, and that includes you. Being open and honest with each other means that we can give your child the care they need.

However, PICU is a busy unit, so we do have some guidelines for your child’s stay here. If it is your first time on the unit, please let someone know and they can show you around.

Visiting policy

A member of staff will give you information about our current visiting policy. Ask your nurse how many visitors are allowed at 1 time. As parents or guardians, you can visit your child at any time. However, we encourage you to get some rest overnight. It is important that you are well rested and looking after yourself. We know it is hard to leave your child, but you can call the unit if you wake up and want to know how your child is.

Sometimes when a procedure is being completed on the unit, we will ask all visitors to leave, even if the procedure is not for your child.

Mobile phones

We ask for all mobile phones to be kept on silent while you are on the unit. If you need to take a phone call, please take it away from the unit.

We also ask that you protect the privacy of other people on the unit, and staff, by not recording or filming while you are on the unit. You can take pictures of your child, but please do not include others in your photos unless you have their permission. Please be aware of reflections or people in the background.

We know it is difficult being away from your family. You can video call your family, but please make sure other people on the unit are not in the video.

Security

To keep your child safe, access to the unit is through an intercom system. During busy times it might take us longer to answer, but please be patient. When you enter PICU, a member of staff might ask you who you are. This is to protect all of the children we care for.

Password

A password system is used for all children. You will be asked to share 1 with the nurse. We will use this password when you call us for information about your child. We can only give information to parents or guardians over the phone, so we ask you not to share this password with other family members. If they ring we will ask them to contact you directly.

Infection control

We ask all visitors to remove their coats before entering the unit. There are hooks to put your coat on. No coats or large bags are allowed on the unit, but we do ask you to keep all valuables with you.

Hand hygiene is very important. We ask everyone on the unit to use the alcohol gel, or wash their hands in the sinks at the entrance, when they enter and leave the unit.

Your nurse will tell you about the ways we keep everyone on the unit safe. If your child is in isolation, please ask if there are any precautions that you should be taking. If you have any questions, please speak to your nurse.

Looking after yourself

We know that your child being on PICU can cause mixed emotions. You might have anxiety, feel you are not in control, or feel angry. These feelings can be difficult to express to anyone. There is no right or wrong way to deal with these emotions.

Here are some ideas to help with some of your stress.

- Ask questions about your child's care, what has happened so far, and what might happen next. It is OK to ask these questions more than once.
- Many people find writing things down helpful, including a list of questions they want answers to.
- Make sure you talk openly to everyone. By all of us doing this, and listening to each other, we can make sure we work together to care for your child.
- Try and take support from others. Friends and family are important in getting you through this difficult time.
- You might find it difficult to keep everyone around you up to date. Choose 1 person to give information to, and that person can then update others for you.
- Make sure you take regular breaks. You might not feel like it, but taking some time away from the unit can really help. There is a small outdoor space in the atrium on the 3rd floor, and directly opposite Evelina London is Archbishop's Park where you can get some fresh air.
- We promise it is okay to leave. We would tell you not to if we were worried.

Places to eat

You can make yourself tea or coffee in the parent’s room. If the supplies run out, let a member of staff know so that they can be restocked. On the unit there are also some water coolers for you.

There is also a fridge and microwave in the parents’ room. Please label any food you bring in with your name and the date. Please keep the area clean and tidy for all families to use. We are happy for you to bring hot drinks onto the unit if they have a lid, but please do not bring hot food onto PICU.

There is a coffee shop on the 3rd floor of Evelina London. At the main entrance of St Thomas’ Hospital there is a coffee shop and M&S (as well as some other shops). There is also a restaurant called Shepherd Hall on South Wing, and Toms@Riverside café on North Wing near the main entrance. These are open 7.30am to 3.30pm.

Postnatal care

Your child might have been admitted to PICU soon after birth. If this is the case, you might need postnatal care, even if you did not deliver in this hospital. Speak to your nurse who can arrange a walk-in appointment in the postnatal clinic.

Breastfeeding and expressing

While your child is on PICU, they might not be able to feed how they used to, or how you thought they might. Breast milk gives your child comfort and nutrition. It is easier for babies to digest, and can help protect them from an infection.

We have all the equipment you need to express breast milk in a dedicated room. Your nurse can show you where it is. You can bring the breast pumps to your child's bedside. Please return the pumps to the room afterwards, so that other people can use them.

The staff caring for your child can offer you support in expressing. You might find it helpful to read our information about expressing your breastmilk. Ask a member of staff on the unit for a copy.

We have a freezer on the unit, where a small amount of your milk can be frozen. It can be frozen for up to 3 months. Label your milk with your child's name, and the date and time that it was expressed. If you collect a lot of milk in the freezer, please arrange for some of it to be taken home. When your child leaves the hospital, remember to collect any milk you have in the freezer.

If you are expressing, you can have food vouchers to use in the hospital's restaurants. Ask the nurse looking after your child for more information.

There are support videos from unicef,
web www.unicef.org.uk/babyfriendly/baby-friendly-resources/breastfeeding-resources/

Support for you

Diaries and photos

One of the things a lot of families find helpful, during their time on PICU and after, is using our dairies.

Staff on the unit use diaries to keep a record of your child’s progress. You might find this helpful to process what has happened, and to show your child when they are better.

You can take photographs of your child while they are on PICU. These can help your child process their experience when they leave the hospital, or could be for siblings to see.

Counselling and psychology support

We know that it can be a very difficult time for you and your family when your child is in hospital. Some parents benefit from talking to our parent counsellors or psychology service.

You can talk about possible challenges you might have, and have space to think through your feelings to help you make sense of your situation. You can talk with the counsellor or psychologist on your own, or with a partner. It is your choice

If you think this service would be helpful, please speak to your nurse who can refer you.

Spiritual health care

The chaplaincy is a confidential service available 24 hours a day, 7 days a week. It is available to all patients, families and carers.

They offer pastoral, cultural, spiritual and religious support to members of all faiths and beliefs, as well as people who have no religious belief.

In special circumstances, a Christening or other religious ceremony can be arranged on the unit. You can also invite your own religious leaders onto the unit to do these. Speak to a member of staff if this is something you want to arrange.

Chapel and multi faith rooms

These are in the South Wing of St Thomas' Hospital and are open each day. The chapel is on the 1st floor, and the multi-faith rooms are on the ground floor. There are washing facilities.

Language support services

If English is not your first language, we can use Language line (a telephone translation service). We can also use a face-to-face translator to support you. If you use British Sign Language, we can use a live video service. The team caring for your child will use these services to keep you up to date on your child's care.

More support

During your child's time on PICU, they might have been diagnosed with a long-term condition. If this is the case, the team can give you information to help you. We have put together some links that might also help:

Rainbow Trust supports the whole family if a child is diagnosed with a life-threatening or terminal illness, **web** www.rainbowtrust.org.uk/support-for-families/for-parents

Echo supports children with a heart condition, and their families, **web** www.echo-uk.org

Samaritans offer support for anyone, at any time, for free, **phone** 116 123 **web** www.samaritans.org

Leaving PICU

When your child no longer needs intensive care treatment, they will be transferred to a children's ward. This might be at Evelina London, or your local hospital.

Before your child is ready to leave PICU we will try and prepare you as much as we can for the transfer. The decision to transfer your child will be made by the medical and nursing team. This decision will only be made when your child is ready to move.

You might be happy that your child is ready to leave PICU, but also concerned about what might happen next. We encourage you to ask questions or raise any concerns you have.

You will slowly see a decrease in the monitoring of your child. We will remove any lines or equipment they no longer need, and lots of their medicines might be stopped. You might also find that the nurse looking after your child is now looking after more than 1 child. This is a sign that your child is getting better, and does not need the level of support they previously did.

We will try and regain a more normal routine for you and your child before you leave PICU. You might find it helpful to get more involved with your child's care and everyday needs. You know your child best, and it is important to try and encourage a more normal day and night structure to their day.

Transfer to a ward at Evelina Children’s Hospital

It is normal to feel nervous about your child moving to a new ward and environment. It is possible to arrange a visit to the ward before your child leaves PICU. Ask your nurse if you would like them to arrange this.

When we transfer your child, we will share the details of their stay on PICU and any ongoing medical and nursing plans with the ward. This is called a handover.

After this, your child’s care will be taken over by the ward team. If they have any questions or concerns that need PICU input, they can contact us easily.

Your ward nurse can show you around when you arrive. You will notice that the nurses on the ward might have a small group of children that they are also looking after. This is because your child is getting better, so will not need the same level of nursing and medical care that they did on PICU.

The wards have accommodation for 1 person at your child’s bedside. If you have been sleeping in the PICU accommodation rooms, please return your swipe card to the ward clerk on PICU before your child is transferred.

Transfer to a ward at your local hospital

Being transferred to another hospital can bring mixed emotions. You might be pleased to be closer to home, but anxious that you are away from specialist services that your child has had. Speak to your child’s doctor or nurse about any concerns you have. We can arrange any support you need.

We will arrange transport to take you and your child to your local hospital. A nurse will travel with you on this journey. As space is often limited in the ambulance it might not be possible for more than 1 person and 1 small bag to travel with your child. You might need to make plans for a family member or friend to pick up any extra belongings.

We will always try and give you an expected time when the transport will arrive, but sometimes this does change at short notice. Before the transfer we will work closely with the team at your local hospital. We will share the details of your child's stay on PICU, and any ongoing medical and nursing plans with the ward. This is called a handover. The hospital can contact us at any time if they want to talk about your child's treatment or needs.

Your experience on PICU

We value any feedback about your time on PICU. It helps us improve the way we look after and support the children and families on PICU. There are surveys at the front desk, and we would be grateful if you can take time to complete one. If you have any concerns about your child's care, the Patient Advice and Liaison Service (PALS) is available to you, **phone** 020 7188 8801 **email** pals@gstt.nhs.uk.

The team looking after your child

Advanced nurse practitioners (ANP) are highly skilled nurses with lots of training to care for children, and carry out procedures used on PICU. Your child will be given a doctor or ANP at the start of each shift, who will be responsible for your child's care. They will feedback to the consultant and other specialist teams.

A consultant is the doctor in charge of the unit. Each week we have a different consultant in charge. They work closely with other staff to monitor and look after your child. We have lunchtime and evening ward rounds, where your child's care will be discussed. You are welcome to stay during this time and ask any questions you have. If you cannot stay for the ward round, your nurse can ask the consultant your questions.

Dietitians help your child get all the nutrients they need. While your child is on PICU they might not be able to eat and drink as they usually would. The amount of fluid they have will also be much less than they have at home. Dietitians help your child get all of the important nutrients they need for their medical condition, and to develop and grow. They might recommend a different type of milk to help with this.

A doctor will look after your child and be responsible for their treatment. Your child will be given a doctor or ANP at the start of each shift. They will feedback to the unit's consultant and any other specialist teams involved.

Family liaison nurses will support your family while on PICU. They will liaise with other teams in the hospital to support your family.

Health care assistants work with the nurses to make sure the unit runs smoothly.

A matron works closely with all members of the team to make sure we give an excellent quality of care. We have a team of matrons and senior nurses on PICU.

Nurses work closely with you and the rest of the team to give your child the care they need, both physically and emotionally. Your child will be given a nurse at the start of each 12 hour shift. Depending on your child’s needs, the number of children the nurse is caring for will change. Usually 1 nurse cares for 1 or 2 children.

The nurse in charge of each shift will supervise and organise the unit. You can speak to them if you have any questions or concerns about your child’s care. Please speak to your nurse if you want to speak to the nurse in charge.

Nurse specialists might be linked to other specialist teams in the hospital, or be part of the research, governance, infection control, or education team on PICU.

The palliative care team work closely with PICU. Children are referred to this team when they have a condition that is likely to shorten their life, or if they need complex care. This team helps to manage symptoms, support with advanced care planning, and give end-of-life care if it is needed. They help organise palliative care in the hospital, community, hospices, school and social care settings.

Pharmacists visits the unit every day, and look at the medicines your child has been given. They might ask you some questions about the medicine your child takes at home, and any allergies or vaccinations they have had.

Physiotherapists review each child regularly and decide if they need treatment. We have a team of respiratory physiotherapists who specialise in treatment for children on the unit, especially those who are ventilated. Treatment can involve different techniques that help remove the secretions that build up in your child’s lungs.

Play specialists use play activities to help your child cope with any pain, anxiety or fear that they have. Play can also be used as a distraction during any procedures that your child needs. We sometimes have other therapeutic support workers, such as musicians and a therapy dog.

The research team are important as they give us up-to-date information so we can give your child specialist care. You might be asked to take part in some studies during your time on PICU. All research is voluntary. There is no pressure to take part, and the treatment your child receives will not change.

Technicians make sure all the equipment used on the unit is kept serviced and up to date.

The ward clerk is usually the first person that you meet on the unit. They are based at the front desk, and look after medical records and answer the phone. They will answer the door when you buzz in. They are not here 24 hours a day, so please bear with us if the door is not answered quickly.

Volunteers spend some of their free time with us. They are here to support you and will introduce themselves when they are on PICU.

Wider therapy team. Depending on your child's condition, we might refer them to the physiotherapy, occupational therapy or speech and language therapy teams.

Equipment used on PICU

Your child will not need all of the equipment listed here. If you have any questions, speak to your nurse.

Arterial lines are thin tubes that might be put into your child's arteries to monitor their blood pressure. These lines can also be used to take blood from your child.

Cannulas are small, plastic tubes that are put into veins. While your child is on PICU they will need different medicines to help them get better and keep them comfortable. Many of these medicines are given through the cannula. This means the medicines go directly into the blood stream and can work more quickly.

Central lines are thin tubes put into larger veins in the neck or groin. These allow us to give more medicines at a time. The medicine might be given constantly through a pump which will be at your child's bedside.

Dialysis or haemofiltration gives your child extra support to remove fluid from their body. Not all children need this. It is used if the kidneys are not working as well as normal. It can be needed if your child has had heart surgery, or if they have been very unwell before coming to PICU. If it is needed, we will put a tube into your child's tummy (abdomen) or a main blood vessel to remove waste fluid from the body. You will be given more information if your child needs this procedure.

Drains are tubes that link wounds to external bags. These are used if your child has had surgery, so we can monitor any bleeding or oozing. Your child will be on pain relief while any drains are in place.

ECG (electrocardiogram) is a test that looks at your child’s heart rhythm.

ECHO (echocardiograms) is an ultrasound scan of the heart. It is often used if your child has a heart defect.

ECMO (extracorporeal membrane oxygenation) is sometimes used if your child is very unwell. An ECMO machine pumps blood from your child’s body, through the machine to add oxygen to the blood and remove carbon dioxide. This might be needed if your child’s heart or lungs are not working well. You will be given more information if your child needs ECMO.

Endotracheal tube (ETT) is a tube that attaches to a ventilator to help with your child’s breathing. When the tube is in place, we use tape to secure it to their face. These tapes sometimes need changing to keep the tube secure. The tube passes through the vocal cords, so you will not be able to hear your child speak or cry when they have this tube in place. They will also need help when they cough. Each nurse is trained to pass a suction catheter down the breathing tube to clear mucus from the lungs.

EVision computers are around the unit. All of your child’s documentation and observations are recorded on these computers. All information is confidential, and if you need access or copies of anything this has to be specially requested. Ask a nurse for more information.

Monitors are the screens that are attached to your child with leads and wires. They monitor heart rate, blood pressure, oxygen levels and other vital signs. The measurements appear as waves and numbers on the screen. An alarm will sound if anything changes from what is normal for your child. We know the beeping can be alarming. It does not always mean that something is wrong, but tells staff that something has changed.

Nasogastric tube (NGT) is a small, plastic tube that is put into your child's nose and down into their stomach. It is used if your child cannot eat and drink as normal. They might have expressed milk, normal formula, or a special medical feed through this tube until they can eat again. An NGT allows us to meet your child's nutritional needs and make sure they have the fluid they need.

Splints are put on your child's arms to limit movement and keep their arms straight. This is so they do not pull any wires or their breathing tube. Splints should not be uncomfortable, and are worn to protect your child. We remove them as soon as it is safe to.

TPN is used if your child cannot eat or drink. If this is the case, they will have fluids through their cannula to keep them hydrated. However, if they cannot eat or drink for a longer period of time they might have TPN. This is nutrition given straight into their bloodstream.

Urine (pee) catheter is a small, plastic tube which is put into your child's bladder. The catheter is attached to a bag next to their bed. It is used to monitor how much they pee. If your child does not need a catheter, we will still measure how much they pee by weighing their nappies.

A ventilator supports your child's breathing. Sometimes, children need more help with their breathing so we use a mask, or some prongs in their nose. If this is the case it will be explained to you at the time.

X-rays might be needed while your child is on PICU. This is done by placing a board behind your child's back, in their bed, and using a mobile machine to take the X-ray. During this time we will ask you to step away from the bed space to protect you.

Contact us

If you have any questions or concerns about your child's stay on PICU, or would like to contact the ward, please use the phone numbers below.

Forest ward
Reception, **phone** 020 7188 4500 or 020 7188 4501
Bed 1 to 7, **phone** 020 7188 5888
Bed 8 to 12, **phone** 020 7188 4504
Bed 13 to 17, **phone** 020 7188 4505
Cubicle 18, **phone** 020 7188 9721
Cubicle 19, **phone** 020 7188 5881
Cubicle 20, **phone** 020 7185 8685

For more information on conditions, procedures, treatments and services offered at our hospitals, please visit **web** www.evelinalondon.nhs.uk/leaflets

Trusted Information Creator
Patient Information Forum

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