WELCOME TO THE PAEDIATRIC INTENSIVE CARE UNIT (PICU)

Imperial College Healthcare NHS Trust

COSMIC

Caring for babies & children in intensive care

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PART ONE - ABOUT US

PAEDIATRIC INTENSIVE CARE UNIT

We are a fifteen-bedded paediatric (children's) intensive care unit. We provide specialist intensive care to children from birth to 16 years. Sometimes we may care for older children who have more complex medical needs while they are transitioning to adult services. We care for children requiring both intensive and high-dependency care. We have 3 bays and 4 side rooms.

We look after children with a wide range of diagnoses but we specialise in infectious diseases and we are also a Major Trauma Centre.

We are located on the 7th Floor of the Queen Elizabeth Queen Mary (QEQM) Building. Our unit has swipe card access so you will need to press the buzzer to gain entry to the ward. During office hours our administrator will be able to let you in. Out of hours, the entry phone is manned by clinical staff so please be patient with us if we don't answer straight away, we are probably dealing with a clinical matter and will let you in as soon as we are able. Please don't let other families into our unit as we are trying to maintain the safety of all the children in our care.

OUR PHILOSOPHY ON PICU

On PICU our philosophy is to embody the West London Children's Healthcare (WLCH) guiding principle, which is 'that everything we do is in the best interests of children and young people.'

As part of WLCH we combine the Trust Values of both St Mary's and Chelsea and Westminster NHS Hospitals.

At St Mary's Hospital these are;
Kind – We are considerate and thoughtful, so you feel respected and included.
Collaborative – We actively seek others' views and ideas, so we achieve more together.
Expert – We draw on our diverse skills, knowledge and experience, so we provide the best possible care
Aspirational – We are receptive and responsive to new thinking, so we never stop learning, discovering and improving.

At Chelsea and Westminster Hospital these are;
Putting patients first
Responsive to and supportive of patients and staff
Open, welcoming and honest
Unfailingly kind, treating everyone with respect, compassion and dignity
Determined to develop our skills and continuously improve the quality of our care.

We will treat you, your child and your family with kindness and compassion. We understand how stressful it is to have a child on PICU and we want to support you. We also expect you and your family to treat our staff and other families on the unit with kindness and respect. We aim to treat everyone as a unique individual. We will constructively challenge unkind or disrespectful behavior to ensure the safety of everyone on the unit.

We recognise and value your important role in the care of your child. We will involve you as partners in care so please speak to your nurse about how much you would like to be involved in your child's care. We will talk to you regularly, try to avoid medical jargon and keep you fully informed. We will collaborate and seek the expertise of other specialties where necessary. We want you to ask questions if you are unsure and tell us if you have any concerns so that we can work together in the best interests of your child.

As a team we pride ourselves on our high standards of clinical care. We deliver evidenced based healthcare to ensure we are acting in line with best practice.

As a unit we are dedicated to research so that we can improve our practice and contribute to the development of new treatment strategies. We also value feedback as this helps us to continually enhance our clinical care.

TELEPHONE NUMBERS

Description	**Phone**
PICU Reception	020 331 26307 (Mon-Fri 9am-5pm)
Main Office (Bay 1 and Bay 2)	020 331 26466/26380
Cubicle 12	020 331 26310
Cubicle 13	020 331 26344
Cubicle 14	020 331 26337
Cubicle 15	020 331 26327
Bay 3	020 331 26331/26330

Please feel free to call us anytime of the day or night for an update on your child. Please be patient with us if we do not answer the phone straight away. We are not allowed to give out information to other family members or friends without your permission.

ADDRESS

Pediatric Intensive Care Unit
(PICU)

St Mary's Hospital
7th Floor, QEQM Building South
Wharf Road London
W2 1NY

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Cosmic Charity

Acrow West, Unit 20E St Mary's Hospital
South Wharf Road London
W2 1BL

WHY YOUR CHILD NEEDS PICU

Children need PICU or Paediatric High Dependency Unit (PHDU) care for a variety of reasons. If your child is requiring intensive care it means that they need a breathing tube to be inserted and for their breathing to be supported with a ventilator. This means they need continuous and intensive medical and nursing supervision. They may also require support for other organs; for example medication to support their heart function or dialysis to support their kidney function. High dependency care means that your child might require assistance with their breathing but without the need for a breathing tube, instead using face or nasal masks. They will also require a higher input of nursing/medical care for monitoring and medication than can be provided on a general ward. Generally speaking when your child requires PICU care they will have one dedicated nurse at their bedside throughout their care and when your child requires PHDU care they may have a nurse who cares for them and also another PHDU patient. However there may also be times when a nurse cares for two PICU patients or a PICU and PHDU patient. Please be reassured that allocation of nurses to patients is considered very carefully by senior nursing staff and in line with best practice guidelines.

Children are admitted to our PICU from paediatric wards within St Mary’s Hospital, our own Emergency Department, from theatre and also from other hospitals. Not all hospitals are able to provide PICU or PHDU level care so your child may have been stabilised at your local hospital and then transferred to us by a specialist retrieval team.

On arrival to us we may ask that you sit in our family room while we receive handover from the team and then transfer your child over to our monitors, equipment and medication so that this can be carried out in a safe and controlled manner. We do understand it is very difficult to leave your child with a team you have only just met especially when they are so critically unwell and we will endeavour to have you back with your child as soon as is possible. When your child is admitted to PICU we will inform your health visitor, school nurse and any other health professionals involved in your child's care of your admission so that they can provide any support you may need.

WHEN CAN I VISIT MY CHILD?

We understand that you will want to be with your child as much as possible and so for parents/guardians you are able to visit your child at any time of the day or night. However, we do encourage you to try and rest where you can. We only allow two visitors at the bedspace at one time. This is for your child's safety so that the nursing and medical team are able to access your child and the equipment/medication that they require quickly and safely. For visitors other than parents/guardians we ask that they visit between the hours of 10am to 8pm. We do have a family room on the unit but this can get very busy. We politely ask that additional visitors wait in the café area on the ground floor while they are not at the bedside so that the family room is kept for parents/guardians. Siblings are allowed to visit but they must be supervised at all times, both at the bedside and also in the family room.

When you arrive please take off your coats/jackets and leave these in the family room, this is for infection control reasons to protect your child. Please wash your hands using soap and water at the sink just before you enter the clinical area. There is also gel sanitiser throughout the unit and at every bedspace and we ask that you please use this to help us maintain the safety of all our children and reduce the risk of infection.

We ask that anyone wishing to visit is well. If you have diarrhoea/sickness, coughs/colds or have been in contact with any infectious diseases you will not be able to visit. This is to ensure the safety of all the children in our care. If you have any queries regarding visiting please speak to the Nurse-In-Charge

PART TWO - MEET THE TEAM

A large team of people called the Multi-disciplinary Team (MDT) will look after your child whilst you are on PICU. You, as the parent/guardian, are also a vital part of this team and we want to work in partnership with you. Later in this booklet, we will describe what you can do to help care for your child.

NURSING TEAM

We have a large nursing team on PICU, which consists of staff nurses, sisters, senior sisters and our matron.
The nurses work 12.5 hour shifts. Day shift 07.30-20.00 and Night shift 19.30-08.00.Nursing handover is at the start of every shift (07.30 or 19.30). We receive a main briefing in our staff room then the bedside nurses go to the bedspace to receive a detailed handover about the child they will be looking after. As well as one bedside nurse allocated to each PICU patient and one bedside nurse to 2 PHDU patients, there will also be a Nurse- In-Charge and a 'Runner'.

The Nurse-In-Charge is responsible for the overall management of all patients and the flow of patients through the unit. They should introduce themselves to you at the start of the shift and wear a red Nurse-In-Charge badge. The 'runner' is a nurse not allocated to a specific patient, they support the bedside nurses and are also available to receive new admissions. Depending on staffing, there may be one or two 'Runners'. In Bay 1, there is a large whiteboard with the names of the allocated bedside nurse, Nurse-In-Charge, 'Runner', Duty Consultant and the physiotherapist.

FAMILY LIAISON NURSING TEAM

The Family Liaison Team is made up of two very experienced ex-PICU nurses who work Monday-Friday office hours. They will come and introduce themselves to every family to see how they can support you. The scope of their role is vast and they are able to help with both practical aspects and emotional support. They are able to sit and listen to you and support you with conversations with the medical team about your child's condition. The Family Liaison Team are also a link between hospital and community so if your child has additional needs and requires community care they are able to maintain communication between the various teams involved to ensure continuity of care.

MEDICAL TEAM

We have ten Consultants in our Medical Team, and each week we have a ‘Duty’ Consultant who will take the lead on patient care for the week. There is also a ‘second on’ who will take over from the Duty Consultant in the evening to care for the patients overnight, then hand back to the Duty Consultant the following morning. You will meet the Duty and ‘second on’ Consultant during the morning ward round. The weekends will be covered by a different Consultant from the week, depending on their rota. The Consultants are present on the unit during the daytime and also overnight if necessary.

We also have a team of junior Doctors who care for the patients. Similar to the nursing team, the junior Doctors are usually allocated to a specific patient, and will also introduce themselves to you during their shift when they come to examine your child. The junior Doctors work slightly different shifts to the Nurses they start later and finish later. There are also some non-clinical or ‘short day’ Doctors on during the daytime who will be undertaking office-based/administrative work.

PHYSIOTHERAPISTS

We have a team of physiotherapists, working a 7-day service across PICU and the children’s wards. We work closely with the nursing and medical teams to identify those requiring therapy input. We support children with their breathing by using techniques to assist with coughing and clearing secretions and also those children requiring rehabilitation.

OCCUPATIONAL THERAPISTS

We have an Occupational Therapy team who provide a Monday to Friday service across PICU and the Children’s wards. Their role includes supporting children who may require rehabilitation, supporting and promoting developmental care for infants and supporting parental involvement in the activities of daily living for their child.

PHARMACISTS

The PICU pharmacist will not be wearing a uniform and will come and speak to you at the beginning of your child’s admission regarding any medication your child might be on at home and also any drug allergies. Throughout your child’s admission they will be reviewing your child’s medication chart in conjunction with the medical team.

DIETICIAN

Good nutrition on PICU will help with your child's recovery. Dietitians help your child get all the nutrients they need, they will assess their needs based on age, feeding history and growth. While your child is on PICU they might not be able to eat and drink as they usually would, they may be fed via a tube in their nose or mouth or are given nutrition directly into their blood if their gut isn't working properly. Dietitians work out how much nutrition each child needs and will advise what formula to use and help to troubleshoot if there are any issues with food tolerance (this is when food is not absorbed properly causing bloating and sickness). The amount of fluid they have will also be much less than they have at home. As your child starts to recover, the dietitian works closely with other members of the multidisciplinary team, such as Speech and Language Therapy (SLT), to help re-establish eating without the need for a tube and to optimise growth.

The dietician will also be able to provide breastfeeding advice alongside our breastfeeding link nurses. Breast milk provides both comfort and nutrition. It is easy for babies who are sick to digest and is full of properties that help to protect your baby from infection.

While your baby is on PICU it is important to keep up your supply of breast milk, even though your baby may not be able to breast or bottle feed. You can express your breast milk and it can be frozen and stored, so that it is ready to be used whenever your baby needs it. It is very important to remember to eat and drink well while you are expressing your breast milk.

There are two main hormones that are important in breastmilk production. Prolactin helps make your milk, and oxytocin releases your milk from your breast. Both hormones are stimulated by removal of milk, touching your baby and being close to them, breast massage and nipple stimulation. The more frequently you express, the more breastmilk you will make.

You should aim to express approximately 8-12 times in a 24 hour period to mimic your baby's feeding pattern. It is important to express at least once during the night, between the hours of 2am and 4am as your body releases a surge of prolactin.

Please speak to your bedside nurse or the Nurse-In-Charge if you need help/support with breastfeeding and they will link you in with one of our breastfeeding link nurses or the dietician. For more details on breastfeeding, please see scan the QR code or follow the link below
https://padlet.com/imperialinfantfeedingteam/Paediatrics

PLAY SPECIALIST

The play team covers PICU and the paediatric wards. The nursing staff can refer your child to the play team and one of the play specialists will be able to come and visit your child. They can offer different types of play support depending on the needs of your child; for example, therapeutic play as part of rehabilitation, developmental play for those children with additional needs or loss of skills due to hospitalisation, normalising play to alleviate boredom and maintain skills or distraction techniques to manage procedures.

PICU TECHNICIAN

Our technician is responsible for the maintenance of all our equipment on PICU. They also assist with preparing equipment for transfer to scan and help to train staff with the large variety of equipment we use on PICU.

PICU ADMINISTRATOR

Our administrator sits at the front desk and works Monday-Friday office hours. They will welcome you into the unit and can assist you with queries.

PICU HOUSEKEEPER

Our housekeeper is responsible for the maintenance of our stock and supplies

PICU DOMESTIC

We have a domestic team to clean and maintain our high standards of cleanliness on PICU. If you have any concerns regarding the cleanliness of the unit please speak to the Nurse-In-Charge

RESEARCH ON PICU

St Mary's Hospital is closely affiliated with Imperial College, London, and together they form the UK's first Academic Health Science Centre- a university NHS partnership to enhance the translation of research discoveries into improvement in human health. Our PICU participates in a range of studies, meaning that medical decisions and treatments are backed by solid research evidence ensuring that our patients receive the most effective and appropriate care available. Please see our research board (located opposite Bed 2) for our current studies. If your child is eligible for any of these studies, you will be approached by a member of our research team. Participation in research is voluntary and if you choose to decline this will not in any way change the care that your child will receive.

The PICU Research Nurses have a background in PICU and infectious disease nursing, and are passionate about improving health through research. If you have any questions or would like to discuss research within the PICU, please ask your bedside nurse to contact the Research Nurses.

We look forward to discussing the exciting research opportunities within our unit with you and your family.

PART THREE - UNDERSTANDING PICU

PICU is a very daunting environment your child will be connected to various pieces of equipment and medication. They may look different - often children on PICU can become swollen due to excess fluid. It is a busy ward with a high patient flow and activity level. It can be quite overstimulating in terms of noise from alarms and equipment. You will understandably also be very worried about your child. All of these factors contribute to what is quite a traumatic experience. This next section aims to introduce how PICU works and explain some of the equipment you may see.

A TYPICAL DAY ON PICU

Time	Activity
07:30 - 07:40	Nursing team arrive for main handover
07:40 - 08:00	Bedside handover Nurse-In-Charge handover (staff room)
08:00 - 08:30	Bedside Nurse performs safety checks and patient assessment
08:30 - 09:00	Medical Team handover
09:00 - 11:00	Morning Ward Round Physios review and treat patients
11:30 - 12:00	PICU Planning Meeting (Senior Nursing and Medical Team)
12:00 - 16:30	Planned procedures/investigations Second physio treatment
16:30 - 18:00	Evening Ward Round
18:00 - 19:30	Ongoing nursing and medical care of patients
19:30 - 19:40	Night nursing team arrive for main handover
19:40 - 20:00	Bedside Handover Nurse-In-Charge handover (staff room)
20:30 - 21:00	Night Medical Team handover
21:00 - 23:00	Night medical team assess patients
23:00	Night ward round with Consultant
23:00 - 07:30	Ongoing nursing and medical care of patients

WARD ROUNDS

There are two walk-around ward rounds during the day. The PICU Doctors and Nurses will review, examine and discuss every patient and make a plan for the day. During the ward round you will be able to stay and listen to the round for your child. When the team are discussing other children you will be asked to wear the noise cancelling headphones available at your bedspace. The ward rounds follow a systematic approach to ensure the team address each aspect of your child's care. At the end you will be able to ask questions but the Duty Consultant may ask to meet with you after the ward round to be able to discuss your child's care in more depth as they need to be able review and make a plan for every patient on the unit.

Our technician is responsible for the maintenance of all our equipment on PICU. They also assist with preparing equipment for transfer to scan and help to train staff with the large variety of equipment we use on PICU.

TUBES, LINES AND EQUIPMENT

Below is a description of some common equipment you may see on PICU. Your child will not necessarily require all of the following.

Breathing Tube (also called an endotracheal tube or ETT) – this is a tube inserted through the nose or mouth into the lungs. Putting the breathing tube in is called intubation and removing it is called extubation. Once the breathing tube is in it will be connected to a ventilator to support your child's breathing. In order to put the breathing tube in your child will require medicine to put them to sleep like when someone needs an operation. Your child will then need medicine to keep them calm whilst they need to stay on the ventilator. Whilst your child has a breathing tube in place they will not be able to speak/cry.

Ventilator – this is a machine which will provide breathing support for your child. It works by pushing air and oxygen into the lungs at a set pressure depending on how unwell your child is. As your child's condition improves the pressures will be reduced (also called weaning) and the amount of oxygen your child needs will reduce. The ventilator can be attached to a breathing tube or also to a face or nasal mask, this is called non-invasive ventilation.

Child with non-invasive ventilation

Suction Catheters - if your child has a breathing tube they will be able to cough but will need assistance to remove the secretions. Another smaller tube is inserted into the breathing tube which encourages your child to cough then suction is applied to remove the secretions. Your child may also require their nose or mouth to be suctioned to help clear secretions. Samples of secretions from the nose and breathing tube will be taken for investigation.

Lines/Access There are many different types of intravenous access. Which line your child needs depends on the type of medication they require. Some common lines you may see are:

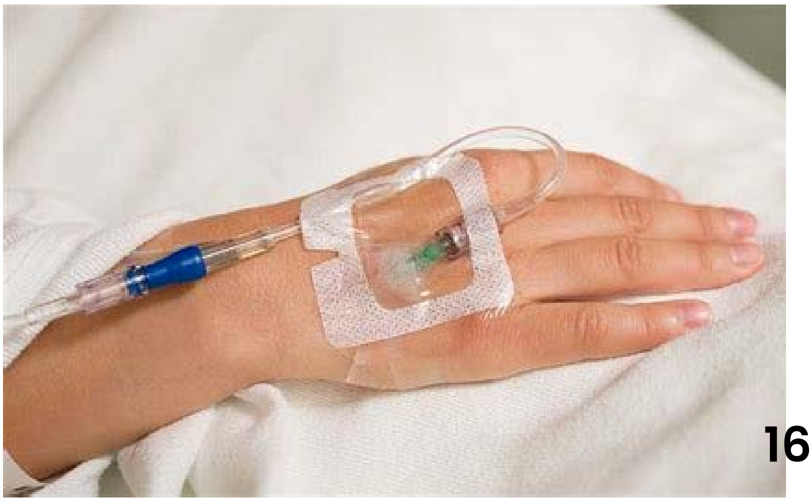
1.Peripheral Intravenous ('into a vein') Line (also called cannula) - a small tube is placed into a vein using a needle which is then removed. These lines are used to administer intravenous medication. They are secured using steri-strips and a clear dressing. Your child may need a splint and bandage to keep this safe. These are generally placed in veins in the hands, wrists, arms or feet. Cannulas do not always last longer than 3-4 days and may need to be replacedsooner.

2.Peripherally Inserted Central Catheter (PICC) This is a long thin flexible tube which is inserted into a vein on the arm and where the end of the line sits in a large vein just before the heart. PICCs are able to stay in place longer than a peripheral intravenous line so are used if your child requires a longer course of medication.

3.Midline These are similar to a PICC but much shorter so the end of the line sits in a vein close to the shoulder. These also last longer than peripheral intravenous lines and can also be bled back for blood samples.

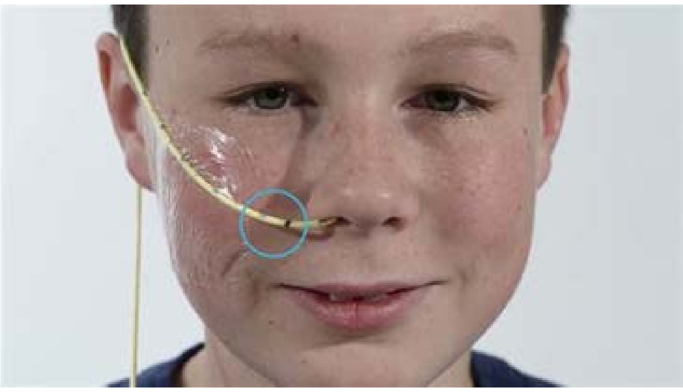
4.Central Venous Line - this is a larger tube placed into a larger vein usually in the child's groin or neck. These are inserted under sterile conditions and last longer than peripheral lines. You can also use these lines to take blood samples. Some medications we use can only be given through a central line.

5.Arterial Lines - this is a special cannula which is inserted into an artery. A continuous infusion of saline is run through this line and it is transduced to measure the pressure. This means a continuous blood pressure can be obtained in a waveform on your child's monitor. This is the most accurate way to measure your child's blood pressure. You can also take blood samples from an arterial line.

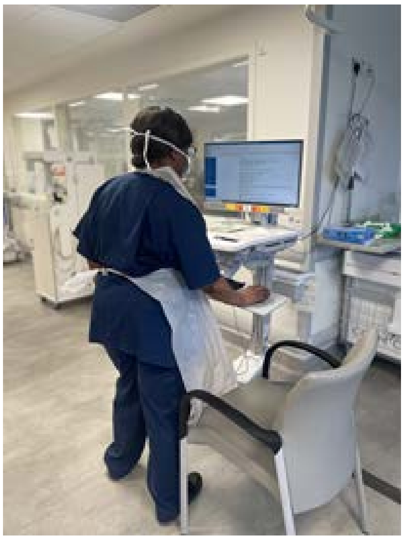


Urinary Catheter – this is a tube placed into your child's bladder to measure their urine output.

Nasogastric Tube – this is a tube placed through your child's nose into their stomach so that we can give them medication and feed them milk whilst they are unable to eat and drink normally



Computer Station – each bedside also has a computer station this has a programme on it where your child's care is documented. This includes both medical and nursing notes. There are also some mobile computer stations which are taken on ward round.



Monitor and monitoring – each child will have their vital signs monitored and this will be displayed on a monitor at their bedside. You will see various numbers and waveforms displayed in different colours. We routinely measure heart rate, blood pressure, oxygen saturations, breathing rate and temperature. Your child’s monitor is also connected to a central monitor in the main office so can be viewed by the Nurse-In-Charge and Medical Team. Please feel free to ask about the numbers displayed but try not to be distressed when the monitors’ alarm, often it is as simple as your child is moving or a lead has become disconnected. Your nurse will respond appropriately to alarms and knows when to escalate for senior support.

ECG – (electrocardiogram) Heart Rate and Rhythm

Arterial Blood Pressure Waveform

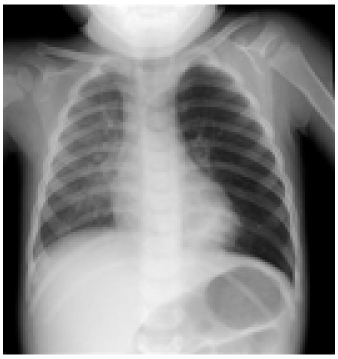
End tidal Carbon Dioxide

Oxygen Saturations

Infusion pumps – The intravenous medications administered to your child often need to be given continuously or at slow rate and infusion pumps are used for this.

Medication – your child will require a variety of different medication whilst on PICU. In order to keep your child comfortable whilst requiring ventilation your child will be given a combination of analgesia (pain medication) and sedatives. Sometimes if your child is very unwell or needing high pressures on the ventilator they may also require a muscle relaxant. These medicines run as infusions on our infusion pumps through a cannula or central line. These will be weaned as your child's condition improves. Sometimes your child may need medication to support their blood pressure, these are also given as slow continuous infusions. There are many other common classes of medications used depending on your child's diagnosis and include; antibiotics, antivirals, anticonvulsants (to control seizures), diuretics (to support your child's renal function and get rid of extra fluid) and bronchodilators (medication to reduce swelling in your child's airway).

X-Rays – Chest x-rays are taken to check the position of the breathing and nasogastric tube and also allows us to check the lungs. You will be asked to step away from the bedspace at the time of the X-ray but this only takes a minute.



DISCHARGE FROM PICU

Once your child no longer requires PICU or PHDU care they will be discharged or 'stepped down' to a ward for their continued recovery prior to going home. If St Mary's is your local hospital or your child is still requiring one of our specialist teams then your child will be discharged to one of our paediatric wards. Otherwise your child will be discharged back to your local hospital to one of the paediatric wards there. Leaving PICU can be quite daunting for families. Whilst you will be relieved your child is improving, stepping away from the high nursing to patient ratios, access to the medical team and continual monitoring is quite scary. Please be reassured we only discharge children once they are medically fit to do so and we give a thorough medical and nursing handover to the local team. If you are being discharged back to your local hospital transport will be arranged to take you and your child with a PICU nurse escort.

PART FOUR - YOUR ROLE ON PICU

We appreciate that you know your child best and we want you to be involved as much as you would like during their admission. We encourage you to bring in any important items for your child, for example; toys, blankets, comforters, books, music player. You can also bring in photos from home and put them on your child's whiteboard at the back of their bedspace. It is helpful for us to know their likes/dislikes, what they like to be called and what/who is important to them.

We can provide nappies, wipes, baby milk, food and towels. If your child prefers a particular cream/toiletry product please feel free to bring these in and they can be kept at your child's bedside in their bedside trolley.

Children are usually nursed without clothes because of the lines and monitoring leads required for their care. However hats and socks are often useful for small babies. For older children please ask your nurse what would be helpful. We will maintain the dignity of your child at all times.

You will be able to get involved with your child's care if this is something you feel comfortable with. We appreciate it is daunting to see your child with lots of lines and tubes. You can assist with nappy changes, mouth/eye care and turning your child. Please just let your bedside nurse know what you would like to do or not do. We will support you to do as much as you feel able to.

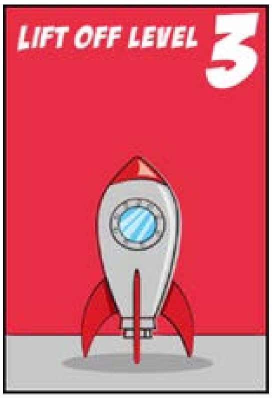
HELPFUL TIPS FOR PARENTS/CARERS ON PICU

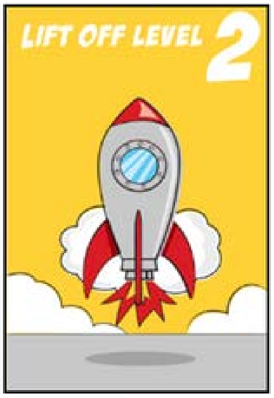
- Even if you don't feel like it try to drink plenty of fluids and try eating at least small amounts
- Try to take regular breaks – this could be a walk down the corridor or down to the café or a walk along the canal
- Try to rest overnight whilst your child is ventilated and sedated because they will need you more once they are awake
- Nominate one family member or friend to update other family members/friends regarding your child's condition so you don't have to cope with lots of phone-calls
- Make notes during your child's admission, this could be questions to ask or just noting down key events
- Please ask questions – no question is silly, we want you to be informed
- Try not to google things about your child the internet is not always reliable. Ask the nursing or medical team about reputable websites
- Try not to focus on the numbers on the monitor or pressures on the ventilator let the medical and nursing team worry about those – you focus on your child
- The PICU journey is a bit of an emotional rollercoaster try to take each day and not think too far ahead – be kind to yourself
- Talk to us about how you are feeling so we can support you and direct you to other forms of support.

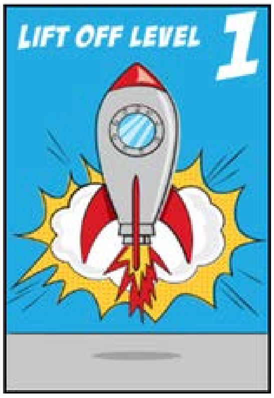
LIFT OFF

Here on PICU, we have implemented an initiative called 'Lift Off', which helps guide the type of activities your child will be supported with during their admission. Lift Off aims to encourage movement and engagement through developmentally appropriate activities. Keeping your child active and moving may help maintain or improve their muscle strength and potentially aid weaning from the ventilator. As well as having a positive physical impact, movement and play can also help improve the experience you and your child have whilst on Intensive Care. Being more awake, your child will be able to have more interaction with you.

Each day, your child will receive a 'Lift Off' level (3, 2, or 1) depending on how long they are into their admission, and their medical status. Activities will be supported by the whole team, which includes nurses, therapists and doctors. We will aim to complete Lift Off activities during the day to create a routine for the children.







LEVEL 3

- All children in the first 12 hours of admission, as well as those receiving high level medical support are set at "Lift off level 3". Although it is unlikely they will be allowed out of their bed or cot during this time, there are still many activities they can engage with, for example;

- Cares such as; brushing and washing hair, brushing teeth, washing
- Massaging
- Encouraging non-nutritive sucking on a dummy
- Listening to stories/music

- Expressing milk to support breast feeding
- Talking , singing, reading and playing
- Positive oral touch e.g. stroking your child's face, cheeks and forehead
- Use of bonding squares or Zaky hands

LEVEL 2 AND LEVEL 1

As your child moves to Level 2 and then Level 1, opportunities for them to participate in out of bed activities will increase.

With support from the MDT your child may:

- Transfer out of their cot or bed for cuddles with you
- Sit out in a chair or on the edge of the bed
- Spend time playing on a floor mat
- Mobilise around their bed space

PART FIVE - SUPPORT FOR YOU

CHAPLAINCY AND FAITH SERVICES

The Chaplaincy team offers confidential religious, spiritual and pastoral care to all families. The service is available Monday-Friday 09.00 - 17.00. There is also an out of hours service if you feel your need is urgent. Please speak to the Nurse-In-Charge to arrange this. The Chaplaincy team is made up of Anglican, Jewish, Muslim and Roman Catholic Chaplains. Representatives from other religions and traditions can be contacted on request. Your own minister is also welcome to visit just speak to the Nurse-In-Charge to arrange.

Christian Chapel - First Floor Mary Stanford Building
Muslim Prayer Room and Multi-faith room - Ground Floor Clarence Wing

If you require further information on Mass/Prayer times please speak to the Nurse-In-Charge

ADDITIONAL SERVICES

Intepreting Services - We have access to face to face intepreters for most languages/dialects. Please inform your bedside nurse and we can book these. We can also access a telephone interpreting service when necessary.

Wi-Fi - To connect search for 'NHS Wi-Fi' on your mobile phone or laptop device and sign up.

Pharmacy - There is a Lloyds pharmacy on the Ground Floor of the QEQM building. Opening hours: Mon-Fri 09.00-18.00, Saturdays and BHs 09.00-13.30, Sundays 10.00-13.30

Union Coffee Café - Found on the ground floor of the QEQM building. It serves a selection of hot and cold beverages, food and snacks. Opening Hours: Mon-Fri 07.00-19.30, Weekends 08.00-20.00

There is a 24 hr TESCO on South Wharf Rd, which also has a cash point. There are a variety of cafes, restaurants and shops along Praed St. Towards Edgware Rd there is a Post Office, a Superdrug and further along a small Marks and Spencer. St Mary's Hospital is also right next to Paddington station which has a number of eateries and shops

COSMIC HOUSE – PARENT ACCOMMODATION

Cosmic House opened at the end of 2019 and has 12 bedrooms, a kitchen/dining area, lounges, play area and laundry facilities. The accommodation allows families to stay on-site and be within close proximity to their critically ill child at all times, and provides a safe and supportive environment for families to get a little bit of respite from the difficult situation that they find themselves in.

- Supports over 400 families with critically ill children every year
- Provides a 'Home from Home' environment and some resemblance of normal family life for families
- Keeps families together at a time of crisis
- Provides a place of respite for parents whilst they support their seriously ill child

Cosmic House is looked after by our Accommodation Manager (or our PICU staff out of hours). On arrival to PICU you will be asked if you need a room and you will be given a welcome pack and key (which you will be asked to pay a small deposit for if you are able) and you will be asked to sign a behaviour contract/tenancy agreement/fire guideline. If there are no rooms available in our accommodation you will be found a room in a local hotel or within the hospital.

If you experience any problems with the accommodation please speak to the Accommodation Manager (during office hours) or the Nurse-In-Charge (out of hours).

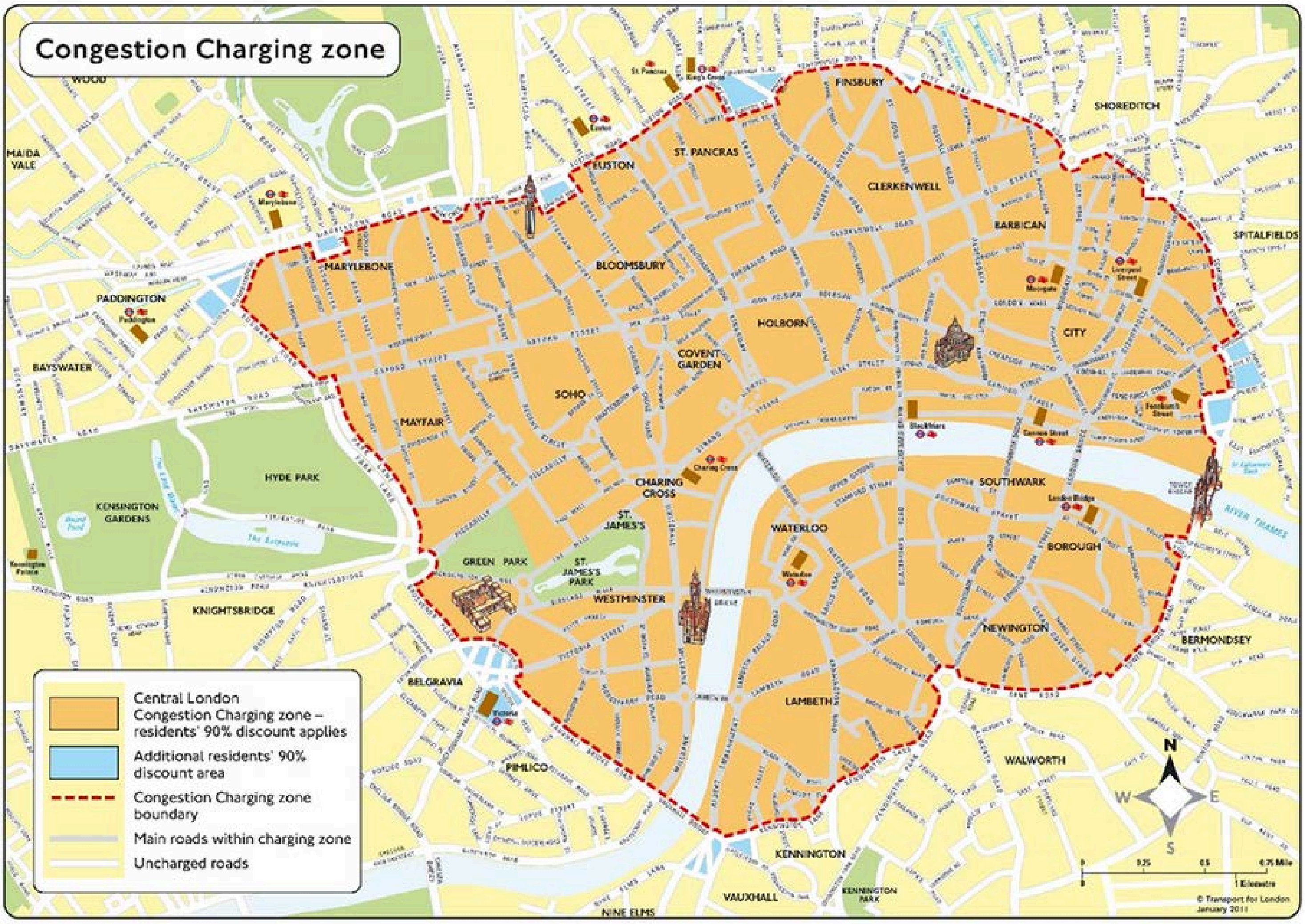
Sleeping at the bedside is not permitted; this is because we need to be able to attend to your child quickly and safely. However for some of our awake PHDU patients we may allow you to be at their bedside for their emotional well-being. We ask for your understanding and trust that we try to be fair to everyone and maintain safety for all the children whilst also acknowledging the different needs of all of our families.

If you do not want to stay in our accommodation or you have to go home Cosmic may be able to assist you with some of the travel costs to and from the hospital. Please speak to the Family Liaison Team about this.

CAN I PARK MY CAR NEAR THE HOSPITAL?

There is metered parking at the hospital, but the number of spaces is very limited and closely monitored by traffic wardens. We would recommend that you and your visitors travel to the hospital by public transport of taxi whenever possible. If you do need to bring your car please speak to the Family Liaison Team who may be able to assist you with parking.

If you are going to drive please be aware that St Marys Hospital is near the Central London Congestion Zone. Please also be aware of the Ultra Low Emission Zones (ULEZ) applicable to certain cars. Please use the Transport for London website to check your vehicle and for details on payment.



PART SIX - WE'D LOVE YOUR FEEDBACK

We aim to provide the highest standard of care to our children and their families. We are always keen to receive feedback so that we can continually develop and improve our service. On discharge you will be asked to complete the 'Friends and Family Test' on our i-pad. There are also posters on the unit with a QR code so you can feedback in this way also.

If you are dissatisfied in any way with your child's care we would ask that in the first instance you speak to the Nurse-In-Charge and the Duty Consultant. We will listen to you and aim to rectify the issue. You can also speak to the Family Liaison Team or our PICU Matron. If you feel that your complaint has not been managed satisfactorily you are able to contact the Patient Advice and Liaison Service (PALS) and Complaints Team. You can contact the team on 02033127777. They have an office on the ground floor of the QEQM building and the opening hours are 10.00-16.00 Mon-Fri. Alternatively you can email imperial.PALS@nhs.net

PART SEVEN - COSMIC CHARITY

Cosmic is the charity that supports the children's and neonatal intensive care units at St Mary's Hospital in Paddington and Queen Charlotte's & Chelsea Hospital in Hammersmith. We help our patients and their families and enable our dedicated team of nurses and doctors to treat hundreds of babies and children in intensive care. We go above and beyond what the NHS can't afford, purchasing vital state-of-the-art equipment, providing training for health professionals and supporting families through one of the most difficult times in their lives with one-to-one support, advice, counselling and accommodation. We also fund a programme of groundbreaking research into life- threatening diseases.

For more information and to keep up with upcoming events follow us on social media!

@cosmic_charity **@CosmicCharity** **@CosmicCharity** **@Cosmic**

To contact The Cosmic Team call **0203 312 6175**, **or email** **info@cosmiccharity.org.uk**
www.cosmiccharity.org.uk

COSMIC
Caring for babies & children in intensive care

PART EIGHT - NOTES/PATIENT DIARY

Please use this section to make notes, write a diary of your child's admission or write questions for the team.

Date:

Date:

Date:

Date: