

Preparing for your planned admission to the Paediatric Intensive Care Unit (PICU)

This booklet belongs to:

**Name and telephone number
of GOSH Consultant:**

**Name and telephone number of
GOSH Clinical Nurse Specialist:**

Information for children and young people

Contents

	Page
What is PICU?	3
Common questions about coming to PICU	4
Planning for your admission	6
What you will see on PICU	7
Who you will meet on PICU	8
Supporting you on PICU	10
Important information about you	12
Personalised Daily Routine	13
Communication Diagrams and Tools	14
Word Search	16
Glossary of useful terms	17
After PICU	19
Useful contact numbers	19

What is this booklet about?

This is a booklet for you to find out more about what it will be like when you have an admission to the Paediatric Intensive Care Unit which we sometimes call PICU.

There are some parts in this booklet which will tell you about what PICU is like and other parts where you can write some of your own questions or things you have found out about PICU.

What is PICU?

PICU stands for Paediatric Intensive Care Unit. This is a specialist ward where children and young people are cared for when they need support from the intensive medical and nursing care teams. On PICU every patient will have at least one nurse looking after them – this is due to the high level of care and support required. The nurse will make sure the patients they look after have everything they need.

You don't just have to read about PICU – you can come to have a look around the unit, and talk to some of the staff, before your stay. That way you can see what happens in PICU. You can arrange this by talking to your Consultant, clinical nurse specialist or by calling the PICU Family Liaison Nurses on 020 7829 6723.

You can fill in information about this visit in the box below.

I have arranged to meet _____ (name)
on _____ (date) at _____ (time) to visit PICU

When you heard that you need to go to PICU,
you might have wondered...

Why am I going
to stay on PICU?

Children and young people come to stay on PICU for different reasons. Sometimes they might need to have extra support with breathing and/or specialist equipment. Other times they might need to stay in PICU for a short time after they have had an operation to make sure they are ok and ready to be moved to another ward for recovery.

How long will I be on PICU?

This will vary for everyone. It is expected that you will need to stay on PICU for at least _____ days.

[Ask your nurse to help you fill this in]

What's different about PICU?

You might have already spent some time on a different ward or visited one of the wards in the hospital. There are lots of things which are similar to other wards. There are still lots of doctors, nurses and other staff who will be looking after you throughout the day but on PICU you will see the staff around more of the time. Professionals from other wards who you know already might visit you on PICU, but you will meet lots of new doctors and nurses too. There is a space later in this booklet for you to write any names and contact details of people you might have already met on PICU if you have visited, or anyone you would like to visit you when you are there.

I am going to PICU because _____

[Ask your nurse to help you fill this in]

What will happen while I'm on PICU?

When you come to Intensive Care after your operation you are likely to need a tube that will help with your breathing. This is quite normal after a long operation, or for young people that have breathing problems before their surgery. The tube will either be in your mouth or in your nose. This is called Intubation. The tube may be attached to a breathing machine called a ventilator. This is called Ventilation. When you have a tube in you will not be able to speak but try not to worry, the nurses and your family will help you to communicate by writing things down or you can point to what you want. Having a tube in your nose or mouth does not hurt but may feel a bit irritable. To prevent any distress or discomfort from this you will be given medicines via your veins which will make you sleepy, and control any distress and discomfort. This is called Sedation. The doctors and nurses will also help with any of the discomfort or pain that you may possibly feel.

Can people visit me on PICU?

Yes. Usually your closest family will be with you when you first wake up on PICU (this might be your Mum, your Dad or your carer). If you have brothers or sisters they can also visit you when you feel ready for this. Usually only three people can be by your bed at any time (so that it doesn't get too crowded!) Friends can also visit once you are on the mend.

Sometimes young people like to have lots of visitors, others just want one or two of their closest family; do let the nurse know who you would like (or not like) to visit.

Can I eat and drink when I'm on PICU?

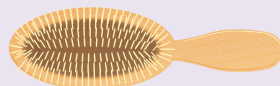
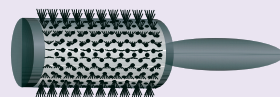
While you have a tube in you will not be able to eat or drink by mouth but you might have a feeding tube into your tummy to ensure that you're not hungry.

Things to think about before your admission

Things to bring in

You will have a good idea about the things you would find helpful to have with you. Other young people have said that these things can be helpful...

- A favourite DVD
- Music
- Books and magazines
- Computer games
- A list of things you would like PICU staff to know about you
- Personal care items like shower gel, deodorant, hairbrush, hair bobbles (if you have long hair!), toothbrush and toothpaste (the smaller the better!)
- Remember on PICU you can choose who you would usually like to help you with your personal care—the bedside nurse or your mum, dad or carer
- Clothes—underwear, pyjamas (ones with buttons at the front are ideal), normal clothes for during the day, slippers (for when you feel well enough to walk around on the unit)
- Favourite pillow, blanket, toy, or a lucky mascot?
- Photos of your family, friends or pets!
- Earplugs and/or a sleep mask (there is always low level lighting on PICU, even at night time so some people find it hard to sleep)
- This leaflet!



What you will see on PICU...



A typical bedspace in PICU



The ventilator and tubing



The monitor to observe your vital signs

Who you will meet on PICU and what they do

There are lots of different people you might meet on PICU. Below is a table of some of these people and how you can contact them if you would like to find out more about their role.

The PICU team	Names & phone numbers	Have you met them?
Doctors and Nurses You will meet a number of different doctors and nurses when you stay on PICU; sometimes it might seem like you are meeting new staff every day! All the doctors and nurses on PICU are part of a team and so will be working together.	Don't worry about filling in this one in as you'll meet lots of different doctors and nurses.	
Family Liaison Nurses These are special nurses who you may meet on PICU or if you come and visit before. They won't be wearing uniforms like the other nurses. Their job is to meet with all the families and find about how you and your family are managing. They can also help with any questions you might have about being on PICU and arrange for you to meet with the psychologist or play specialist.		
Play Specialist A Play Specialist is someone who prepares children and young people for all sorts of procedures and operations, provides distraction during things like blood tests and dressing changes and provides things to do when you are feeling up to it to stop you getting bored. They can also help if your brothers, sisters and friends want to visit. Remember to bring in your favourite stuff, like music, DVDs and books!		
School At GOSH there are school teachers who can help young people continue with their school work while they're here. This is different for everyone - some people stay here longer and so this can be more important. The key thing to remember is to not worry too much about missing schoolwork, that's what the school teachers are here to help with.		
Physiotherapy The physiotherapist works alongside the doctors and nurses. Physiotherapy (or Physio) is important on PICU as it helps keep your lungs clear while you are on a ventilator. This type of physio is often called chest physio. The physio will help you to take deep breaths and cough to remove phlegm on your lungs. This is a normal part of caring for someone who is on a ventilator and helps to reduce the amount of time you need to stay on the ventilator. If you need it, the physio may also keep an eye on how your arms and legs are moving and help you to get mobile again.		

The PICU team	Names & phone numbers	Have you met them?
Psychologist A psychologist is not a medical professional and so cannot prescribe any medication. Their job on PICU is to support children and parents on the ward, as we know that it can be a difficult time. They offer support and help with any thoughts and feelings you might have about being on PICU. This could be helpful if you are feeling worried, scared or sad, or if you would just like to meet with someone outside your family. Don't worry if you are having trouble speaking—you can still have a conversation with the psychologist by writing down what's on your mind on paper or on tablet computer. The psychologist can also talk to the doctors and nurses on your behalf, for example if there is something that you would like to be done differently.		
Social Worker & Family Support Worker There are two social workers on PICU who are there to help you with any problems you may be having while you are at GOSH and also at home. Sometimes this might be about making sure you and other members of your family are feeling safe and secure, or maybe to help ensure your views are heard by the Doctors and Nurses or even your own family. We can also help with practical issues and can make sure you or your family get advice and support about money, school or other difficulties. This could include setting up an appointment with a Family Support Worker or the Citizen's Advice Bureau. You can talk to a social worker in private if you are worried about anything – just ask the nurse looking after you and one of us will come up and see you.		
Adolescent clinical nurse specialist Our adolescent clinical nurse specialist provides independent support for anyone aged 11 or above wherever they happen to be in the hospital. He is available if you want someone to talk to about anything at all. It doesn't have to be related to your treatment or being in hospital—it could be about school, relationships, or anything else.		
Chaplains The Chaplains are a friendly team who will come and chat to see how you are doing. They are not medical but are interested in the whole of you, about how you are feeling, about things and people that matter to you, the things sometimes called "spiritual." On our team we have Chaplains from different faiths, so if you have a faith, we can pray with you or talk about these things as well. We look forward to meeting you!		
Other Teams (Fill in the contact details of the other GOSH teams you already know)		

Supporting you on PICU

Top tips from young people who have stayed on PICU

- "Let whoever is looking after you know about privacy and things you would like staff to know about. For example, would you like the curtains closed or open when you're asleep?"
- "Plan the things you want to bring in like books, music and DVDs"
- "There are lots of people around PICU—that's normal"
- "It will be noisy at times—you might want to bring headphones for when you are awake"
- "It feels ok being on PICU and it was not as scary as some people might think it would be"
- Stay Calm!
- Do remember that you will never be alone at any time whilst on PICU

Common thoughts and feeling about being on PICU

Young people have told us they have felt happy when waking up on PICU because they know their surgery is over. It is also really normal to feel a mixture of things when you wake up or are recovering on PICU.

Some people talk about having felt:



Bored



Scared



Confused



Sad



Frustrated

Some things that might help if you are feeling worried or anxious about being on PICU

It's ok to feel a little worried

It's normal to feel worried or nervous about being on PICU...

PICU looks and sounds quite different to other wards (you might notice this on your visit). It can be really normal for this environment to feel strange, especially when you wake up. Often these worries will get smaller as you become used to the environment

Letting people know

It is likely that you won't be able to talk when you first wake up on PICU...

Often there can be lots of really good questions you might have at this point. Young people have told us that it has been helpful to write these down so the PICU staff can try and answer them for you. One helpful way to do this is to use the PICU tablet computer or pen and paper. There are also some communication tools at the back of this leaflet to help you with this.

Communicating with the team

Staff on PICU are really happy to spend time with you and your family to understand a bit more about how you are feeling...

If you are not yet able to talk to them, you can use the PICU tablet computer or a pen and paper. That way you can ask the nurses lots of questions and let them know about some of the worries or feelings you have.

If you still feel worried

As we mentioned there is also a psychologist who works on PICU. She can meet with you to hear a bit more about what you might be finding difficult...

Young people have told us that they sometimes find it helpful to talk to someone outside the family so that they can be really honest about what they're thinking and feeling. The psychologist can also talk to the doctors and nurses on your behalf, for example if there is something that you would like to be done differently.

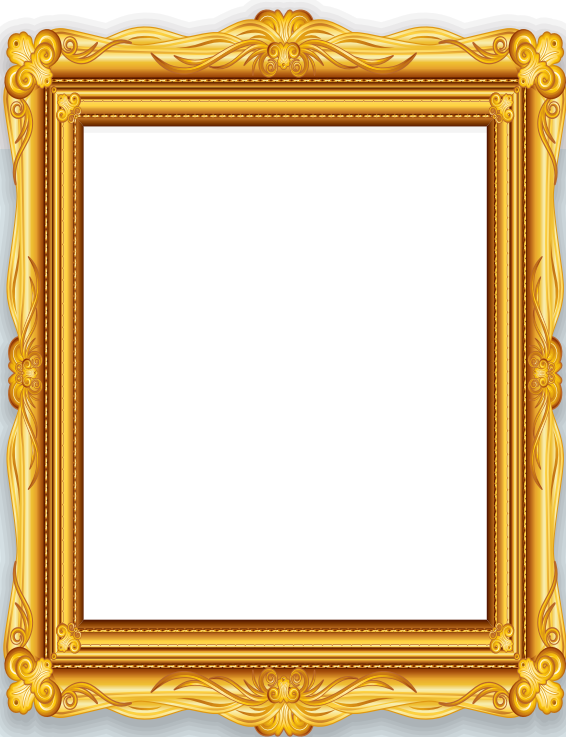
What helps when you're feeling anxious?

You might already have some really good ideas about what helps when you're feeling anxious or worried. You may have even tried out some of these when you've been in hospital before?

Things I find helpful to do when I'm feeling worried or anxious:

Key points about me

It will be really helpful for the PICU staff to know a little bit about you...



Draw or stick in a picture of yourself here

Five things that are important for your doctors and nurses to know, such as likes/dislikes

1.

2.

3.

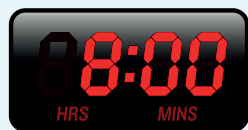
4.

5.

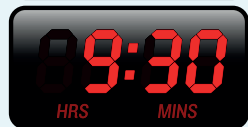
PICU Daily Routine

Young people on PICU have told us that it can help to plan your day. In the space below add in when you would (ideally) like to wake up, have visitors, including the physio or friends, and when you'd like to go to sleep.

Unfortunately it might not always be possible to stick to these times but the team will do their best to meet your needs.

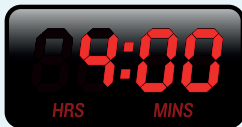
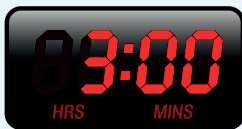
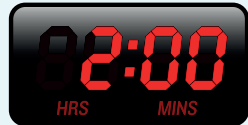
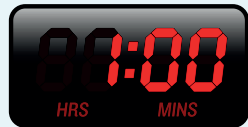
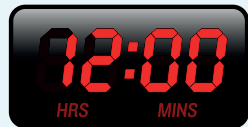


Day Nurse arrives



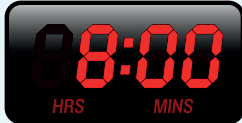
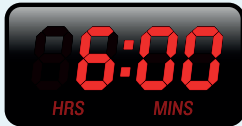
Ward Round

– parents and visitors have to leave the ward



Ward Round

– parents can stay

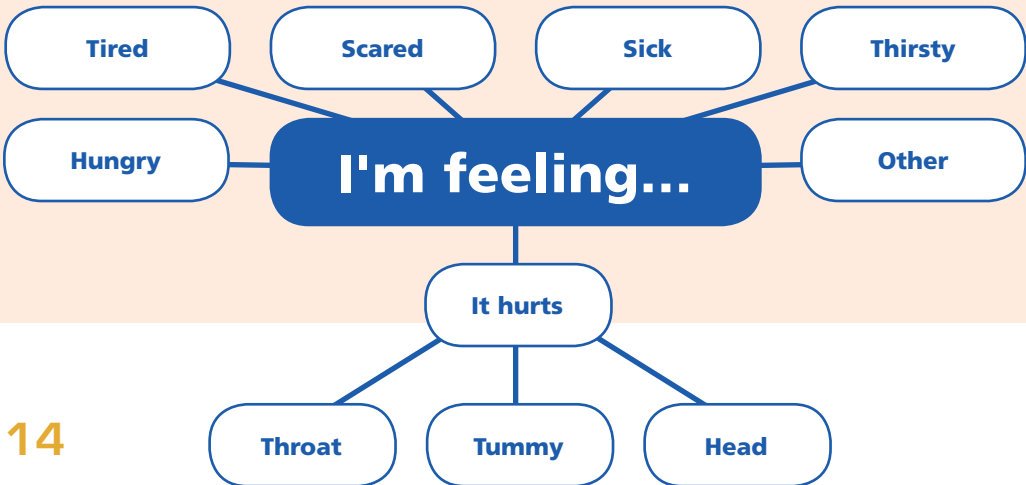
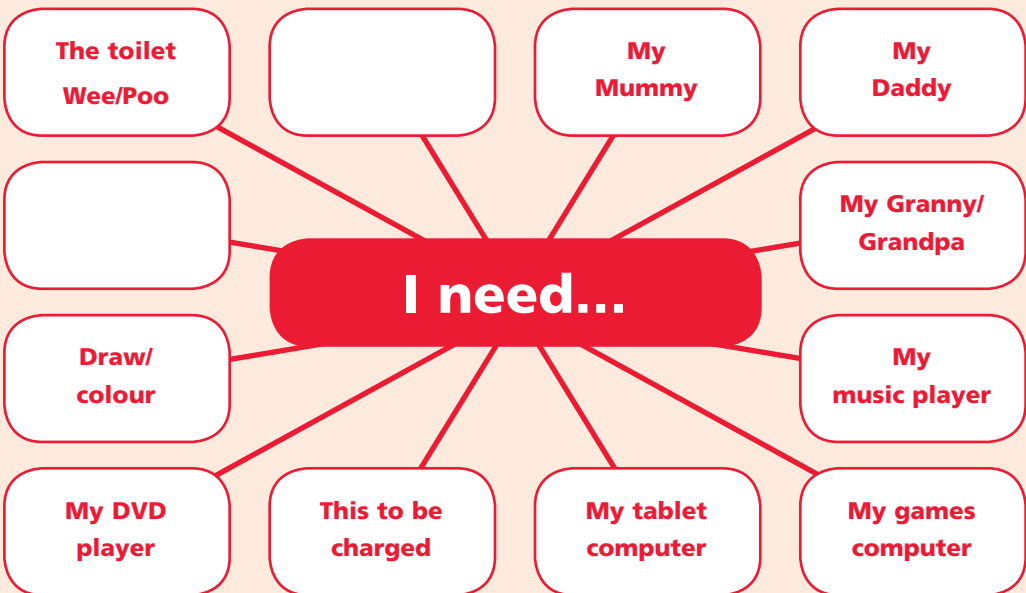


Night Nurse arrives

Here are some ideas of things you could do to fill your time: Watch films, play games, read books/magazines, listen to music, keep a diary!

You could ask your bedside nurse to help you fill this in...

Communication diagram



Communication board

Q W E R T Y U I O P

A S D F G H J K L

Z X C V B N M

1 2 3 4 5

6 7 8 9 10

YES

NO

OKAY

Word Search

M V P L D E T G I Z H U O G Z N A E U N
M T A I F U W U O B R B D K J X X N H N
I I P E M U G S D B R A C E W E Q D O V
G P C M Z F U X X H I F O Q P R R O B A
P M C S H K M L X J M A P C Z T C T V J
S G U R D D I C Z B I B N A R X O R P O
A H H C S H B N O V D W G L K N J A Y V
P J P J S S O G E T P E T U R D R C O Y
L V H N E I E N U X V U U N N I Z H E Z
G M H Y T T T N U V M W B N X I Q E P D
L E O C T I A K I H R F E A E X S A N A
Q L U J L I B B I L P E L C C O N L F B
S S I A C T R M U V G M N U N P M T N K
M S T K D B V U C T S W E D I S H U B E
Z O E T A B U T X E N O H M J D I B T T
R Q L R H G A G J C X I L B Y W S E G R
Z Y I O E F P A I Y K X N U J E K K C T
P C F D U U P U G Q G O G L K U S X W Z
J G U M Q Q Q E F Y O R X K T N N J H P
C H Z O M V N U F P I T G C K B W U W J

CANNULA
CPAP
DRUGS
ENDO TRACHEAL TUBE
EXTUBATE

FLUIDS
INTUBATE
LINES
NG TUBE
OXYGEN

SEDATE
SUCTION
SWEDISH NOSE
VENTILATOR

Glossary of useful words

CPAP:

A type of ventilation that gives support to help with your own breaths. This is the most minimal type of ventilation.

Drugs:

There are a number of drugs, otherwise known as medications that are used on PICU. There are antibiotics (to prevent infection), pain relief (to keep you free from pain and keep you comfortable), sedation (to keep you nice and sleepy, as required), steroids (most likely Dexamethasone) - this drug is used to minimise reduce swelling in your airway, as your airway can be a little swollen after surgery.

Endo Tracheal Tube/ETT:

This is a plastic tube that will either be inserted in your mouth or in your nose and into your airway. This tube is very important and needs to stay until the doctor removes it in a controlled way. The tube will be taped to make sure it is very secure. It is very important that you don't pull at this tube.

Extubate:

To remove the endotracheal tube.

Intubate:

Insert the endotracheal tube via a cannula.

Fluids:

The doctors and nurses can give you fluid which is usually made up of important electrolytes like sodium, potassium and glucose. You may have fluid for the first day or so of admission to PICU, and then you will be given milk through your NG tube.

Cannula/Lines:

You will have cannulas/lines, which are small plastic tubes into your veins. These are used to give you fluids and medications. They are removed when they are no longer needed.

Naso Gastric or NG Tube:

A tube that goes up into your nostril, down through your oesophagus and into your stomach. The nurses can put special milk feeds down your NG tube because you will not be able to eat or drink by mouth.

Oxygen:

A vital gas our organs and tissues require to function. When you are poorly or ventilated you may require some extra oxygen. We can give extra oxygen via the ventilator, or when your ETT has been removed we can give oxygen via a face mask or through small prongs in your nostrils called nasal cannula.

Suction:

When you have an ETT we have to make sure the tube stays clear removing secretions/ mucous from your chest. The nurses and physios can do this very effectively by performing suction. A fine suction tube will be inserted into your ETT to remove the secretions. This procedure can make you cough, but coughing is a good thing and helps to move secretions also.

Swedish Nose:

A small filter attached to the end of your ETT when you are breathing by yourself without a ventilator.

Ventilator:

The machine that breathes for you or helps you breathe whilst you are sedated and sleepy. The ventilator has tubing that attaches to your ETT. This can be a noisy machine at times.

What happens after I leave PICU?

When the Doctors and Nurses have decided that you no longer need the intensive medical and nursing care provided on PICU they will talk to you about this and let you know what happens next.

Sometimes young people go to a different ward at GOSH, others go to their local hospital and sometimes they go straight home.

If there was one thing I'd tell another child coming to PICU it would be:

One thing I wish I'd known pre-PICU:

Useful telephone numbers

GOSH switchboard 020 7405 9200 Internal ext. 5000	PICU Internal ext. 8808 / 5151
Family Liaison Nurse Internal ext. 6723/8207	Clinical Psychologist / Social Worker 020 7829 8896
Play Internal ext. 8849	Chaplains Internal ext. 8232

Comments & Feedback

How helpful have you found this leaflet?

1 2 3 4 5 6 7 8 9 10

1 = very unhelpful

[Please circle]

10 = very helpful

Would you recommend this leaflet to another young person?

Any other comments or suggestions:

You can give this feedback form to a member of staff or place it in the PICU comments box, thank you!

© GOSH NHS Foundation Trust
September 2015

Ref: 2015C0183

Compiled by the Paediatric
Intensive Care team in
collaboration with the Child and
Family Information Group

Great Ormond Street Hospital
for Children NHS Foundation Trust,
Great Ormond Street,
London WC1N 3JH
Tel: 020 7405 9200

www.gosh.nhs.uk

Information for children and young people