

When your child is in the Intensive Care Unit (ICU)

A guide to understanding
the psychological aspects
for children and families

Great Ormond Street Hospital
for Children NHS Foundation Trust

Critical Care at Great Ormond Street Hospital is made up of three units: the Cardiac Intensive Care Unit (CICU), the Paediatric Intensive Care Unit (PICU) and the Neonatal Intensive Care Unit (NICU).

Whether your child is at one of these units as part of a planned admission or

admitted in an emergency, the ICU environment can prove to be demanding, worrying and intense.

The staff teams here aim to alleviate some of the stress to families by talking to you openly and listening to you so that we can work together in the best interests of the child.



Reactions and feelings that families may experience

Each family will experience their time on ICU in their own individual way and find different aspects of the situation more or less difficult. There is no right or wrong way of dealing with this stressful time.

Common reactions from parents can include:

- Feeling anxious, irritable or becoming easily upset
- Experiencing shock, helplessness, loss of control, and fear
- Finding it difficult to maintain the role of a parent when there are many different people looking after your child and/or when your child is asleep or heavily sedated
- Functioning on auto pilot
- Not wanting to leave your child's side
- Having difficulty concentrating and absorbing information, needing it to be broken down, repeated, and written down
- Trouble sleeping or eating
- Losing track of time and the situation
- Feeling guilty
- Feeling anger and despair if there are unexpected set-backs with recovery

These are all normal reactions to a stressful event which everybody has to a greater or lesser extent; they can last for a few days or weeks depending on your child's recovery. Usually, as you gain more control over the situation and your child's health starts to improve, the stress reactions will reduce. However, it is not uncommon for parents to remain vigilant for setbacks for the duration of their child's admission.

When children have setbacks on intensive care, parents can feel like they are on a roller-coaster ride, having 'good days' and 'bad days'. Parents may think they need to remain 'strong' for their child and family which can be an added emotional strain.

Common reactions from children in the family can include:

If there are other children in the family, they may also be upset by the disruption and worry of having a brother or sister on intensive care. This can be shown in a variety of ways:

- A change in behaviour, including 'acting out' or misbehaving'
- Being 'as good as gold'
- Tearful
- Appearing quiet and withdrawn
- Becoming 'clingy'
- Some brothers and sisters may feel ignored, or that you are favouring your sick child by spending a lot of time at the hospital.
- If the disruption to family life is prolonged, you might notice that your other children are performing less well in school than normal. This often resolves itself but can be an additional worry at a stressful time.
- Some brothers and sisters ask a lot of questions, while others do not ask any.

Taking care of yourself and your family

To be a helpful support to your child during this difficult time, you need to look after yourself and your family too. The professionals undertaking the tiring and emotionally challenging work of caring for your child all need to take breaks from the intensive care environment; the need is equally great for yourself.

Tips for parents on ICU:

■ Take care of yourself.

Anxiety is a normal reaction in this environment but it can be reduced by taking regular breaks away from the ward and trying to eat and sleep, even though this may be difficult at times. It can be helpful to structure your day with regular times for meals and rests to break up the time you spend on the unit. Proper food and rest will enhance your ability to listen and understand the significant information that you

will be given about your child. It might feel odd, but trying to do things that make you feel more relaxed and improve your mood like going for a walk, taking a bath, or meeting with friends will help you manage your anxiety even if these things only last a short while. It is OK to leave the unit, go somewhere else and even enjoy yourself at times. This does not mean you do not care about your child; it is just one of the ways in which your body and mind try to cope with a stressful situation.

■ **Ask questions.**

If something is not clear or you need information during your child's admission, ask for an additional explanation or information. It can sometimes be helpful to write down a list of questions before you go to meet the doctor or nurse. Don't worry if you forget to ask something that feels very important; you can always ask more questions at another time.

■ **Gather support from family and friends.**

Sometimes, it can be helpful to contact one or two key people and ask them to contact and update others rather than doing all this yourself.

■ **Prepare yourself** for any setbacks, but concentrate on the steps to come and try not to become discouraged.

■ **Just being there** for your child during this time is as much as anyone could ask of you. Talk to your child's nurse about being involved in the daily care of your child, such as washing or nappy changing. Parents have told us that this can lessen the feeling that there is nothing they can do to help.

Tips for supporting your child on ICU

- You are the best person to reassure and comfort your child. You can offer them distraction by reading or, if your child is old enough and awake, playing a game.
- Give your child a secure feeling and help them to feel safe. Tell them what is going on, what is going to happen next and check that they understand. Due to the effects of the medication, they might forget and have to be told again each day or several times a day. Let them know that you are there for them. Where possible, say when you are leaving and when you are coming back. Try to make the hospital environment feel familiar by bringing in a photograph or toy. If it is medically safe, you can also use touch, for example, stroking or holding to help your child feel secure.
- Try to stick to a daily routine and work together with the medical and nursing staff to achieve this. This way, the hospital environment becomes more controllable and predictable for your child.
- Help your child understand what is happening by answering any questions they have in an honest way that is appropriate for their level of understanding and sensitive to their emotional needs. If you are unsure about how to answer your child's questions, you can always ask advice from the medical, nursing or psychosocial teams.
- Encourage your child to talk about how they might be feeling. It can be helpful to name difficult feelings (such as anger, happiness, sadness, and worry) for your child and explain that they are normal and understandable feelings to have in this environment.



Tips for supporting brothers and sisters:

- Take time to explain, at a level that is appropriate to their developmental stage and in a way that is not over emotive, what is happening to their brother or sister who is ill.
- Reassure them that they were in no way responsible for what has happened and that the same is not going to happen to them.
- Try to answer their questions as honestly as possible. If you do not know the answer, say so.
- Set aside special time with them, especially if you are spending prolonged periods at the hospital.
- Don't worry if you cry in front of your children, but do explain why you are upset and ensure they know it is not because of something they have done.
- Maintain some routine and familiarity. Keep up expectations for appropriate behaviour and keep to the boundaries you would set at home. This can be reassuring for children when other things have to be different for a while.
- Brothers and sisters of all ages are welcome to visit, but we usually find that they benefit from some preparation first. This may involve talking, or perhaps showing them photos, so that they know what sights and sounds to expect.

It is usual for children, particularly younger ones, to only want to spend a short period of time at the bedside. Accept their choices and allow them to go off and play in the playroom if they want to. They may want to draw, write or make something for their brother or sister who is ill. This can be particularly important if they cannot or do not wish to visit.

Adjusting to life after intensive care

Patients need help from their family and friends during their recovery, but the trauma and distress experienced by parents and other family members may mean that they are just as much in need of support. Sometimes people put their feelings 'on hold' while their child is on intensive care and it is only afterwards that they begin to feel upset.

Parents have told us that they have experienced:

- Difficulty sleeping, feeling constantly exhausted
- Anxiety and worrying, panic attacks, phobias
- Depression
- Feeling very emotional (sad or irritable and angry)
- Feeling jittery, difficulty relaxing
- Going over what has happened again and again
- Nightmares, bad dreams
- Difficulty concentrating
- Overworking
- Stress and tension in relationships (particularly between parents)
- Difficulty coping with their child, or his or her brothers and sisters.

If any of the above become unmanageable, it may be helpful to talk to a health care professional and possibly a psychologist.

Here are some other suggestions to help you cope with life after intensive care:

- Accept help and support from friends and find out about local emotional support from your family doctor (GP) and other health professionals. There may be specific support groups that you could contact.
- Take time to be with your family and also to be alone to restore balance to your own life.
- Eat a healthy diet, ensure good rest and exercise.

The Paediatric Clinical Psychology Service at GOSH

There is a psychology team at GOSH, specifically for the intensive care units, who can offer support to you and your family. They can work with you on a number of issues, including managing stress and anxiety during your child's admission, helping with decision making, helping your child cope with procedures, and working with brothers/sisters. We can see you by the bedside or in a more confidential space away from the bedside if you would prefer.

There are also other psychosocial professionals on the unit – including a social worker, a family support officer, play specialists

and chaplains – who work very closely with the doctors and nurses and have a lot of experience in supporting parents and families who have a child on an ICU.

As members of the Critical Care and Cardio-Respiratory Psychosocial Team, we are often on the unit and we might visit you by the bedside and offer support. If you would like to speak with us at other times, you can discuss this with your doctor or nurse. If you would like to contact a Psychologist directly, please call 020 7405 9200 extension 5166 and ask to speak to one of the ICU Psychologists.

Notes

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Compiled by the Critical Care and Cardio-Respiratory Psychology Team
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