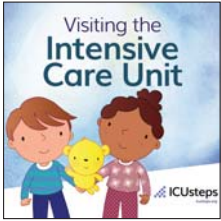


# Information sheet

## For parents or carers



This is a parent or carer information sheet for *Visiting the Intensive Care Unit*, an activity book for children who are visiting a relative in an intensive care unit (ICU). The activity book will help introduce children to ICUs and has activities to help them understand what ICUs do and what they might see when they visit one. There are also sections in the book for children to fill in about how they feel and about their relative, if they would like to.

For many families, critical illness is unexpected. This means there is no time to emotionally prepare, and it can be difficult to understand what is happening. Along with the many worries you may have, it can be hard to know the best way to help the children in your family. Below is some information that may help you to help a child in this situation:

- Explain to the child what is happening in a straightforward and simple way (e.g. "Daddy had bad headaches, which made him very poorly. We took daddy to hospital and the doctors said the headaches were a sign of a bigger illness in his head. The doctors and nurses are doing everything they can to help him"). What you tell the child will depend on their age and why their relative was taken into the ICU, but it is very important that you do explain what is happening. Not knowing is likely to make them feel anxious or confused.
- Encourage the child to ask questions. In this way, they can guide you with what they want to know. Children and young people can be good at asking for the information they need, though sometimes younger children can find this easier to do, while older children and young people can be more reluctant. But regardless of their age, it is important to let them know it is ok to ask questions, and that they can ask either you or other close relatives or friends.
- Check the child's understanding of the situation. Let them know it is ok to not have understood everything.
- Be honest if you don't know what is going to happen. It can feel difficult to admit this uncertainty to a child, but it is more upsetting for them to be told everything is going to be ok, if it may not be. If you are not sure what is going to happen, try to say something they can understand that will help them feel secure and reassured, for example, 'Daddy is very ill but the doctors are doing everything they can to help him'.
- Give regular updates to the child as appropriate and let them know they can ask questions whenever they want to over the time ahead (because different worries and questions are likely to arise at different points for the child). It can be reassuring to let the child know that as soon as you know more, you will tell them. This can be a matter of judgement about how much detail to go into, though, and will depend on the age of the child. Also, the condition of critically ill patients can regularly change between giving cause for concern and looking more hopeful, so you may not want to tell them hour by hour updates, for example.
- While talking with the child, it can be helpful to be doing another activity together at the same time, perhaps colouring or playing with toys, if the child is younger, or for teenagers, when out walking or doing household jobs, such as cooking. This can make the conversation a bit more comfortable for you and the child.
- Some children might like to have a particular time that is set aside to talk, but other children might find this uncomfortable, and prefer to talk at a time that suits them. Even if you have a scheduled time to talk, let the child know that they can ask questions at other times as well. When they are talking with you, if it is possible, try and make sure this time is protected and that you are not interrupted or distracted (for example, trying to do other things at the same time, such as taking telephone calls or talking to other people as well).
- Tell your child's school, and any other relevant groups, that the child's parent or relative is in intensive care. Let the child know that it is ok for them to talk to friends, teachers and family about what is happening.
- Encourage the child to keep a diary, if they would like to. It could include a brief description of each day and any souvenirs that they would like to include (such as pictures and so on). This helps the child understand what is happening and makes it easier for them to talk to their relative about what happened in their life while they were in hospital.

- Try to keep to the child's routine as much as possible while their relative is in ICU.
- It may be helpful to find a way for the child to still feel connected to the person in hospital. They could send letters or pictures in, record a message or some music for them, or have two small cuddly toys, one which they keep and one which the patient keeps in hospital.
- Remember mixed feelings are normal. It is ok for the child to feel upset, worried, angry, guilty or happy at different times. The child won't always act as we expect and this can feel unnerving, for example, they may be very upset and tearful one moment or running around giggling and playing the next.
- It is ok for the child to see that you are upset as well. It may even be helpful for them to see that you are upset, because seeing you express emotions will help them to learn about normal emotional responses, and that people can experience very difficult thoughts and feelings and be supported through those feelings. However, if you feel overwhelmed by your emotions most of the time, it might be distressing for the child to see that. Try to talk to friends and family about how you feel. You can also speak to staff on the ICU who may be able to advise about where to find support for yourself and/or your family during this difficult time.

You may need to consider whether a child should visit their parent or a close relative in an ICU. You should check with staff before bringing children to the unit and talk to the child about it. If the child decides they want to go into the ICU, prepare them for what they might see, including the machines, what they do and how the patient might look. The activity book may help with some of these discussions, for example on pages 6 & 7 there is a picture of an ICU.

### After ICU

Once the patient leaves the ICU, the child may need support for some time. At times, it may be helpful to mention the patient's stay in hospital so the child knows they can talk about it and ask questions. If the child is very young, they may find it easier to show their feelings by drawing pictures or acting out what happened with their toys or playing hospitals. It's important to take it at their own pace, and not force them to talk about it, but give regular opportunities for them to talk if they want to.

Remember that children can ask very blunt questions, so if the patient doesn't feel strong enough to cope with this, ask another family member or friend or their teacher to talk to the child about their experiences and feelings.

If the child is bereaved, specialist help may be needed to help them to come to terms with what has happened. Further information is available from the 'Useful Contacts' section in our online booklet *Intensive Care: a guide for patients and relatives*.

### Further help

**ICUsteps** is a charity set up by former intensive care patients and their family members, in partnership with healthcare professionals. Our website contains patient and relative information including our guide *Intensive Care: a guide for patients and relatives* and information about local support groups. [www.icusteps.org](http://www.icusteps.org)

### Support for parents and carers

**Winston's Wish** is a charity for bereaved children, and they also produce an information book *As Big As It Gets: Supporting a child when a parent is seriously ill*. This includes information and activities, sources of information and support and recommendations of books that may help children during this time.

Advice for families, books and resources are available through their helpline **08452 03 04 05** or visit [www.winstonswish.org.uk](http://www.winstonswish.org.uk)

**Family Lives** is a national family support charity providing help and support in all aspects of family life.

Their helpline is **0808 800 2222** or visit [www.familylives.org.uk/](http://www.familylives.org.uk/)

### Helpline for children and young people

**ChildLine** is a free helpline for children and young people in the UK, and they can call to talk about any problem that they have.

The free helpline number is **0800 1111**. It is open 24 hours a day, 7 days a week.

This sheet was written by Catherine White, ICUsteps with advice from Dr Katie Redwood, Clinical Psychologist, University Hospital Southampton and in consultation with Winston's Wish.