

The Recovery Journey after a PICU admission



A guide for families

Introduction

This booklet has been written for parents and young people who have experienced a Paediatric Intensive Care Unit (PICU) admission. It explores the journey that you may experience after discharge.

We spoke to lots of families who have spent time on PICU. What we learnt from them has helped us to make this booklet. For most families, discharge from PICU is a welcome relief, but we also learned that the year after discharge from PICU can be hard and the recovery journey may raise unexpected challenges.

It is important to remember that everyone is different and there is not one right way to recover. Different families will cope in different ways. This may be influenced by the reasons for your PICU admission and your natural coping style. Families tell us that it can be helpful to know what to expect and what feelings and challenges you may encounter.

We hope that this booklet will help you think about the challenges you may face after a PICU admission. It is designed to give you some ideas about how to look after yourself and your family as you travel along the road to recovery.



What is recovery?

In hospital, there is often lots of talk about recovering and “getting better”. By this we usually mean **physical recovery** – your child regaining full strength and fitness. Because your child has been so unwell, physical recovery is what many people including doctors, family and friends will focus on. However, physical recovery is only one part of the recovery process.

There is also **social recovery** and **emotional** to think about. Social recovery involves returning to normal life, for example getting back in touch with friends or returning to school. Emotional recovery involves thinking about what has happened, reflecting upon it and eventually moving on from the experiences in PICU. Both emotional and social recovery are just as important as physical recovery.

The road to recovery can be even more challenging if your child has ongoing difficulties such as continuing health problems or disabilities.

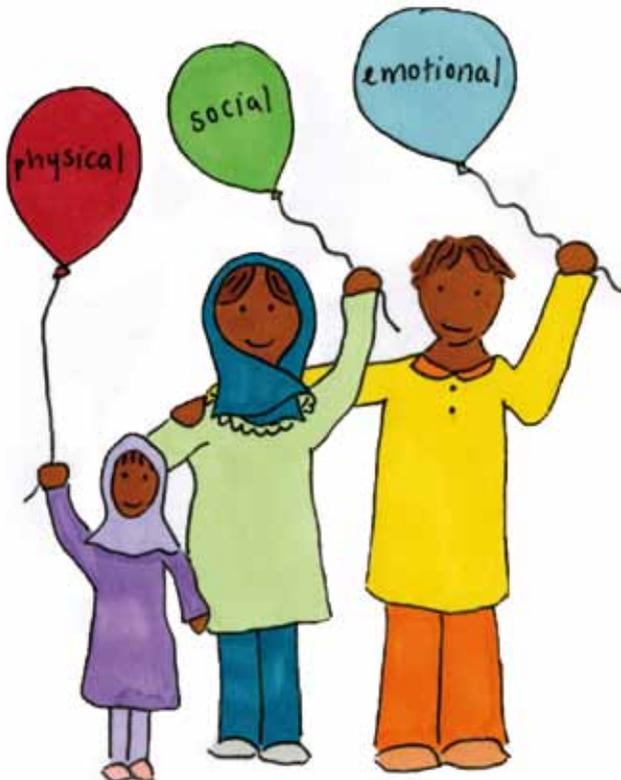


The effect on the family

It is helpful to keep in mind that a PICU admission does not just affect the child, but impacts on the whole family.

You may find that you also need some time to recover and often this process will be similar to your child's recovery. With your child on PICU, you may not have slept well or eaten regularly – getting back into a healthy routine will be part of your **physical recovery**.

Reconnecting with the wider world and perhaps returning to work may be part of your **social recovery**. Finally, having a child in PICU can be deeply upsetting for parents and family members so it is likely you'll need time for **emotional recovery** – just as your child will.



Straight After Discharge

The families we spoke to told us that after discharge from PICU, they wanted to focus on 'getting back to normal. By this they meant being back at home and returning to what they usually did.

Many families said they needed coping strategies to deal with the demands of being back home after a hospital stay. Some families said that coping strategies like returning to old routines and "just getting on with it" really helped in the short-term after discharge.

There are lots of other healthy coping strategies which can help you to feel better. These include getting enough sleep, taking gentle exercise, eating healthily, seeing supportive close friends and family and giving yourself time to readjust to the home environment. It may be tempting to use unhelpful coping strategies, such as comfort eating, or not eating enough, smoking or using too much alcohol. In the short term these behaviours can sometimes seem helpful, but in the long term they can be unhelpful and damaging to your health.



Adjusting to a 'New Normal'

Lots of families talked about wishing that things could return to how they were before the PICU admission. As time went on they realised that the illness and admission had changed them and their family. They noticed that things were different to how they were before.

Some of these changes can be difficult to get used to, and may be upsetting. It is important to know that it is not unusual to feel sad, angry or scared about what happened or to feel upset by the new changes. Many families noticed positive changes too. These included having more perspective on what was important in life, focusing more on family life, or becoming a stronger person who is more able to cope with life's ups and downs.

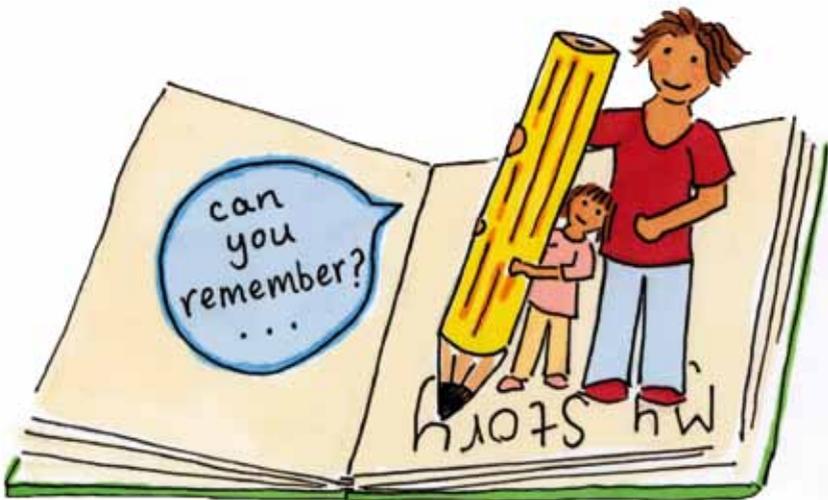
It is likely that you will experience a mix of changes, some positive and some which are more difficult to come to terms with. It is important to remember that **life changes anyway**. Even without the PICU admission, things would still be different. This can be helpful to remember if you find yourself wishing things would return to how they were before.

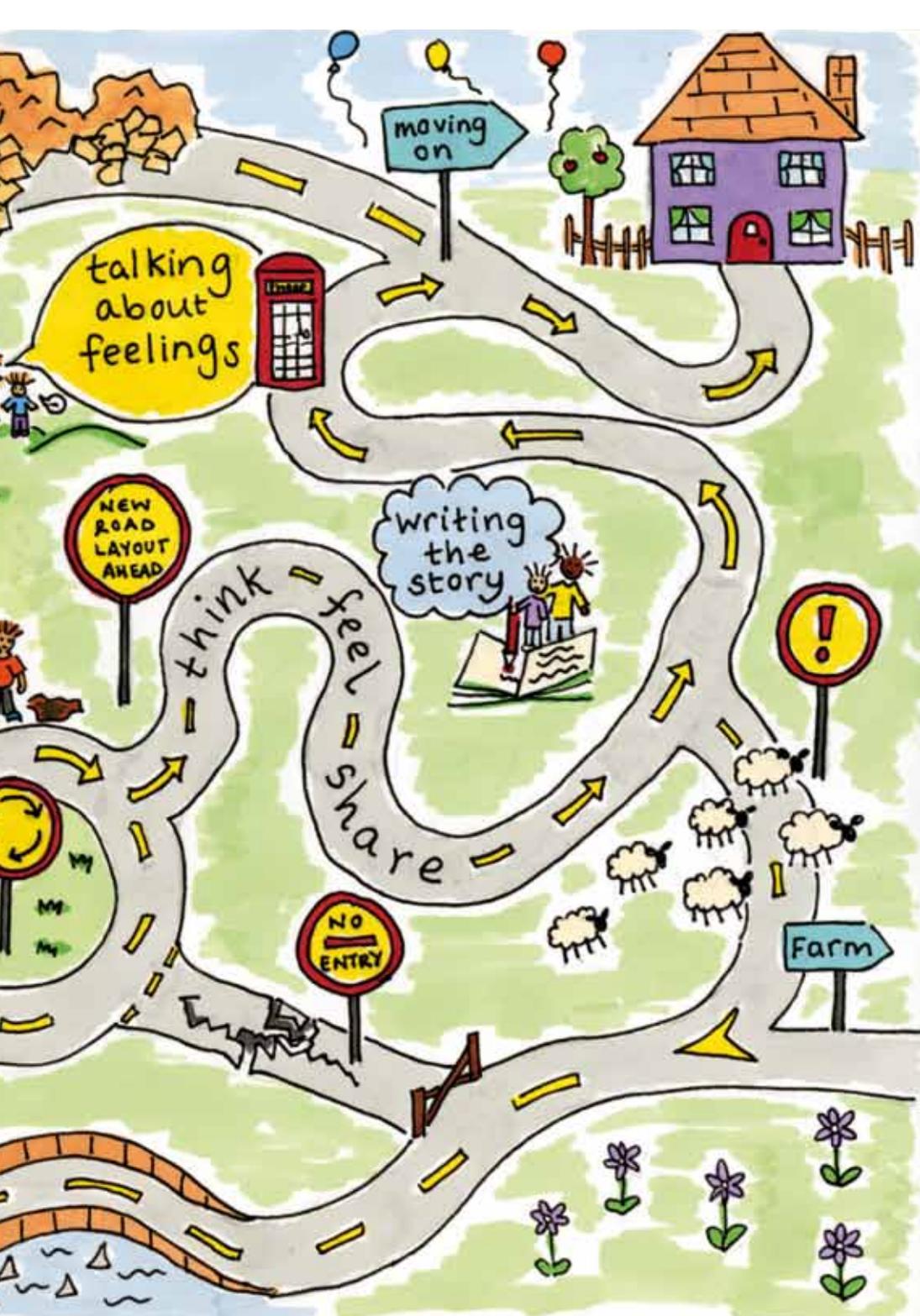


Building the story

As time passes families often find themselves thinking about what happened to them in hospital. For some families, certain images tended to stick in their minds, whilst for others it was the whole experience that they thought about. Thinking about what happened is a normal part of recovery from a serious illness or accident. In time it can be helpful for families to have a clear and complete 'story' about what happened to them and their child.

Building a story about what happened involves **thinking, feeling and sharing** the story with others. You might need to ask others about 'missing bits' of the story which you don't remember. You might decide to write it down or to share it with someone else to see what they think. Reliving and remembering the events of your child's admission can be painful. However many families said it was important to go through this stage as it helped them to understand things better, and through this, to move on with their lives.





Long Term Recovery

The families we spoke to all said that with time they were able to move on from the experience of a PICU admission. This meant they felt emotionally recovered and were not less so preoccupied with what had happened.

Long term recovery involves accepting that PICU was a part of your family's history. This may sound simple, but it can be a big step to recognise the impact that the experience had on your child and family and to accept that the experiences are now a part of who you have become.

At first it may feel as though the road to recovery is endless and that discharge is just the first obstacle of many, but be assured that with time, the recovery process does become easier. As time passes, life becomes a little less uncertain, and families tell us that they begin to know what the road ahead may look like. With courage, strength and support, and the PICU admission behind you, you can begin to make plans for the future. Having goals that you want to achieve can help you and your child to look forward to the future.



Roadblocks

The road to recovery is not always smooth and some of our families talked about obstacles, or 'road blocks' which can get in the way of recovery or slow it down.

- **Story-making too early and getting overwhelmed**

Being discharged from hospital can be overwhelming. Many families feel they need a break from thinking about their experiences. Giving yourself time off from thinking can allow your body and mind time to recover. In time you will find that you feel ready to address your thoughts and after a little 'head space' will find thinking about the admission easier and less painful.

- **Getting stuck in the story**

Some people find that they cannot stop thinking about what happened and feel they are constantly preoccupied by worrying thoughts. This is not unusual as a PICU admission can be very traumatic and it can be hard to find someone who understands just what you've been through. It can help to talk it through with family, friends, or a professional, such as a psychologist or your GP. Other things that can help are writing the story down or having a change of scene or pace - such as having a holiday or going back to work. These things can help you to organise and make sense of your thoughts.



Roadblocks

- **Worrying you are not normal**

Families respond to a PICU admission in different ways – some are very distressed or overwhelmed, whilst others show little emotion.

The same is true for recovery – some families think about the experience a lot, whilst others focus only on physical recovery and think of little else.

Recovery takes time and operates at different speeds, so you may find that you or your child has recovered physically but that you are still putting together what happened or get upset when talking about it. Give yourself time, be patient with your feelings and remember there are lots of kinds of ‘normal’ – recovery is a highly individual and personal journey.

- **When your child won't talk**

Some children won't want or be able to talk about what happened in hospital. Sometimes these children may be covering up their feelings or memories as they don't understand them or because they arouse strong feelings which are difficult to manage. They might also worry about upsetting other people.



Roadblocks

It may be the case that your child has very few memories about their admission and are not talking simply because they remember little and feel unaffected.

In either case, gently discussing the hospital experience from time to time can help your child to see that it is OK to talk about it and that it does not have to be overwhelming.

Parents can help by trying not to force their child to talk. Instead, try giving them lots of emotional support and simply letting them know that you are ready to listen when they are ready to talk.

It can help to sit down together and do an activity such as looking at photos from their admission. When a child does start to talk, make sure that you listen carefully and encourage them to talk about their feelings.



Roadblocks

- **When you don't know how to explain**

Children may ask questions which are difficult to answer. This may be because you don't know the answer or because you find it difficult and upsetting to talk about the PICU admission.

A psychologist or counsellor may be able to give you support with answering your child's questions and explaining what happened to them. If you are struggling to come to terms with the events, they may also be able to help you to understand and manage your own feelings.

Planning what you want to say to your child, using words they understand, will help you to explain things and help your child to form a 'story' of their experiences. Asking for help from a partner or close friend or using story books or toys can make it easier to explain.

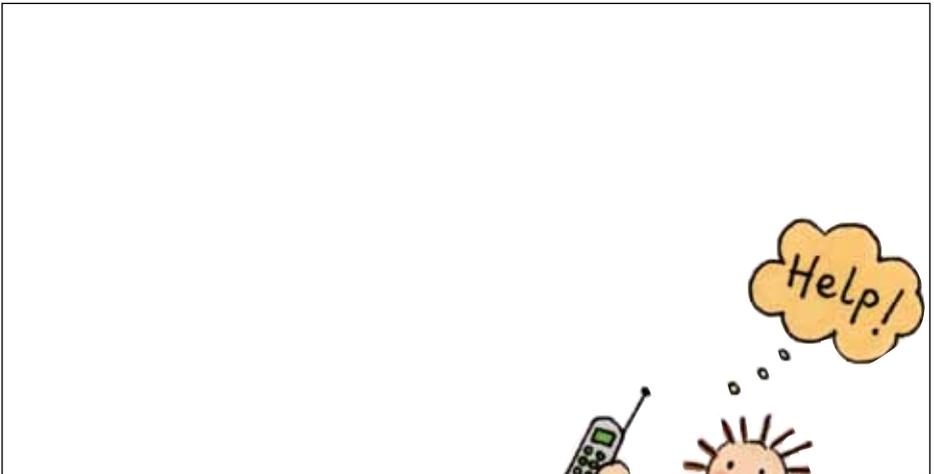


Further Support

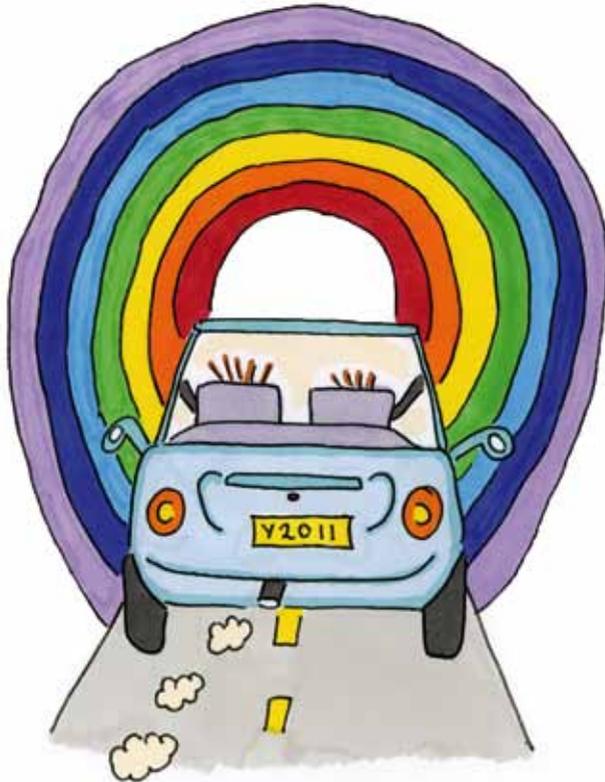
Most families who have had a PICU admission are able to make the journey of recovery without additional help. However some families do find it more difficult and it's important to remember that you don't need to struggle alone. There are people on hand, with experience, who can help you.

Speaking to your GP, your child's nurse or doctor, or a psychologist may help smooth the road to recovery for you, your child and your family.

Contact Details at your hospital



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conjunction with the University of Surrey.

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