

When your child is transferred from the Paediatric Intensive Care Unit (PICU)

A guide for children and their
family

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This booklet aims to answer some of the questions you may have when your child is being transferred from intensive care (PICU) to a ward at Evelina London Children's Hospital, or to a hospital closer to where you live.



We appreciate that leaving PICU may be stressful for you and we encourage you to ask any questions or raise any concerns with the nurse looking after your child.

The decision to transfer your child has been made jointly by the medical and nursing teams but please talk to us if you are concerned about this decision.

What can we expect before transfer?

Before your child leaves PICU we will try to prepare them and your family for the transfer. Things that we will do include:

- changing how we monitor your child such as removing heart monitoring equipment (ECG), taking out drips and lines that are no longer needed, and reducing or stopping certain medicines
- encouraging and supporting you to continue your active involvement with your child
- encouraging a normal day and night routine for your child.



You might also notice that your child is now being looked after by a nurse who may also have another patient to care for. This shows that your child is getting better and does not require the level of support they previously did.

Points to remember

- The move from PICU to the ward can be a stressful time for children and their families.
- There are many differences between PICU and the ward – your child will require less monitoring on the wards and there will be fewer nurses and doctors.
- Your child is going to the ward because they are improving and this is a positive step towards their recovery.

My child.....

Is being transferred to.....

What to expect on a ward at Evelina London

It is very normal to feel anxious about moving to an unfamiliar place.

If you have not already visited the ward your child is moving to, we can arrange a visit for you. Sometimes a nurse from the ward will also come down to meet you before your child is transfer. This can be very helpful. The ward staff will welcome you and show you around, once your child arrives and is settled in.

The PICU team will provide a thorough handover to the nurses and doctors on the ward.

You will notice that the nurses on the ward may have a small group of children and families that they are also looking after. This is because your child is getting better so should not need the same level of nursing and medical care as they did in PICU. If you are concerned about this, please speak to the team looking after your child.

The wards offer accommodation for one parent at your child's bedside. If you have been sleeping in the PICU parents' room, we would ask that you please return your swipe card to the receptionist on PICU so that we can offer this room to another family on PICU.

The PICU outreach team will come and visit your child in the first 24 hours after they leave PICU. This is so that they can review your child and make sure the ward team is clear with the plan for your child's care.

Who can I talk to if I think we might need some extra help?

We understand that it can be a very difficult time for you and your family when your child is in hospital. The nursing staff looking after your child will always listen to your concerns and worries and try to help you.

If, however, you are feeling overwhelmed or confused about what is happening, then you might find the Evelina London counselling service useful. This service is free of charge. To contact the counsellors you can:

- ask your child's nurse to contact them on your behalf
- call and leave a message, **t:** 020 7188 4538
- email, **e:** CounsellorsChildrensServices1@gstt.nhs.uk
- write to them at Counsellor Practitioner Service, 2nd floor, Gassiot House, St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH.

Towards the end of this booklet you will find **The recovery journey after a PICU admission**. This information was written by Dr Gillian Colville and Ellie Atkins and reproduced with the permission of St George's University Hospitals NHS Foundation Trust. It has useful advice on how to look after your family once your child leaves PICU.

Please speak to the team looking after your child if you think you or they need additional help and support.

What if we are being transferred back to our local hospital?

We will arrange transport to take you and your child to your local hospital. A nurse will accompany you on this journey.

As space is often limited in the ambulance it may not be possible for more than one parent and one small bag to travel with your child. You may therefore need to consider making arrangements for a family member or a friend to pick up any extra belongings.

We will try to give you an expected time when the transport will arrive but this might change at short notice.

We will liaise closely with the team who will care for your child at your local hospital so that they are aware of your child's progress and any ongoing needs. The hospital can also contact us at any time if they wish to discuss your child's treatment or needs.

Being transferred to another hospital can bring mixed emotions. You may be pleased to be closer to home but anxious that you are away from the specialist services you have received. Please feel able to discuss any concerns you might have with the ward team and they should be able to arrange support for you. Each hospital will have a Patient Advice Liaison Service (PALS) if you need to raise a concern.

The recovery journey after a PICU admission: a guide for families



This information was written by Dr Gillian Colville and Ellie Atkins and reproduced with the permission of St George's University Hospitals NHS Foundation Trust. It has useful advice on how to look after your family once your child leaves PICU.

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 learned 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 to 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 information 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 recovery** 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 recoveries 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.

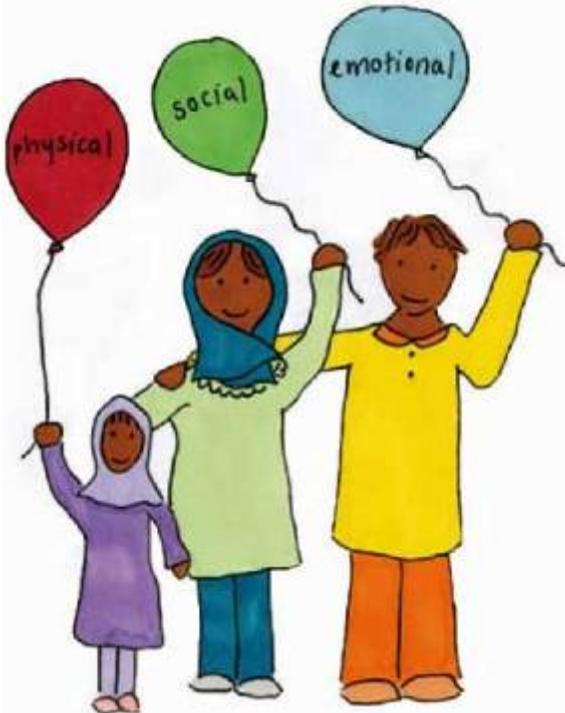


The effect on the family

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.

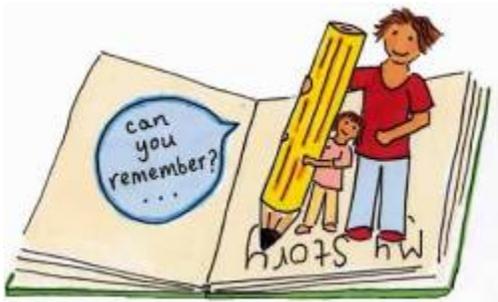
It is likely that you will experience a mix of changes, some positive and some which are more difficult to come to terms with. It is important to remember that life changes anyway. Even without the PICU admission, things would still be different. This can be helpful to remember if you find yourself wishing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



Alternatively 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.



Useful resources

Evelina Children's Heart Organisation (ECHO)

ECHO's mission is to provide support for children and young people with heart conditions who receive treatment at the Evelina Children's Hospital.

w: www.echo-evelina.org.uk

Contact a Family

The only national charity that exists to support the families of disabled children whatever their condition or disability.

w: www.cafamily.org.uk

Bliss

Bliss offers a wide range of services that provide confidential advice and support to the families of premature and sick babies. These services are free of charge and are available to help the whole family.

w: www.bliss.org.uk

ICUsteps

A charity set up to provide support for the adult patient and their relatives post discharge from intensive care. Although not specifically for children you might find this a useful resource.

w: www.icusteps.org

Contact us

You can contact the Evelina London Paediatric Intensive Care Unit (PICU) on **t:** 020 7188 4500.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** www.evelinalondon.nhs.uk/leaflets

Evelina London Medicines Helpline

If you have any questions or concerns about your child's medicines, please speak to the staff caring for them or contact our helpline.

t: 020 7188 3003, Monday to Friday, 10am-5pm

e: letstalkmedicines@gstt.nhs.uk

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

If you need an interpreter or information about your care in a different language or format, please get in touch.

t: 020 7188 8815 **e:** languagesupport@gstt.nhs.uk

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