



When your child gets better

Discharge from PICU



Respecting everyone
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Bristol Royal Hospital
For Children

When your child is well enough to leave the paediatric intensive care unit (PICU), they will either return to a hospital near where you live, or they will be transferred to one of the wards here within the children's hospital.

Before your child leaves PICU, we try to regain as normal a routine as possible for them. We will gradually stop a lot of the monitoring and may remove all monitoring completely – this depends on the cause of your child's illness. It is also useful at this point to have a few familiar things with your child, for example clothes and favourite toys.

Wherever possible, we aim to transfer you and your child as close to your home as possible, as this can make family arrangements and visiting much easier for you.

We appreciate that leaving PICU may be another very stressful time for you and your child, and it may provoke feelings of fear and anxiety. Additionally, it may seem to you that your child is still too ill to be transferred to a general ward. However, it is important for you to know that we only discharge children from PICU when they are getting better.

The decision to transfer your child from intensive care will have been made jointly by all the medical consultants and other health professionals involved in your child's care.

Being well enough to leave the intensive care unit is a very positive step. At this step, your child will be well enough to no longer need the most intensive level of care, and moving to the ward is all part of their ongoing recovery.

It is important for you to know that prior to discharge from the PICU your child may share a nurse with another child on the unit, or their nurse may be helping other staff and therefore may not be with your child at all times.

This is a sign that your child is improving and needs less intervention and support. If you feel you need anything at any time, do not hesitate to ask any member of the intensive care unit staff.

It is also important to know that staffing in a general ward area, whether in the children's hospital or at your local hospital, is very different to staffing in intensive care. This can come as a shock sometimes.

In intensive care, you will have been used to one nurse being with you and your child all the time, or sharing one nurse between two families. Staffing in the ward areas is different for various reasons, but your child is getting better now, and is either able to do more for themselves again or you will be able to care for them.

Transfer to a ward within the children's hospital

If you have not already been to the ward that your child is being transferred to within the children's hospital, one of the nursing staff will try to arrange a visit for you, so it will be a little more familiar to you before discharge from PICU.

A nurse from the **outreach team** will come to say hello to you and your child on PICU before you are transferred to the ward, and they will visit you again once you have settled in on the ward.

This team of nurses works closely with PICU and the ward team to ensure that the transition from PICU to the ward is as seamless as possible.

The outreach team may visit your child several times to check on their progress. They are a valuable link between the intensive care unit and the ward staff.

It is normal to feel anxious about moving to an unfamiliar environment, where the routines are different and there is less equipment, noise, and activity.

You may feel insecure with your child not having constant monitoring, and it may also be difficult for you to adjust to your child's nurse not being with you all the time. On the ward, nurses will also be caring for three or four other children and their families too, but your child will be cared for; it will just be a different level of care and your child will be doing well.

You must be reassured that the transfer out of intensive care is because your child is improving. However, if you have any concerns, just ask one of the nurses.

All wards have a slightly different layout and a different routine. On the ward your child will be under the care of their specialist consultant. They will have had a thorough handover from the intensive care team. You will see a doctor every day and your child's consultant will have a specific ward round time.

Unlike on the PICU, the doctors are not resident on the ward at all times. If your child needs to see a doctor urgently then the nurses can always contact one.

Accommodation for you once your child leaves PICU is a parent's bed next to your child's bed, or in their room if they are in a cubicle. If you have been using one of the parent's rooms on level 6 of the children's hospital, we would politely ask that you please vacate that room as soon as you have settled onto the ward, so that we can offer that room to another family with a child on the intensive care unit.

You may feel that you would like to talk through some of your feelings and any anxiety you have surrounding your child's recent illness. This is a very common thing to need or want to do, and it can be arranged for you.

There are a variety of ways we may be able to help you. This could be through the use of the LIAISE (Listening, Information, Advice, Involving, Support, Experiences) team, specialist nurses, chaplaincy team, and possibly a clinical psychologist. If you do feel you would like support, please feel free to talk to any of the nursing staff, who can arrange the most appropriate help for you.

Transferring to a hospital nearer to home

We will arrange transport (either an ambulance or ambulance car) to take you and your child to a hospital nearer your home.

Space will be limited. This means it is not possible for more than one parent to travel with their child, or for the vehicle to carry more than one small bag of personal belongings. This is for safety reasons.

You may need to consider making arrangements for a family member or friend to pick up any extra belongings you may have with you.

Your child will be accompanied by a nurse during the transfer.

It is also not always possible to guarantee the time that transport will come, so you may have a little wait on the day you are transferred.

We will liaise closely with the hospital your child is being transferred to, and we will ensure they are fully aware of your child's progress, ongoing treatment needs, and any family support needs.

The hospital is able to contact the PICU at any time if they wish to discuss your child's treatment or care needs.

Being on a general ward is very different to being on the PICU. Not only is the level of staffing very different, but equipment and noise levels are different too, and it can sometimes feel strange not hearing so many machines beeping and buzzing.

Routines on wards are also different. The staff on the ward you are going to will be able to give you any information you need about when doctors will see your child, where you can stay, visiting and so on.

Being transferred to another hospital may bring mixed emotions. You may be pleased that you are nearer to home, but you might be anxious that you are further away from some of the specialist services you may have received whilst on the PICU. All of these feelings and emotions are understandable and quite normal.

You may feel that you would like to talk through some of your feelings and any anxiety you have surrounding your child's recent illness. This is a very common thing to need or want to do.

Support services will be different in every hospital. However, if you feel you would like support, please feel free to talk to any of the nursing staff, who should be able to arrange the most appropriate help for you.

Leaving the intensive care unit and nearing discharge home

Feelings about discharge

Leaving the intensive care unit and nearing discharge home may be an anxious time for you, especially if your child has been on the intensive care unit or in hospital for a long period of time.

Even though you know your child is getting better, you may be feeling worried about going to the ward and getting used to

not having the on hand support and guidance that you have been used to whilst on the intensive care unit.

You may feel you are lacking in confidence in caring for your child on your own. These feelings are normal, especially if your child has been critically ill.

You may also feel quite elated and relieved to finally be going to the ward, nearing discharge home and trying to get back to a normal family life.

Impact of intensive care on your child

Your child may have concerns and anxieties about going home themselves. They may have physical difficulties with some everyday tasks, may be easily tired, and may be quite emotional about having been in hospital and having been so unwell.

Children sometimes remember different parts of their admission to hospital. They may not remember being on intensive care at all, but they may remember an odd occasion, or certain elements of their care.

As a result of some of the medications given to them during their time on the intensive care unit, some children may also have upsetting memories about things which did not actually happen, but which to them feel very real.

Some children may 'go back a step' in their development, perhaps struggling with things they were starting to do before admission such as crawling, walking or toilet training. However, in the majority of cases these things usually catch up again.

Older children, who suddenly find that they have to rely on someone else to meet their hygiene needs for example, can find this reduced independence quite distressing. It is important that they are allowed to talk about these things and express any

worries they have surrounding this or any other part of their illness.

If you have significant concerns about your child's behaviour or emotional well-being, you should talk to your health visitor or GP.

In every area of the country, there are specialist NHS teams who can support children who are experiencing such difficulties. These services are known as CAMHS (child and adolescent mental health services). Your GP may be able to refer you to this service if needed.

Impact of intensive care on you as parents

You and your family have just been through a huge experience. It is common for any overwhelming life experience, especially if the event is unpredictable and uncontrollable, to leave people feeling highly anxious and emotional. This is often because your deep seated assumptions and expectations about the world (for example that the world is a safe place) have been challenged.

You may find that you feel 'on edge' or get easily startled, and that the reminders of the admission leave you feeling tearful.

For some people, the impact of their experience may be felt immediately, but for others there may be some delay. It is vital to recognise and acknowledge these feelings whenever they may arise and accept that it is OK to feel this way.

For some, these feelings will get better in time, and support from friends and family is all they need. Others may feel they would benefit from talking to someone about how they are feeling.

People cope very differently with shared experiences, and you should be prepared that you and your partner may experience different feelings and have different ways of coping with them.

About 30 per cent of parents whose child has been on PICU have flashbacks or nightmares about being in intensive care, as well as the period immediately before admission. These feelings and emotions can be very powerful, and it is important that you give yourself permission to talk about your experiences if they are having this effect on you.

Generally these feelings improve with time, but for some parents and children, professional help may be needed.

Once you are home, if at any time you feel like you need to talk to someone, a good place to start is with your GP.

Your child's GP will receive a letter from the hospital when your child is discharged home, so they will be aware of the situation you have been through.

The provision of psychological therapy varies across the country, so it is not possible to provide you with an extensive list of where to get help from, but your GP will know what is available to you in your area.

In most areas there will be an NHS service to support adults affected by anxiety and depression, and in some areas there are specialist trauma services that can provide valuable support if you are experiencing intrusive memories.

These services have different names in different areas, but often come under the broader term 'IAPT' (improving access to psychological therapy).

Impact of intensive care on siblings

Siblings can also be affected by their brother or sister being admitted to PICU.

They may not have visited their sibling in hospital and may not understand what has happened.

They may have been apart from their family unit for a long period of time whilst their sibling has been in PICU.

Some children may be anxious that their brother or sister may need to be readmitted. They may fear that if that happens their parents will leave them again. This may result in the sibling becoming withdrawn, clingy or moody.

It is important that they too are allowed to talk and express any fears and worries they have.

Notes / queries

Resources available

BLISS

Free phone: **0500 618 140**

Web address: **www.bliss.org.uk**

BRAKE

Telephone: **0808 8000 401**

Web address: **www.brake.org.uk**

Children's Heart Federation

Free information line: **0808 808 5000**

Web address: **www.chfed.org.uk**

Headway

The Brain Injury Association.

Free phone: **0808 800 2244**

Web address: **www.headway.org.uk**

Email: **helpline@headway.org.uk**

LIAISE

Listening, Information, Advice, Involving, Support, Experiences.

Family Information Room

Bristol Royal Hospital for Children

Upper Maudlin Street

Bristol

BS2 8BJ

Telephone: **0117 342 8065**

Email: **bchinfo@uhbristol.nhs.uk**

Meningitis Research Foundation

Free phone: **0808 800 3344**

Web address: **www.meningitis.org.uk**

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While your child is under our care, you may be approached about them taking part in research. To find out more please visit: **www.uhbristol.nhs.uk/research-innovation** or call the research and innovation team on **0117 342 0233**.

For access to other patient leaflets and information please go to the following address:

www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/

Hospital switchboard: 0117 923 0000



Minicom: 0117 934 9869



www.uhbristol.nhs.uk



For an interpreter or signer please contact the telephone number on your appointment letter.



For this leaflet in large print, audio or PDF format, please email patientleaflets@uhbristol.nhs.uk.

