

# COPING AFTER A PICU ADMISSION

*A guide for helping young children and their parents*



## PICU CARE



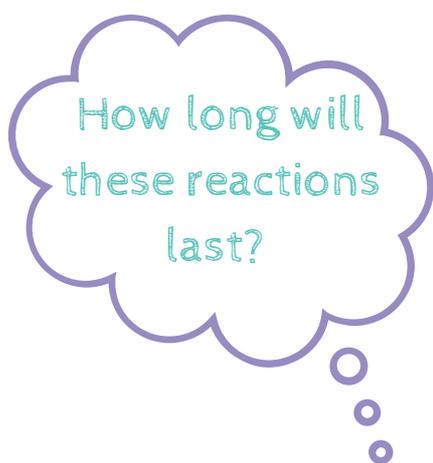
## My Child had a stay on PICU. What can I expect?

Your child has recently become unwell and had a stay in the PICU. They may now be starting to recover from their illness or injury, (or are recovering from this difficult episode of a chronic illness), however it is possible that you and your child are experiencing a number of strong psychological reactions.

You may be wondering:

- What types of reactions are normal to expect in my child?
- How long will these reactions last?
- What can I do to best help my child?
- How might I feel and react?
- What can I do to cope?
- How might this impact on my parenting?

On the following pages this booklet will explain some of the common responses infants, toddlers and pre-schoolers experience after a PICU admission, how long these responses typically last and gives suggestions on things that you can do to help support your child to cope well. Of course, parents/caregivers can also be affected by their child's illness and treatment, and psychological reactions, so this booklet also talks about common responses parents have and suggests things that can help you cope during this tough time. The booklet also outlines possible changes in your relationship and parenting of your child.



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## Common Reactions Young Children Have After a PICU Admission and Things Parents Can Do To Help

Being admitted to the PICU can be physically and emotionally difficult for children and families. Some children may recover from their illness or injury, and their treatment in PICU, with little or no psychological or emotional impact. Others may have strong reactions after an admission to PICU. Children and families are exposed to many potentially frightening experiences related to the child's illness or injury (e.g. events leading to hospital admission, fears for the child's life or ongoing wellbeing, pain), medical treatment within PICU (e.g., being intubated, having cannulas inserted, being in pain, weaning off sedation, etc.) and/or events occurring within the PICU environment (e.g., constant light, sound, alarms going off, seeing other patients in pain or having medical events, separation from caregivers). For example, due to the treatment they receive, some children may develop delirium while in the PICU, and may have experienced frightening hallucinations or dreams. This is sometimes difficult to detect, but can be frightening for both the child and the parent, who may notice their child failing to respond to words or touch as they usually do, or may be shouting or looking at something that parents cannot see.

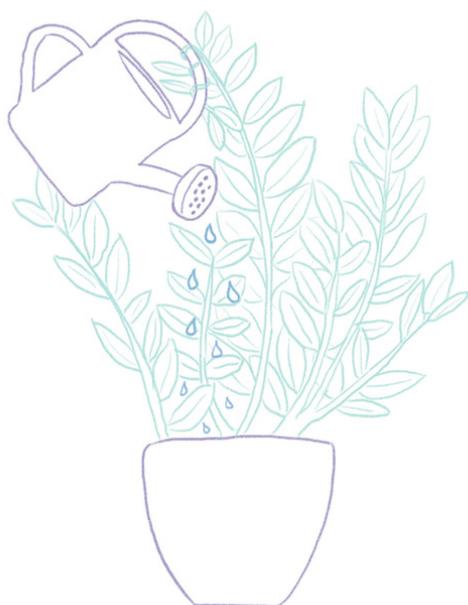
Young children can also be frightened or worried by things that do not seem scary to an adult, and often do not understand why medical procedures are needed. For example, parents may worry about the long-term effects of the illness whereas children may be more scared about separation from their parents, the bright lights and noises or painful medical procedures. Infants and pre-schoolers are more vulnerable than older children as they often cannot talk about their feelings, lack skills needed to cope with strong emotions or pain and need their parents to help them feel safe and secure.

## Common Responses

Young children have limited words to express their feelings but their behaviour and physical reactions can give us important clues about how they are affected. Common responses include:

- Talking about hospital or PICU a lot, or avoiding talking about their PICU admission or treatment or things that remind them of the event
- Getting upset when reminded of their PICU admission or treatment (e.g. hearing noises which remind them of their stay, going to hospital, being asked about their stay by others)
- Having physical reactions to reminders (e.g. sweating, shaking, racing heart)
- Act out their experiences or fears in play (with dolls, teddies and/or other children)
- Having increased nightmares (may not remember what the nightmares are about and/or nightmares might appear unrelated to being in PICU)
- Difficulty remembering parts of their admission to PICU, or the events in the lead up to their admission
- Becoming more quiet or withdrawing from family and friends
- Not playing as much as they used to
- Increased irritability, fussiness, temper tantrums or aggressive behaviour
- Jumping or startling easily when gets a fright
- Changes in sleeping (e.g. problems falling asleep or waking up more often)
- New or increased separation anxiety or excessive clinginess with loved ones
- Acting more clingy, whingy, and fussy
- Acting younger, or stop doing things they used to be able to do (e.g. wet their pants; sucking their thumb, saying fewer words, more dependent on caregivers)
- Eating less (loss of appetite)
- Developing new fears (e.g. monsters, animals, the dark)
- Complaining of stomach aches or headaches

## Things You Can Do To Help Your Child



### Look after yourself

Young children respond best after a PICU admission if their parents are coping well. Children learn how to process and cope with events by watching how their parent reacts. It is therefore very important that parents look after themselves so they can best support their child. See 'Common reactions parents have after their child's admission to PICU and things that can help' in the next section for more information on looking after yourself.

### Provide warmth, safety and security

Help your child to feel safe and secure by doing your best to be calm and comforting. You can do this by giving lots of physical comfort (e.g. hugs, kisses, hand holding), limiting separations where possible at first, and using simple words to explain to your child that they are safe and tell them what is happening to them. Focus on being close and spending special time with your child and doing things together that they enjoy and/or find soothing. Examples of comforting activities include: giving them comfort objects (e.g. teddy bear, photos, blanket), reading story books, singing songs, playing games, listening to music, drawing, blowing bubbles, and doing relaxation exercises (e.g. taking long, deep breaths).



## Talk about the events, PICU admission and treatment

Many parents feel afraid to talk about the stay in PICU or the treatment in case it upsets their child. However, it is important to provide the opportunity for children to talk about it, as this helps them to express thoughts and feelings and to correct any confusion or unusual beliefs they have (e.g. “The illness happened because I was bad”, “The doctor was trying to hurt me”). Even if your child has limited words, it is still important to explain what is happening. The way in which you discuss the PICU admission is important, though. These are some tips that may help you to talk with your child:

### How to ask about their feelings

- Help your child to talk about their time on PICU but let them take the lead. Do not pressure them to talk about it if they are not ready.
- You might ask questions about their thoughts or feelings (e.g. “It might be hard to talk about these things at first, but it can really feel better to get them out”, “Is there anything that you would like to talk about?”).
- Encourage them to play, draw or use other creative activities to talk about the event and to help express their thoughts and feelings.
- Read books related to going to hospital.
- Expect repeated questions as this helps them process what happened.

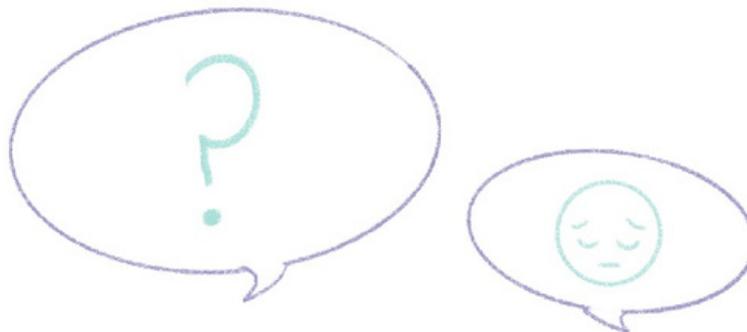
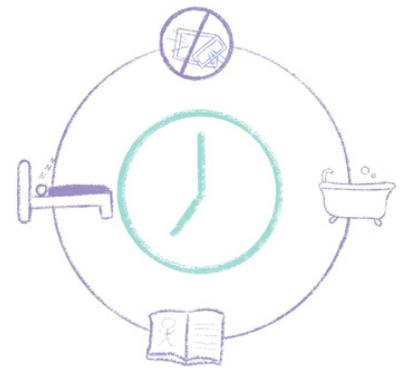
How have you been feeling since the stay in the hospital?

### How to talk about PICU

- Use a calm and relaxed tone of voice when talking to your child about what happened.
- Reassure them that their big feelings and worries are normal.
- Answer questions simply and honestly and use language suited for your child’s age.
- Stick to the facts about what happened and give accurate, age-appropriate information (e.g., “You were in PICU for 1 day and then we went to a different ward”; “Oh yes, you can’t remember that because the doctor gave you medicine to help you sleep”; “You heard a loud ringing noise? That sounds scary. That noise didn’t really happen, you heard it because of the medicine the doctor gave you to make you better.”) Avoid too much detail. Make sure your child has a clear idea about the course of the admission and treatment and understands what happened. Correct any confusion.
- Try to focus the talk of scary/frightening things on something positive (e.g. “The needle hurt your arm? Oh, ouch, I bet it did. The doctor gave you the needle to make you get better.”)
- Help your child understand that the job of hospital staff is to make them better.
- Focus on the positives of what happened and what your child did well (e.g., You were so brave!”, coping strategies the child can use (e.g. big deep breaths, give doggy toy a cuddle, do something you like) and reassure them about the future.
- Make sure your child is not part of adult conversations about the PICU admission and treatment.

## Maintain or return to normal routines and expectations where possible

Have realistic expectations of your child and be patient as they are likely to show some changes in behaviour. However, remember young children function best when their environment is predictable, consistent, and familiar and they have clear guidelines on how to behave. Young children are sensitive to changes in routine and can find this frightening. It is therefore important to return to normal family routines where possible and maintain previous expectations of what is acceptable behaviour (e.g. speak politely to people, use gentle hands and feet). This will help them to feel safe and secure. You can do this by encouraging regular sleep, eating and play routines and preparing them for changes or transitions that are coming up.



## Pay attention to your child's emotional experiences

It is important that parents pay close attention to their child's emotional and behavioural reactions after a PICU admission. It isn't always obvious what might be upsetting your child after a PICU admission (e.g., it might be a certain sound or smell you weren't aware of during their admission). Being aware and responsive to children helps them to feel understood and allows parents to see any early warning signs before problems increase or get worse. Think about what your child's behaviour is trying to tell you (e.g., are they scared, in pain, tired, bored). Talk about and name your child's feelings (e.g., use feeling books, pictures or drawings to help with this) and help them with learning the right way to express emotions. For example, "It's ok to be angry, but it is not OK to hit your sister. Next time use your words".

## Encourage and reward brave behaviour

Give your child lots of praise and encouragement for the things that they are doing well, no matter how small (e.g., “You are so brave for sitting still like that”, “I’m so proud of you...”). Gradually encourage them to get back into doing things that may scare them.



## When to get help

It is normal for your child to show some changes in the first weeks after a PICU admission. However, sometimes no matter how supportive parents are, children may need professional help after a PICU admission. If you are concerned contact your paediatrician or doctor. Signs for when to get help include:

- Symptoms are continuing for longer than 4 weeks or getting worse
- There's a significant and ongoing change in your child's normal behaviour
- Symptoms are occurring more than average for your child's age
- Symptoms are affecting your child's daily functioning and preventing them from engaging in age-appropriate tasks
- Symptoms are affecting your relationship with your child



# Common Reactions Parents Have After Their Child's Admission to PICU and Things That Can Help

A child's admission to PICU and their medical treatment can be very worrying and stressful for parents. It can be very difficult for parents to see their child's pain and distress and this can lead to feelings of helplessness, sadness, guilt, grief, and anger. Parents have the challenge of managing their own fears and worries as well as having to support their child physically and emotionally, plus juggle their normal daily tasks and responsibilities. Parents are typically very good at looking after the needs of their child and other family members. However, it is also essential that parents look after themselves. After all, this is the best way that parents can help their child recover after a PICU admission!

## Common Responses

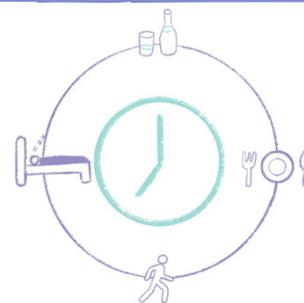
It is normal for parents to feel worried and fearful about what their child is going through. Some common reactions parents can feel within the first days to weeks after the PICU admission include:

- Re-living the event through thoughts or nightmares
- Getting emotionally or physically (e.g. heart racing) upset when reminded of the event
- Avoiding reminders or talking about the event
- Feeling wound up, jumpy, and restless
- Getting angry and irritable
- Having trouble sleeping
- Difficult feelings such as fear, anger or guilt
- Feeling numb and detached
- Having a lack of interest in previously enjoyed activities
- Always on the lookout for potential danger
- Feelings of tearfulness
- Blaming others
- Constant questioning and feelings of guilt (e.g. "If only I had..." "How could I have been so stupid")
- Frequent worrying that it might happen again

## Things you can do to take care of yourself

### Maintain a healthy diet, sleep and exercise

Try your best to get enough sleep, eat regular meals and exercise. Exercise is a great way to get rid of physical energy and can help improve mood and sleep. It is best to avoid a lot of caffeine, sugars, alcohol and drugs.



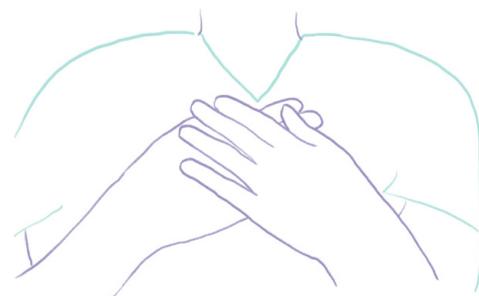
### Seek support from your friends and family

We know that social support is one of the best protective factors for people after a traumatic event. It is helpful to talk to and connect with your friends and family. Talk to your partner or friends about how you are feeling and talk to other families who are going through similar things. Talking is part of the natural healing process. Engage in social activities with friends and family if you can. Accept support (emotional and practical!) that is offered. Talk to hospital staff members about how you are feeling and find out about what support options they have available.



### Be kind to yourself

It is important to remember that it is not possible to protect your child from everything and no parent can handle all situations perfectly. It is normal to feel like you are struggling at this time. Focus on what you have been doing well (no matter how small!) and be realistic about what you can do. Parents often feel that did not cope as well as they “should” have after their child’s PICU admission and worry about how this may affect their child. The important thing is what you do from now on. It is important to focus on your strengths as a parent and use your existing coping strategies and supports.



## Use Coping Statements

When stressed, people tend to have more negative or unhelpful thoughts such as “I can’t cope”, “It’s all my fault”, “He will never be the same again”. These thoughts are unhelpful and they can have a big impact on feelings and your ability to cope effectively.

If you notice yourself having an unhelpful thought or having an unpleasant feeling, try responding by taking a deep breath and telling yourself something that is more helpful in the situation. Ask yourself, what might you say to good friend who was in a similar situation? What is something you have told yourself before that has got you through other tough times? Even if things feel really overwhelming, don’t forget that situations often change with time. Try adding the words “right now” after an unhelpful thought to remind you that this situation may change (or your feelings about this situation may change). For example, “I feel like I can’t cope...right now.”



## Take time out to relax

Make sure you still find time for yourself to relax. This might include talking to a friend, taking a walk, reading a book, taking a bath, listening to music, or watching TV. It can also be helpful to use mindfulness or relaxation techniques such as deep breathing, progressive muscle relaxation or imagery.



## When to get help

Many responses mentioned above are normal responses to a very stressful and difficult situation and often improve over time. However, it is time to get help if:

- These responses continue beyond the first few weeks or are getting worse
- Symptoms are affecting your daily functioning
- Symptoms are affecting your relationship with your child or other family members
- Symptoms are getting in the way of your child’s medical treatment

If you are concerned talk to the staff at the hospital, your GP or a mental health professional.



# Parenting and Relationships after a Child's PICU Admission

Parents may not realise how valuable they can be in helping their child cope after a PICU admission. It is through the relationship with their parents that young children can obtain comfort during frightening and overwhelming experiences. A caring and supportive relationship helps children to feel safe and secure after the admission. However, traumatic events, such as a PICU admission, can affect the parent-child relationship and lead to changes in parenting. While many of these changes are normal in the short-term, they can have a harmful effect on the child, the parent/s and the quality of family relationships over time. This section outlines some of the common ways that parenting and relationships can change after a PICU admission

## Parenting Changes

### Excessive guilt

Feelings of guilt are common for parents after a child's PICU admission and can be about a number of things such as not preventing an accident or injury, not acting quickly enough, the child undergoing painful treatments, or not spending enough time with other children and family members. Parents who struggle with guilt tend to have lots of unhelpful thoughts such as "I should have...", "If only I had...", "I must...". Parents tend to overestimate their ability to have predicted or prevented a bad experience and this leads to excessive self-blame. Even if a parent could have prevented the experience (prevented an accident/injury, sought medical help sooner etc) it is not helpful, for them or their child, to focus on what they should or shouldn't have done. It is important to forgive yourself try to focus on the positives and what you are doing well now to help your child.



## Overprotective

It is very understandable that parents may become more protective after a PICU admission. Parents tend to want to keep their children close, give lots of comfort and reassurance, and watch their child's activities more closely. However, parents sometimes find it difficult to stop thinking about all the bad things that might happen to their child (e.g., "nothing is safe", "I must not let them out of my sight"), give excessive reassurance ("you are safe", "this isn't going to hurt") or not allow their child to return to their normal activities.

These practices may become a problem when parents allow their child to avoid anything that might make them feel anxious or distressed (e.g. avoid doing rehabilitation exercises, avoid the place where they had their accident, etc.). This is not helpful if it stops children learning that they can cope with these situations on their own. Sometimes, parents may increase anxious behaviours in their child without meaning to. Instead, parents can model new coping skills when children are upset, and help children find new coping skills as well (e.g., taking big, deep breaths, cuddling a toy, etc. Paying less attention to fearful behaviour and praising or rewarding brave behaviour is an effective way to manage anxiety.

## Overly distressed and anxious

It is completely understandable that parents may feel distressed after their child has been very unwell. However, when parents are struggling to manage their own feelings it can make it hard for them to be aware of how their child is coping and to give them the right level of support. Parents may become more withdrawn (e.g. less affectionate, spend less time together), more irritable and cranky (e.g. less patient or more critical of child), or respond less sensitively to their child (e.g. less likely to notice or be able to comfort child when distressed).

Parents may also model anxious behaviour without realising (e.g. avoiding doctors, avoid giving child prescribed medications, talk about how they find hospitals scary). Little children in particular may learn fearful behaviour by watching their parents. Some children may become frightened of the same things as their parents or learn that the best way to deal with scary situations is to avoid them.

### More lenient with behaviour management

After a child is very unwell, parents can become more lenient and inconsistent with responding to their child's unacceptable behaviour. This may be because it is more difficult to stick with routines in hospital, because the parent feels guilty or because the child has been through too much already. However, children respond best when life is predictable, consistent and routine, and have boundaries in place to help them know how to behave. It is therefore important to return to normal family routines where possible and maintain previous expectations and rules for acceptable behaviour (e.g. speak politely to people, use gentle hands and feet). This will help reduce behaviour problems from developing or getting worse over time.

### Signs that things are becoming a problem

- It is affecting family life.
- You feel like you are not coping in your parenting role.
- It is affecting your relationship with your child or other family members.
- Your child's behaviour is getting hard to manage.



## Personal coping plan

What does my child find the most comforting when they're upset?

What are some supportive things I can say to myself?

What parenting behaviours are in line with my values?

What can I do to look after myself?

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