



Hospital Jobs

Children with CF require frequent hospital visits and procedures to monitor their health. Common procedures in the first 8 years may include: annual blood tests, CT scans and chest x-rays. These are all routine procedures for the CF team but may be new, unfamiliar and scary to a child who has never done them before.

It can be helpful to remember that a child who has never perceived a procedure as threatening will not develop fear. So as best we can we try to surround procedures with positive engagement. Your CF team is here to help you and your child successfully manage CF as best you can.

SO WHAT CAN YOU DO?

BEFORE THE PROCEDURE

1. Communication

<u>How to discuss procedures with your child</u>: We often consider CF procedures like "jobs". Having a CF procedure is like going to school or going to the dentist. Although it might not be something we like to do, it is something that we have to do and is important to keep us healthy.

In most cases, children cope better when they know what is going to happen before it happens. This also helps them to develop a sense of trust and predictability when in hospital. Provide simple, honest and child-friendly education before procedures. A 'matter-of-fact' but supportive approach is often best. It is recommended that parents do not apologise for procedures as this suggests it is *bad* in the parents' eyes — this can understandably make children more concerned.

When to provide education depends on your child's age. This is just a guide and will vary according to each child:

- 0-3 years immediately before procedure (minutes before)
- 3-6 years morning of the procedure
- 7+ years a week in advance (or more)

If your child has questions or concerns, an honest but reassuring approach is best. For example, "Will it hurt?" "It will hurt a little, like a mosquito bite but then it will go away. You are okay and super brave."

Acknowledge and normalise your child's feelings. Allow them to discuss their feelings and concerns, and encourage any questions they may have. Let them know that others may be feeling the same way and that their feelings are normal and expected.

Suggested education activities:



For older children, pictures or videos may help them to understand what is going to happen. For example, watching YouTube videos of a CT scan or reading a story about the steps involved may be helpful. Sometimes it can be helpful to write out a plan with your child that outlines steps before, during and after the procedure.

Again, it's important to remember that everything is new to your child, so allowing them to learn about what will happen and seeing medical equipment before procedures may help them feel more comfortable. Using play can be really effective for children this age, as this is how they come to understand the world. If you're able, try using doctors' play kits to help your child feel more comfortable. Practicing the procedure on a doll or teddy may be helpful for your child to understand what is going to happen.

Role modelling can also help children this age. At first, your child may prefer to be the "doctor" or "nurse" and do the procedures on mummy, daddy or teddy, but eventually may feel more confident to have the procedure acted out on them. It can be helpful to describe what is happening when acting out hospital procedures. For example, "The strap around the arm feels a bit tight, but teddy is going to take some deep breaths."

2. Choice

During hospital procedures, children often feel that they have no control. Providing small choices wherever possible encourages your child to feel involved.

Here are some examples of choices that your child can make:

- "Are you going to have your needle in your right arm or your left arm?"
- "What toy are you going to bring with you to the room?"
- "After we do our blood test, what are we going to do to celebrate you being so brave?"

If possible, avoid asking questions when your child doesn't have a choice. For example, "Are you ready to do your scan now?" Instead try, "It's time to do your scan now – what are we going to watch on the iPad?"

Be aware that children may try to prolong the procedure using these choices. Don't encourage your child to stall as this can sometimes increase anxiety. Although we're providing choices, the procedure is non-negotiable. If we provide an initial choice and the child is unable to choose within a reasonable timeframe, the procedure will still continue as planned. This can be discussed prior to the procedure so that the expectations are clear.

3. Positioning

As children are not required to lie down for most procedures, nursing staff often spend time discussing different positioning options before starting a procedure. We often find that sitting up is less distressing as children can feel more secure and in control. Sitting up also allows parents or members of the CF team to distract children easier.

Holding a child down may increase their anxiety and increase behaviours, which could result in future difficulties. However, at this age some restriction may be required to either keep your child



still or to complete the procedure as quickly as possible. If this is the case, it's a good idea to use a comforting, rather than confronting, position (e.g. a bear hug on your lap).

Here are some suggested positions:





- · Child sits on bed or adult's lap
- · 'Hugging hold' torso and feet
- Infants from approximately 6 months like to sit up
- Used with or without distraction





- 'Hugging hold' with adult's arm around child's torso and free arm
- Used with distraction
- Adult's free hand on shoulder or forearm of the child
- · Give the child the choice to look

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- · Child sits on adult's lap
- 'Hugging hold' with adult's arm around child's torso and free arm
- Used with distraction





- Adult sits on table with child in 'hugging hold'
- Adult places child's arm in front / around torso





- Adult behind child
- Child is in contact with adult in a sitting or leaning position
- · Distraction is used as a visual block
- Good position for pin care, catheter insertion, dressings

Developed by The Royal Children's Hospital, Melbourne

(https://www.rch.org.au/uploadedFiles/Main/Content/comfortkids/PositioningForComfort.pdf)



DURING THE PROCEDURE

1. Model calm

The simple presence of a parent/caregiver often helps children during procedures. If parents themselves respond to their child's procedures with distress or anxiety, children may learn to do the same and can become distressed. So try to remain calm and have a "we can handle this" attitude. Some parents have difficulty with supporting their child with procedures, so do the best you can and if you need, ask a family member or friend to come along to help.

2. Provide active distraction

Distraction is the most effective way to help children this age in procedures. Distraction may include anything that will help them look away from what is happening during a procedure. Distractions are also effective before entering the treatment room as waiting can sometimes be the most worrying part.

The best distraction is any activity that keeps your child's mind busy, and active activities are often more engaging – i.e. playing a game on an iPad is more 'active' than watching a video. Examples include:

- Blowing bubbles
- Looking at a pop-up book or hidden images book ("can you find the ...")
- Singing along to music or play a game on an iPad
- Use a toy that vibrates this can help distract from the sensation of procedures
- Talking about everyday topics or making jokes

Throughout the procedure, you can redirect your child's attention to their distraction activity by asking questions or using humour. For example, you could ask them to look for items in a *Where's Wally* book, or asking "Who is that?" or "What are they doing?" as they watch a movie.

Relaxation strategies can also be helpful for older children. It is important to note that children this age may not understand 'relaxation' as a concept. Because of this, it is suggested to use specific directions, rather than just saying "relax". Some examples include:

- Deep breathing with eyes closed
- Counting
- Guided imagery e.g. "Imagine you're on the beach. What's on the beach? What can you see?"

AFTER THE PROCEDURE

1. Comfort and resettling

Immediately after a procedure has finished, your child may still feel uneasy. It may be helpful to reengage them in a distraction activity to help move their focus away from the procedure. Many children also benefit from comforting hugs to help them calm down after procedures. These things may help them to recover quickly and feel okay again.



2. Praise

Ask yourself: "What has my child done well during this procedure?" Children respond well to encouragement, so praise them for things they did well, no matter how big or small. Praise them for efforts they made, not just their overall performance (i.e. even if the procedure didn't go well, praise them for small things that they did do well). If a child is distressed they may not look like they are responding to your praise but it is important to acknowledge a job well done.

3. Reward

Providing rewards go hand-in-hand with praise after procedures to reinforce positive behaviours. Rewards do not need to be anything big — a kiss, a sticker, or a favourite drink can be motivating for children after a procedure. It is important to be specific so your child knows exactly what they are being rewarded for. For example, "You held your arms so still during that blood test so you get a sticker!"

4. Make a plan for next time

After providing praise and/or rewards, discuss with your child and/or treating team what did and didn't go well during the procedure. Based on this, make a plan for the next time (e.g. "You did a great job using your deep breathing! We'll make sure we use deep breathing again next time."). You may need to consider trying out different distraction, relaxation or positioning options if the procedure didn't go so well. If you get stuck for ideas, discuss options and ideas with your treating team.

YOUR QCH OCCUPATIONAL THERAPIST CAN:

- Work with you and your child to understand what type of strategies may work best for you.
- Help your child to gradually become more comfortable and confident with procedures.
- Help you and your child understand the steps involved in a procedure and provide child friendly education booklets (called 'procedural stories') so you can be more prepared.

Additional resources: Going to hospital

- Book: Everybody Stay Calm by Angela McKenzie (2014).
- App: Okee in Medical Imaging by Melbourne Royal Children's Hospital, helps children to prepare for medical imaging in a child-friendly, fun game.
- Other apps: Games such as *Angry Birds* and *Fruit Ninja* can help provide active distraction during procedures.
- Videos by The Royal Children's Hospital Melbourne to prepare for procedures such as CT scans, x-rays, and blood tests:
 - o https://www.youtube.com/user/RCHMelb
- Other tips for preparing for hospital admission from a parent perspective:
 - o http://www.happyheartfamilies.com/articles/article/6447579/160939.htm
- Ask your QCH CF Occupational Therapist and team for additional handouts or support.