

HOLISTIC CARE HELPING YOUR CHILD RECOVER FROM CRITICAL ILLNESS



# General Information

Welcome to the Paediatric Intensive Care Unit (PICU). We know that having a child in PICU can be scary and overwhelming. Our team are here to support you and your child while in PICU and value your involvement in your child's care.

Critical illness can have an impact on your child's normal function and ability, long after your child has left the PICU. PICU Liberation is a care approach for critically ill children to reduce the impact of a PICU admission and to help promote recovery. It involves a team effort to optimise many areas of your child's care.

PICU Liberation encourages earlier PICU/hospital discharge and helps long-term developmental and functional outcomes. Liberation consists of important "bundles", that focus on different areas of patient care. This booklet explains some of the key areas for you.

#### CALM & COMFORTABLE

Our comfort promise: we aim to provide the best possible pain relief for your child. While in PICU, your child may experience pain from necessary surgical devices, wounds, or medical procedures. Untreated pain leads to increased agitation and anxiety. We aim to identify pain early and manage it appropriately using both non-medicating and medication strategies. We may need to use sedating medications to keep your child relaxed or sleepy. This is needed to keep them safe and comfortable if they are anxious or distressed.

If your child is receiving breathing support, the doctor will set a sedation target in the ward round which will help the team work to provide enough comfort and safety for your child, but without having them too sedated or sleepy. Where safe to do so, reducing your child's sedation level may allow your child to move or participate in activity, or come off breathing support earlier. Reducing the dose or amount of sedating medications will help to reduce medication related side effects, such as potential to cause dependency, delirium or long-term neurodevelopmental effects if used for prolonged periods.

#### CALM & COMFORTABLE

Each day that your child is in PICU, they will have many assessments to check their progress. During all assessments we watch your child very closely to see how they are progressing. One of those assessments to see if they can breathe on their own, or with less help from the breathing machine (ventilator). This involves us carefully turning down some of the ventilator settings, so you may notice your child using a bit more effort to breathe. However, we will turn the ventilator settings straight back up if your child is struggling. If your child is looking comfortable, the trial may last up to two hours. We are aiming to remove the breathing tube as soon as your child is ready. Either the nurses or doctors will remove the breathing tube when your child is ready.

The nursing staff will turn down and stop some of the medication infusions until your child wakes up. Hopefully, your child will wake up and see that you are there — our aim is for your child is calm and comfortable. Sometimes we will re-start the medication where it was (if your child is very agitated and unable to be comforted); and sometimes your child will not need any more medication for sedation.

#### CALM & COMFORTABLE

Sometimes when there is a lot of stress on your child's body and brain, their thinking and behaviour may change. This change in thinking and behaviour is called delirium. Delirium can contribute to ongoing difficulties well after children go home.

Paediatric delirium can happen on any day, even on the first day a child is in the ICU. Children with delirium may have a variety of symptoms. These symptoms may come and go and can get better or worse from time to time. Children may:

- Be confused about who and where they are, or have difficulty recognizing familiar faces.
- Be agitated and restless, and may pull at lines, breathing tubes and wires.
- Have sudden mood changes, or be hard to comfort with the usual soothing methods
- Have too much energy or be very sleepy.
- Hallucinate (see or hear things that are not there)

The inclusion treats. There are several things that can contribute to delirium, including the child's injury or illness, some of the treatments for their illness, or the PICU environment itself.

#### EARLY MOBILITY

Early movement and rehabilitation helps children to recover from critical illness and can have positive impacts by minimising delirium, improving sleep patterns, strengthening their musculoskeletal system, and improving their comfort and quality of life. Research shows that early mobilisation of critically ill children is safe, when appropriate precautions are taken, and levels of mobility are suitable.

After your child has been in PICU for over 24 hours, they will be allocated a target mobility (movement) level daily by the Doctor during the ward round. You will see one of the animal signs below put on the door of your child's room. This helps the whole team to work towards achieving the mobility goals your child has for the day. These mobility levels fall into the

following categories:

Lizard - not ready to move yet

Koala - very gentle movement in bed with lots of assistance

Wombat - more movement including getting out of bed and assisted activities

Kangaroo - active movement including getting out of bed and around PICU

### OPTIMISING NUTRITION

Good nutrition is very important to help babies, infants and children to recover from critical illness, as well as to grow and develop.

The goals of the Good Nutrition team are:

- ★ To start nutrition as early as possible after admission to PICU. This may be done
  - Using food and drinks orally (if safe to do so)
  - Using breast milk or formula through a tube that goes through the nose or mouth and into the stomach, or
  - Using a special nutrition containing fluid that is given through a drip.
- ★ To monitor and manage bowels appropriately to ensure regular bowel movements
- ★ To have accurate weights, lengths, and head circumferences

Your child should be weighed a minimum of once per week, either using bed scales, baby scales or chair scales.



## CHILD AND FAMILY

Our goal is to keep you, as the caregiver, closely connected to your child and part of the team to get them well.

Children are precious to their parents. Parents/carers are the experts in their child's personality and how they cope and manage with life. The staff in PICU need your help to provide the best care for your child. It is important to us that you are involved in your child's care and recovery. You can assist by helping us to understand how to support your child to cope in the PICU environment, and to help your child trust in the team.

The focus of this area is to ensure that care is personalised to you and your child. To provide the best care, it is important to know about each child and family, including their preferences, values, goals, fears, and past experiences.

We have a team of expert clinicians to help our youngest patients with optimal positioning and developmentally appropriate cares. SOMETHING MORE ABOUT BABY LIB

# **TEAMWORK**



# How can I be involved?

- ★ Stay close to your child.
- ★ Work with the nurse or allied health professional to help your child be brave.
- ★ Stay calm at the bedside speak in a calm, gentle voice to your child
- ★ Help your child to change position in bed, move their limbs for them, or have a cuddle.
- ★ Comfort and distract your child with toys, games, music, and entertainment, such as singing and reading to reduce anxiety and stress (don't forget the electronic devices for the older child!).
- ★ Tell us your child's likes and dislikes, daily routines, and activities.
- ★ Share with us important family traditions or cultural beliefs
- ★ Tell us who is in your family, and what makes your family unique
- ★ Tell us how your child normally copes and behaves and if you have any concerns
- ★ If you are worried about anything please share it with us, though not in front of you child.
- ★ Ask questions if you are unsure of anything.

Please use your child's personal bedside whiteboard (or flower), to document some of the information above. Check with your nurse what level of physical contact is safe/appropriate.