# Our Journey Through the Pediatric Intensive Care Unit





**PICU DIARY** 



Your Pediatric ICU (PICU) journey is like a road trip, with many different emotions, experiences, and things to see along the way. Keeping a written record of the ICU stay can help you and your family remember and process the experience. This diary has many different sections to help you and your family write down your questions and experiences.

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# Your ICU Diary

#### What is an ICU Diary?

An Intensive Care Unit (ICU) diary is a record written by the patient's family in everyday language to help the patient understand what has happened during their stay and to help the family cope with the situation during this difficult period. A stay in the ICU can weaken the patient's perception and memory. Some patients have no or delusional memories afterward. Therefore, it is important to keep a record of the patient's everyday condition.



#### Who writes the ICU Diary?

- You (the patient) and family members.
- PICU team: physicians, nurse practitioners, nurses, therapists, social worker, case manager, child life, etc.

#### What can we write in an ICU Diary?

- The reason and the events leading up to the ICU admission.
- Daily status of the patient.
- Medical measures.
- Daily procedures or treatments.
- Visitors.
- Recovery milestones, such as first opening the eyes, standing or sitting in a chair, coming off the ventilator, etc.
- Anything that may interest the patient (for example, visitors, activities).
- Notes on discharge or transfer from the ICU.

#### Why is an ICU Diary important?

- The ICU diary and photographs are a written record to help the patient have a true memory of their stay in the ICU.
- The dairy helps the patient's family address how they feel during the patient's ICU stay.

#### How do we use the ICU Dairy?

- Try to make an entry each day.
- Write the date and time for each note.
- Focus on the content and not the spelling or handwriting.
- Include photos; make sure the patient is in the picture with you and the people caring for them (please ask healthcare workers if it is okay with them to be in the photo).
- Encourage the patient to provide input, such as paint, fingerprints, stickers.
- Continue writing for some time after the patient is transferred from the ICU.

### Get to know me

Use the section below to provide information about yourself and your family, this will help you remember your stay in the ICU.

	Photo of me	
	l like to be called	
My name is		
My name is About my family:		
About my family: My favorites:		
About my family:		
About my family: My favorites:	Music:	
About my family: My favorites: Food:	Music: Sport:	
About my family: My favorites: Food: Color:	Music: Sport: Activity:	
About my family: My favorites: Food: Color: TV show:	Music: Sport: Activity: Pet:	
About my family: My favorites: Food: Color: TV show: Movie: Book:	Music: Sport: Activity: Pet:	

### **Memories**

Photos of me and my family during my stay in the ICU:

#### The road map



# Experiences you may have

- **Agitation** A feeling of aggravation, annoyance, or restlessness brought on by provocation or, in some cases, little to no provocation.
- **Sedation** Reducing irritability or anxiety by administering sedative drugs, generally to help with a medical procedure or test procedure.
- **Pain** An unpleasant sensation that can range from mild discomfort in one spot to agony.
- Weakness/ Difficulty moving The inability to move in your environment with ease and without restriction.
- **Delirium –** Delirium is caused by an imbalance in the brain. It can be due to a number of conditions, including infection, drug toxicity or withdrawal, and metabolism changes. Some of the signs and symptoms of delirium include:
  - confusion
  - agitation
  - excessive sleep or lack of sleep
  - restlessness and nervousness
- **Anxiety** A feeling of apprehension and fear, characterized by physical symptoms such as palpitations, sweating, and feelings of stress.
- **Depression** A mood disorder that causes a persistent feeling of sadness and loss of interest and can interfere with your daily functioning.
- **Infection** The invasion and multiplication of microorganisms such as bacteria, viruses, and parasites that are not normally present within the body.
- **Pressure Injury** A localized damage to the skin and/or underlying soft tissue usually over a bony prominence or related to a medical or other device.

We call this next section the "information highway" because it contains all of the important information about what you can expect to see and experience during your hospital stay. There is space below each section for you to write. This will help you remember your stay in the ICU.



#### What is mechanical ventilation?

A **ventilator** is a machine that helps move breathable air into and out of your lungs. This is called **mechanical ventilation**. When you feel sick, you may need extra oxygen support, so the ventilator helps you breathe.



Share your ventilation story in the space below
L

#### What is sedation and pain

#### management?

When you feel uncomfortable and agitated, **sedation** is what keeps you calm and helps you sleep. The medications used for sedation are called sedatives. These medications also help you manage your pain.



Share your sedation story in the space below...

#### What is immobility?

You are resting in bed most of the time when you stay in the hospital. This is called immobility. You may lose your muscle mass, strength, and/or lose the range of motions in your joints. You may also have poor tolerance for activity. Therefore, you will need to continue to move your body to



maintain muscle strength. Your family members or clinicians will help move parts of your body to help you prevent or reduce joint stiffness and maintain full of range of motion.

Share your mobility story in the space below...

#### What is delirium?

#### The symptoms of delirium are:

- Confusion
- Unable to pay attention
- Poor sleep pattern
- Interacting less

• Agitated

- Restless
- Hallucinations



Share your delirium story in the space below...

# Calendars

These will help you keep a record of your stay in the ICU, write a short note for each day to help you remember your stay.

#### Month:\_\_\_\_\_

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

#### Month:\_\_\_\_\_

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

# This is why I am here...

Write a little bit about why you think you are here; this may help you remember your stay at the ICU later.



Today the date is \_\_\_\_/ \_\_\_/

Share a little bit about your ICU journey in the space below.

Comments from your PICU team:

Today the date is \_\_\_\_ / \_\_\_ /

Share a little bit about your ICU journey in the space below.

Comments from your PICU team:

Today the date is \_\_\_\_/ \_\_\_/

Share a little bit about your ICU journey in the space below.

Comments from your PICU team:

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Share a little bit about your ICU journey in the space below.

Comments from your PICU team:

Today the date is \_\_\_\_/ \_\_\_/

Share a little bit about your ICU journey in the space below.

Comments from your PICU team:
#### **Coloring Page**

This is a picture for you to color:



Peaksel / CC BY-SA (<u>https://creativecommons.org/licenses/by-sa/4.0</u>). Pediatric Intensive Care Unit (PICU) Our Journey Through the Pediatric Intensive Care Unit

# Love notes from families & friends

This is a place for you to create a collage out of cards from families or friends:

# The family's experience

The family can be impacted in many ways when a loved one is in the ICU:

- **Mental health** Family members with a critically ill child may experience short or long-lasting emotional effects including:
  - o Stress
  - o Anxiety
  - Depression
  - Post-traumatic stress disorder (PTSD)
  - Complicated grief
- **Social health** Family members may experience a change in their previous social life such as:
  - $\circ~$  Less time spent with the sick child's siblings
  - Time away from their job
  - Less time for recreational activities

#### **Emotions the family may experience**

During a loved one's stay in the ICU, the family may experience a "roller coaster" of emotions. This is because like a roller coaster, your ICU journey may have lots of ups and downs.



#### Self-Care Street

We call this section "Self-Care Street" because it is like a path for you to follow to take care of yourself while in the ICU.

Negative and unrealistic thoughts can cause you distress and result in problems. When you suffer from emotional distress, the way that you understand situations becomes skewed (distorted), which has a negative impact on the actions you take (see the diagram below). Thus, it is important to be aware of negative thinking and behavior patterns that reinforce that thinking. Cognitive therapy helps people to develop other ways of thinking and behaving to reduce feelings of distress.

The diagram below helps you to understand how your thoughts and feelings influence your behaviors.



#### How can I take care of myself?

Pediatric Intensive Care Unit (PICU) Our Journey Through the Pediatric Intensive Care Unit

# Parking Lot

We call this section the "parking lot" because it's a good spot for you to pause on your ICU journey and reflect on any questions you may want to discuss with your care providers.



Questions I have...

Your family can share a little bit about the ICU journey in the space below.

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<u> </u>		Intensive Care Unit (PICLI)

Your family can share a little bit about the ICU journey in the space below.

Today the date is \_\_\_\_ / \_\_\_\_/

Your family can share a little bit about the ICU journey in the space below.

Today the date is \_\_\_\_ / \_\_\_\_/ Pediatric Intensive Care Unit (PICU) Our Journey Through the Pediatric Intensive Care Unit

Your family can share a little bit about the ICU journey in the space below.

Today the date is \_\_\_\_ / \_\_\_\_ /

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Your family can share a little bit about the ICU journey in the space below.

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<b>L</b>		Intensive Care Unit (DI	4

Your family can share a little bit about the ICU journey in the space below.

Today the date is \_\_\_\_ / \_\_\_\_/

#### **Collection of business cards**

This is a place for you to collect business cards:

Pediatric Intensive Care Unit (PICU) Our Journey Through the Pediatric Intensive Care Unit Don't get hung up on the hard times, the challenges. Tell your story by highlighting the victories. Because it's your victories that will inspire, motivate, encourage other people to live their stories in grander ways.

> ~ Iyanla Vanzant



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See if you can find all of these figures when you visit C.S. Mott Children Hospital





