



# Our Journey through the **Pediatric ICU**



## HELLO!

This journal is a gift for you, the caregiver of a patient in the UPMC Children's Hospital of Pittsburgh Pediatric Intensive Care Unit (PICU). We are dedicated to the very best care for you and your child. We know that this time can be stressful and overwhelming for your entire family, and this journal is designed to help you and your loved one through critical illness to going home.

Your child may have questions about their time in the hospital. They may need help understanding their illness. A hospital stay can be a confusing time for children of any age and a stay in the PICU can be even more difficult to understand. Many children and siblings will continue to have questions for weeks, months, or even years. We hope this journal will help you answer questions and understand your child's time in the PICU.

There are several sections to this journal. You will find a section to write down your daily thoughts and feelings. You may experience a range of emotions while in the PICU (such as stress, anger, or even joy), and writing them down can help you cope with these feelings. This writing area also has space to write down questions for your child's care team and the answers you receive. There is also a section for you to draw and create art, which you may find calming. There is a section to keep track of procedures or tests that your child may have during their hospital stay. We have also included a section with definitions of words commonly used in the PICU. The definitions will help you explain things to your child when they have questions.

Finally, we have included a tear-out page which you should bring to your child's doctor (pediatrician) or family doctor. This page explains that children may experience "post-intensive care syndrome" after a PICU stay. This means that they may have changes in their behaviors, emotions, or physical abilities which may require therapies or follow-up to support their recovery after this illness.

We have many resources to help you including Child Life specialists, art therapy, music therapy, social workers, and chaplains. Please ask any member of your care team for more information about these services.

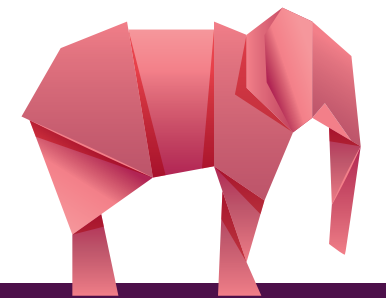
Regards,

The Critical Illness Recovery for ChiLdrEn (CIRCLE) team on behalf of the UPMC Children's Hospital of Pittsburgh PICU

*This journal was funded in part through the generosity of Michael and Ann Popper and a grant from the Beckwith Institute, Wolff Center at UPMC.*

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*“Forsan et haec olim meminisse iuvabit.”*

*(“Perhaps one day it will be helpful to remember these things”)*

*- Vergil, Aeneid*

## JOURNAL WRITING IDEAS

You may use this section to write whatever you feel like writing in the moment. We provided some suggestions below to help you get started. Feel free to write down any questions you think of while journaling in the “for discussion” section as a reminder when you next talk with the care team.

1. Today I feel...
2. One thing that made me feel better today was...
3. What things are out of my control? How does that make me feel?  
What are some things I can control?
4. What is one thing I can do to take care of myself today?  
What obstacles will I face when doing this?
5. What makes me feel calm in the PICU? What makes me feel stressed?
6. What small moment meant the most to me today?
7. What made me upset today? What is something I did to find peace?
8. What is something that I can do to make this a better day than the last?
9. How is my child’s health affecting my health?
10. How am I advocating for my child in the PICU?  
Is the health care team hearing me?
11. What kind of things can I do to help my child heal today?  
What about in the future?
12. How did my child’s condition change today? How did I handle this change?
13. When I look back on this experience, what is one thing I do not want to forget?

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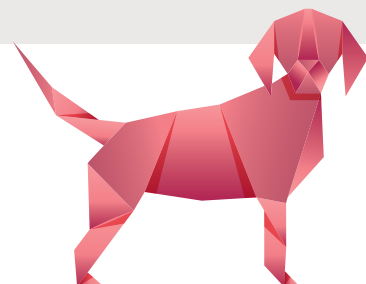
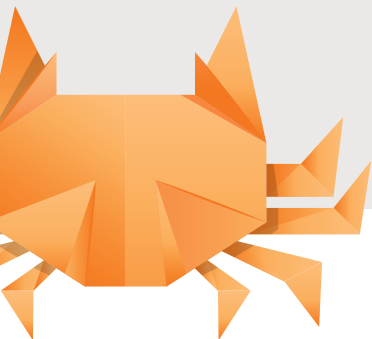
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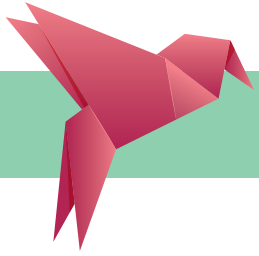
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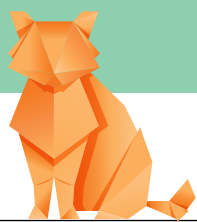
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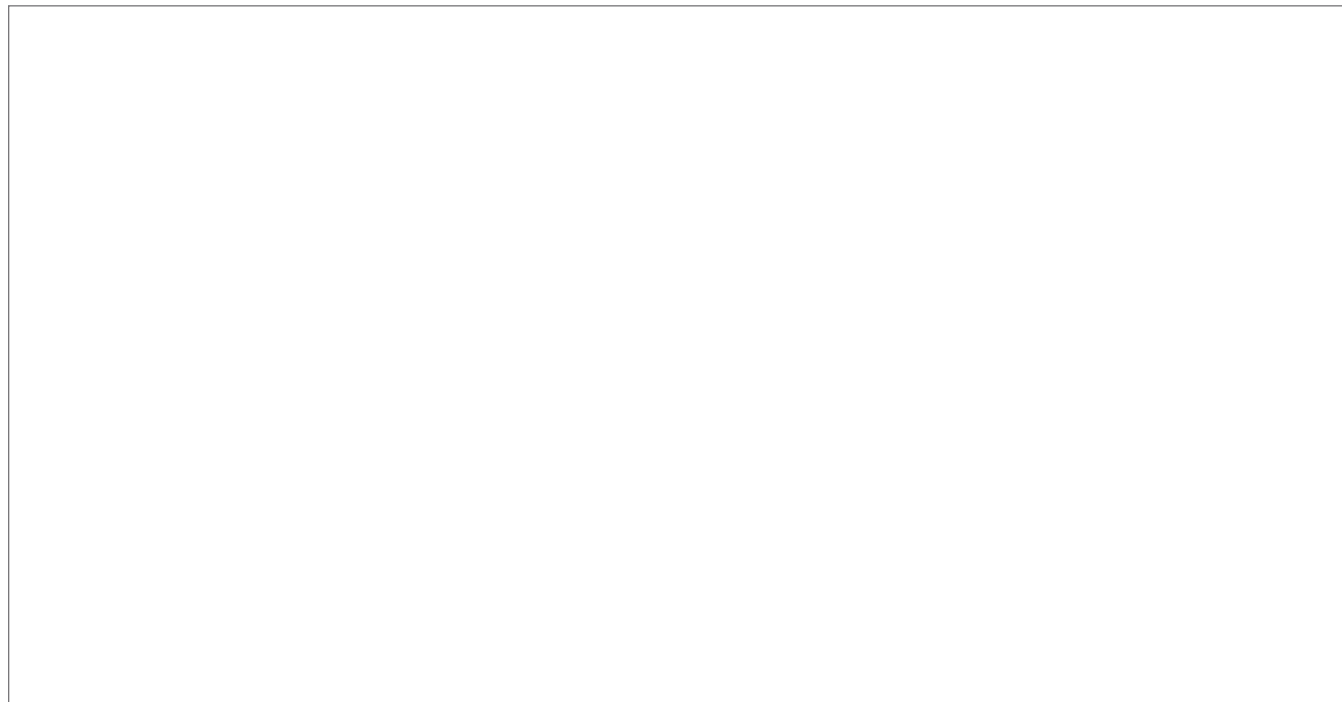
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## ART IDEAS

Reflect on people, places, things, and experiences that make you feel grateful. Here are a few things I am thankful for:



There are many outcomes in life that you cannot control. Here are some outcomes I can control:



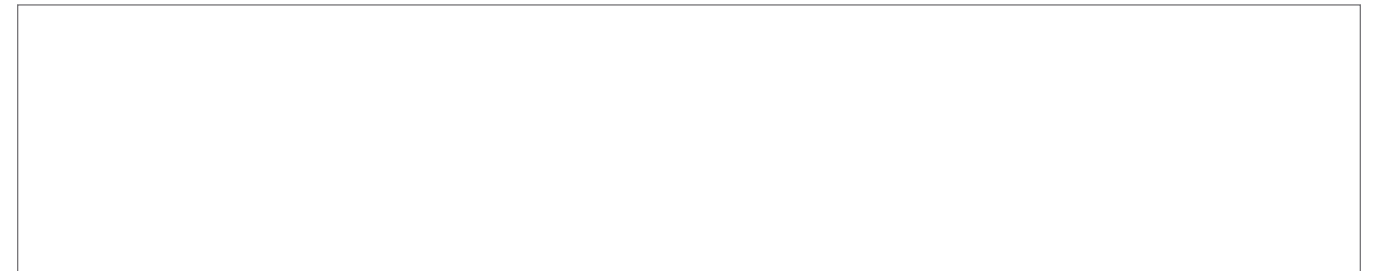
## ART IDEAS

**Using lines, shapes, and colors:**

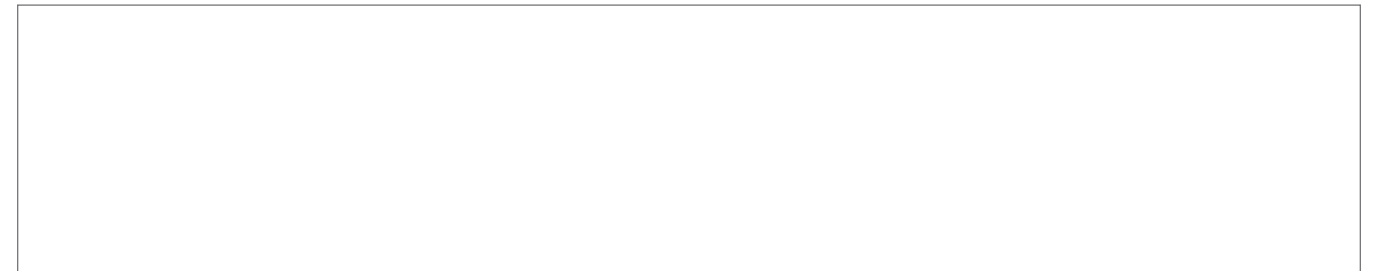
This is how I feel when I am feeling my best:



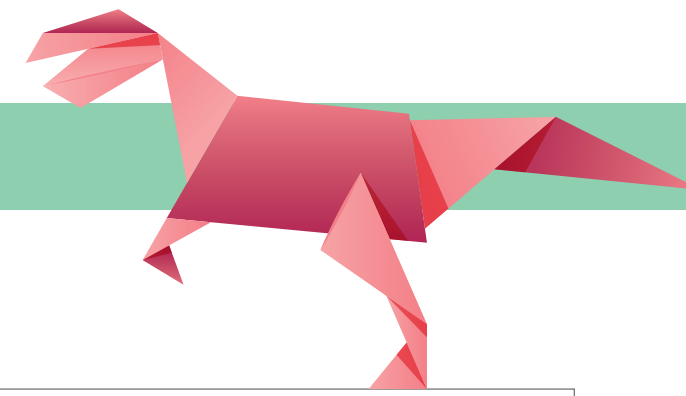
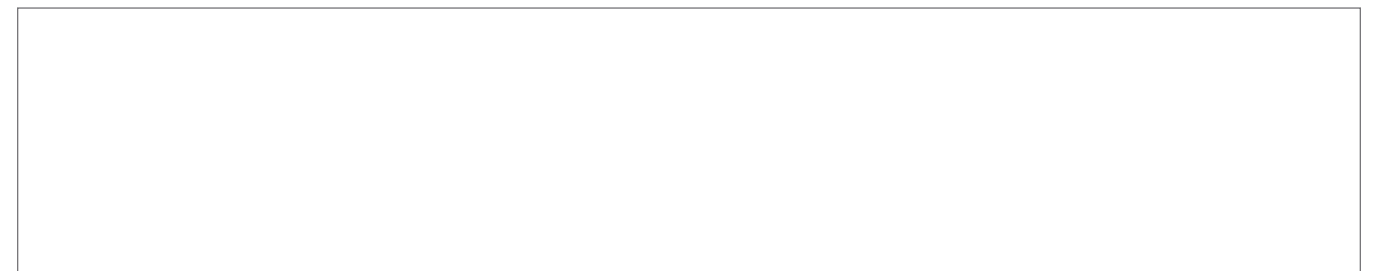
This is how I feel when I am feeling \_\_\_\_\_:



This is how I feel today:

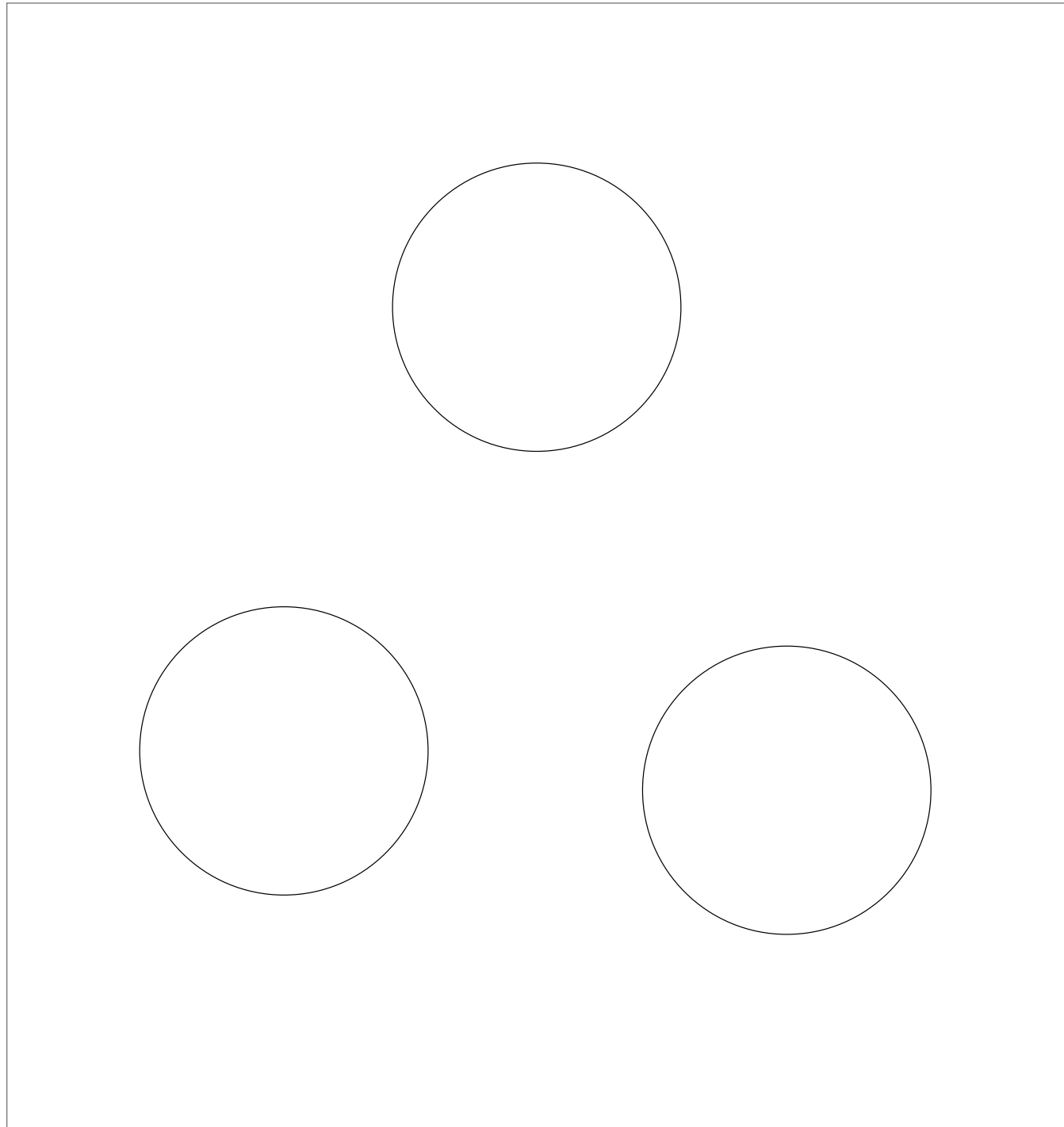


This is how I want to feel by the end of today:



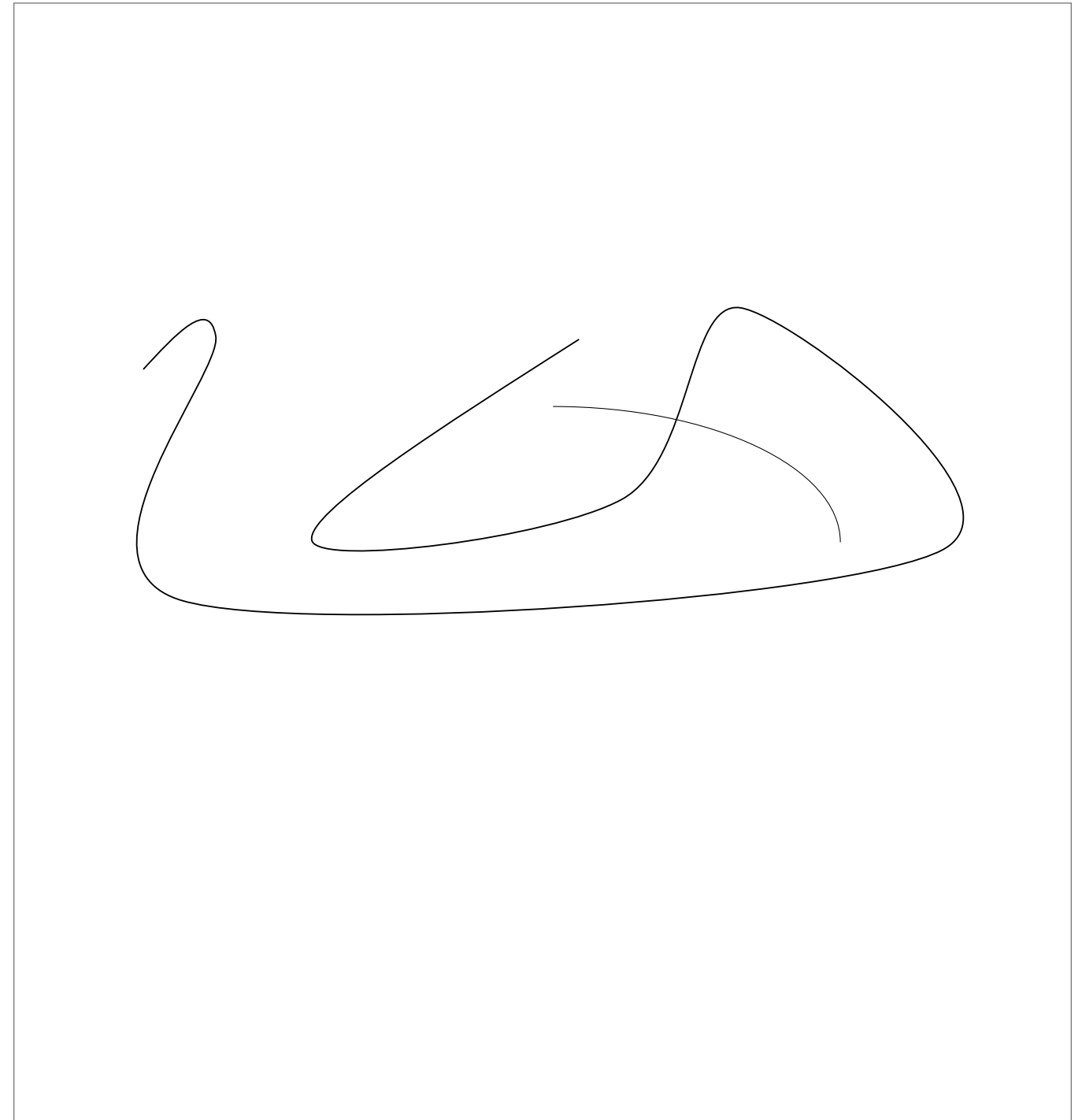
## ART IDEAS

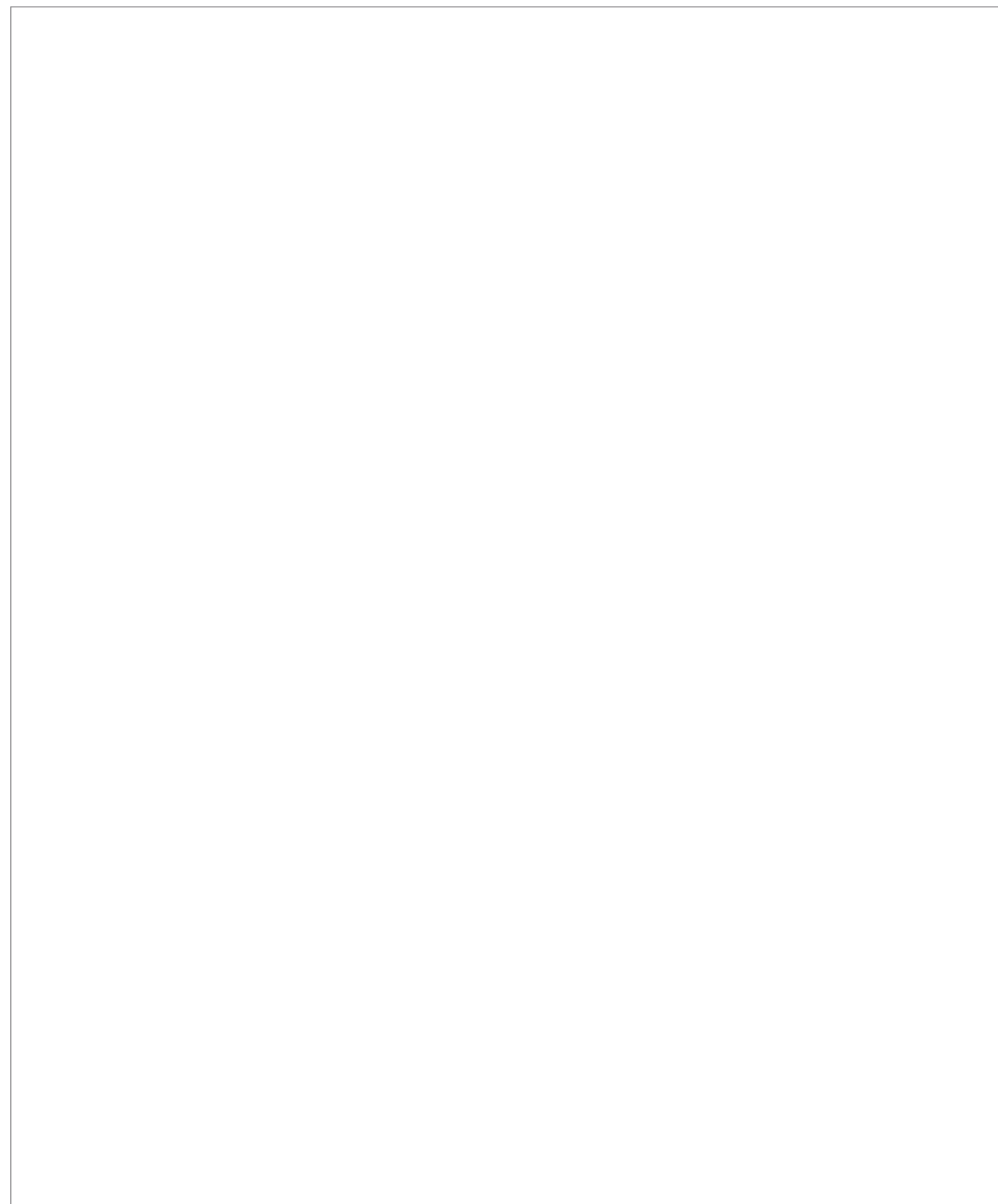
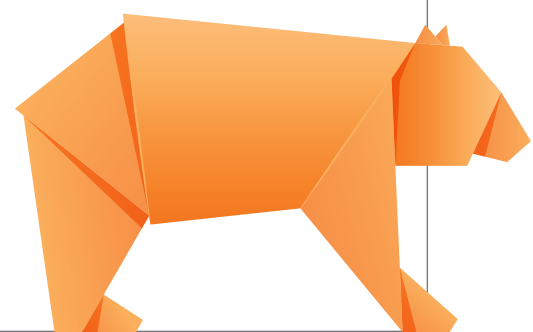
Some people find the symbol for a circle to be relaxing and help focus. Think about your feelings and emotions for this day, this hour, or even just this minute. Express how you are feeling now with shapes and lines and repeat 2 more times throughout the day until all 3 circles are filled.

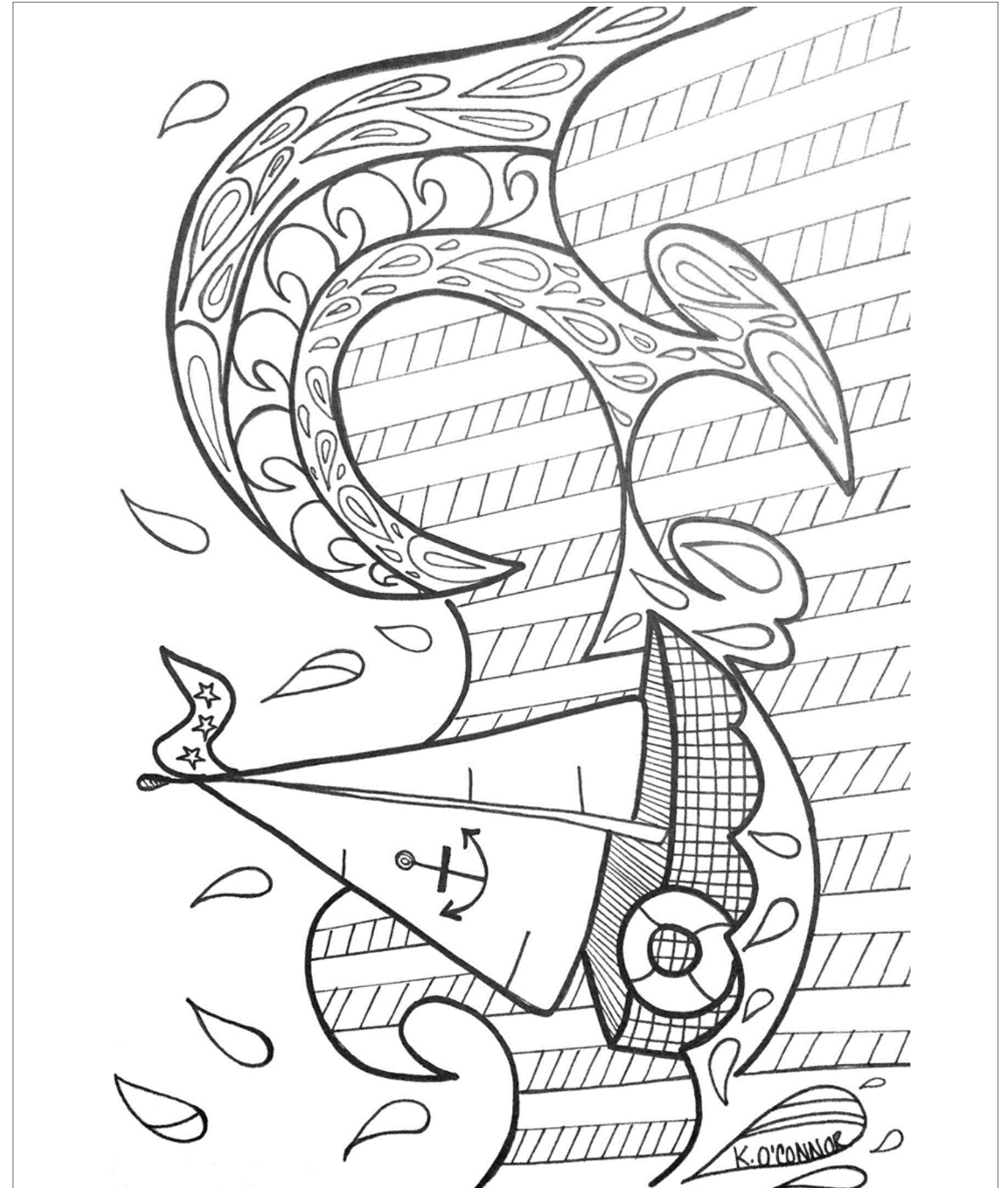
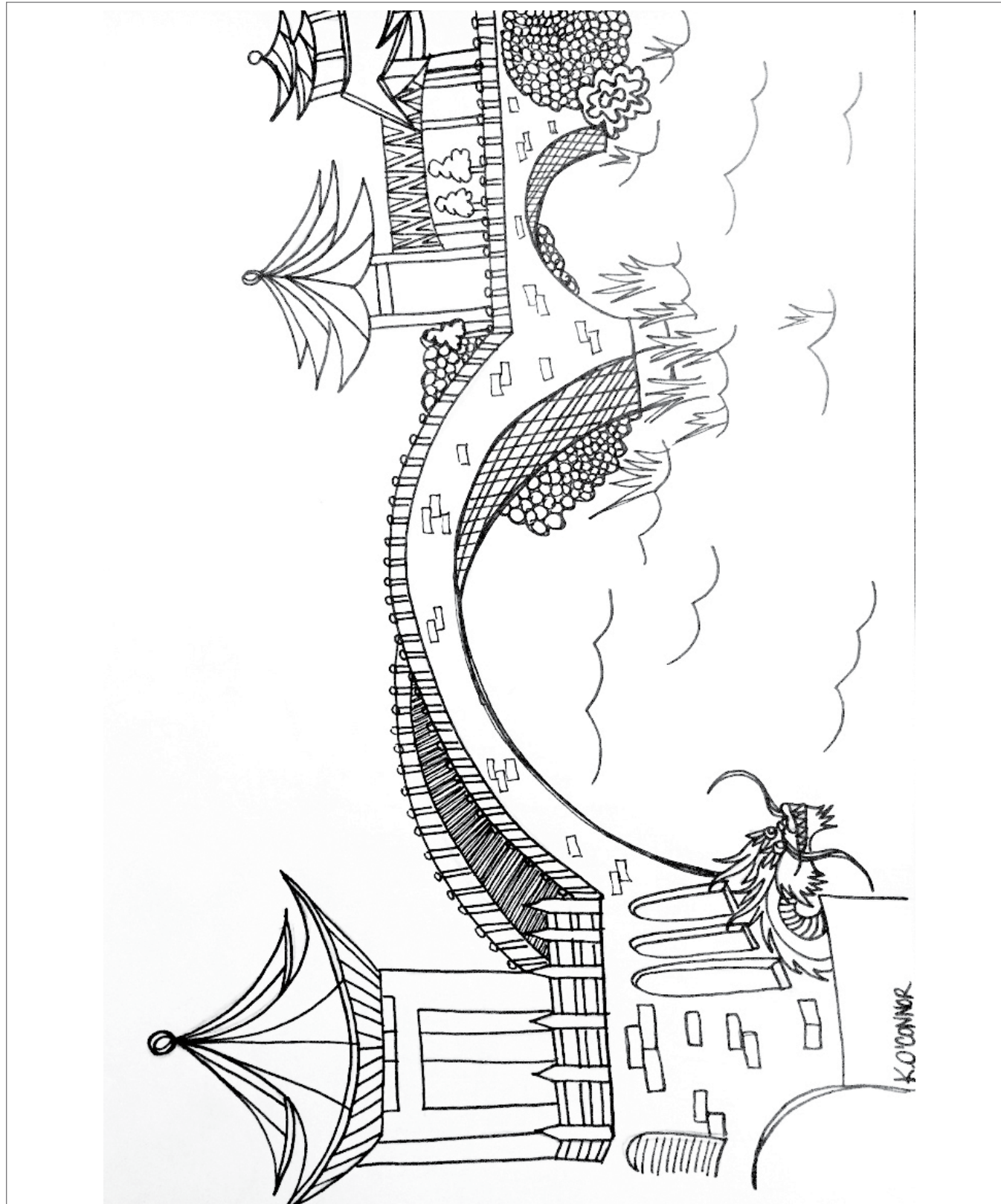


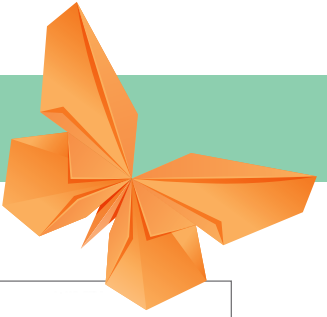
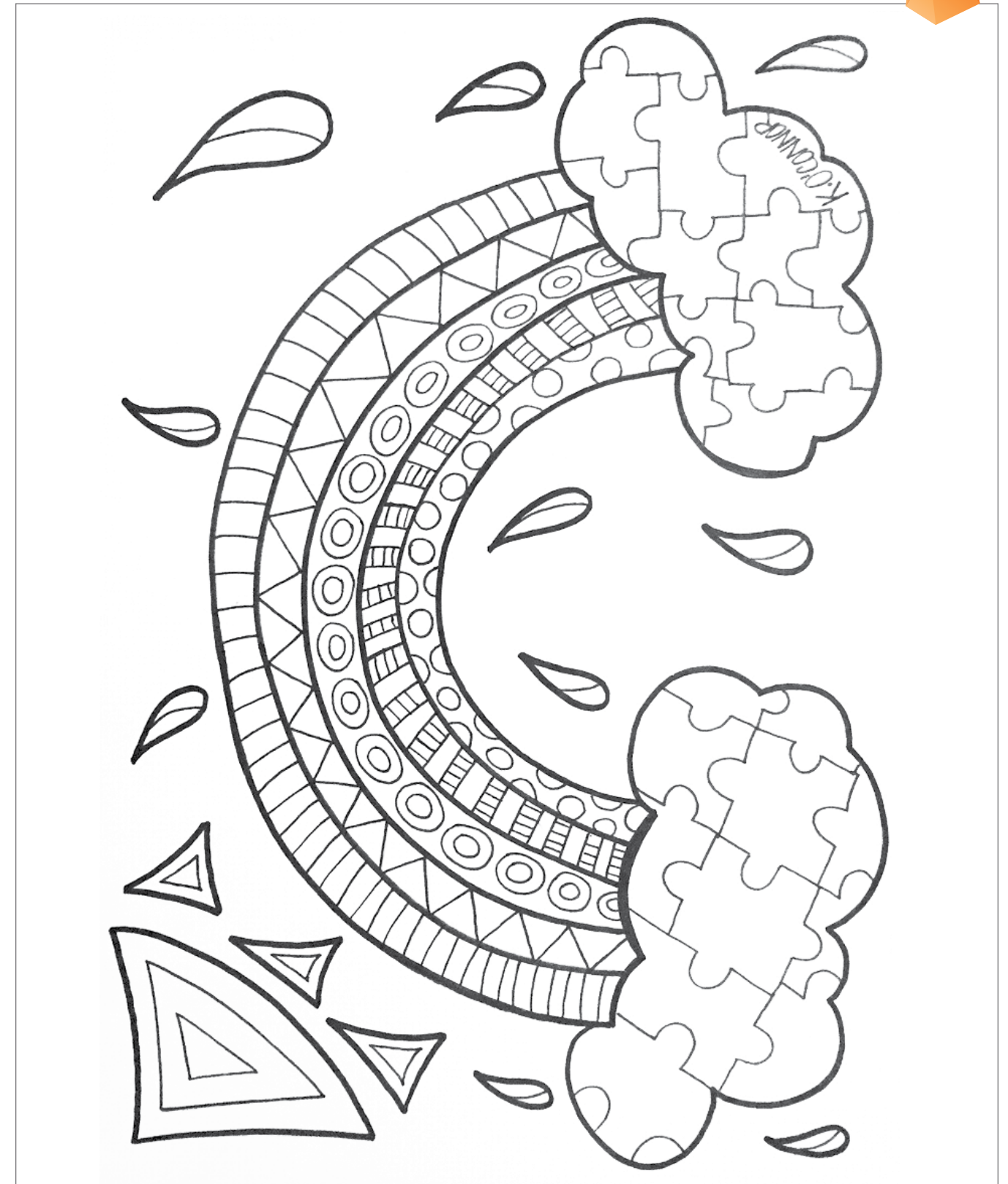
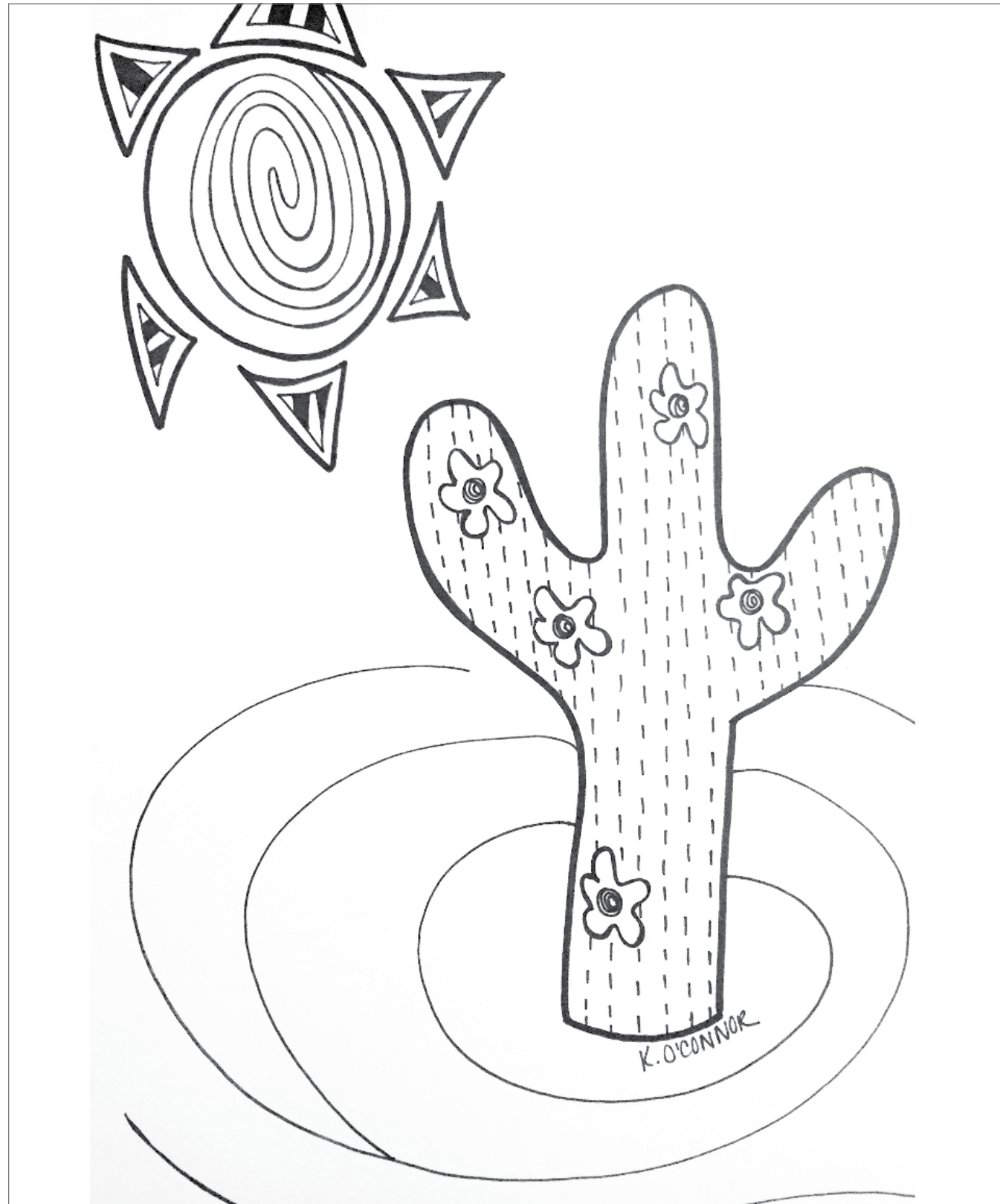
## ART IDEAS

Use a pen or pencil to complete this drawing. Add additional lines, shapes, and colors to transform this scribble into your own doodle.









## MY CHILD'S MEDICAL JOURNEY: A TIMELINE

This part of the book can be used to keep track of things that happen in the PICU each day. Some people say it helps to keep track of their child's progress, procedures, and PICU care. Keeping track may make it easier to see changes in your child, to remember things, and to talk with your child about their time in the PICU if they (or their siblings) have questions later.

Date: \_\_\_\_\_

Progress *(Example: In what ways is your child better today?):*

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Procedures And PICU Care *(Example: Your child will have an x-ray or physical therapy exercises):*

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Goal(s) *(Example: No more fever, sit up for 1 hour):*

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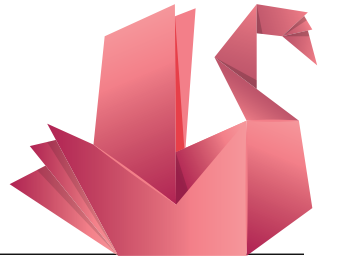
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## MY CHILD'S MEDICAL JOURNEY: A TIMELINE



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## HOW TO TALK TO YOUR CHILD ABOUT THEIR PICU STAY

Child Life specialists provide developmental, social, and emotional support to help children:

- Understand the hospital by using simple language
- Cope with a diagnosis or traumatic event
- Provide support during procedures, tests, and surgeries using preparation, distraction, and relaxation techniques

In addition to supporting your child, the Child Life team can also help support siblings. Please consider asking the medical team for Child Life services if any of these needs arise for your children.



## GLOSSARY OF PICU TERMS

### A

**Alarm:** a beeping or ringing noise made by a machine which alerts the nurse or doctor to pay attention. They can sound scary but are meant to help detect changes in a patient's condition. You will likely hear many alarms during your child's stay in the PICU.

**Antibiotics:** medicines that fight bacteria that make a person sick

### B

**Bilevel Positive Airway Pressure Machine (BiPAP):** a mask that fits on the patient's face that helps give them extra air to support the lungs

**Blood pressure:** a measure of how hard the heart is working to pump blood through the body

**Blood pressure cuff:** a soft band that wraps around the arm or leg and gives a tight squeeze

**Blood sugar:** the amount of sugar in the blood

**Blood draw:** taking a small amount of blood from the vein. Veins are the blue "lines" we see under our skin. Blood travels through our veins to reach different parts of the body.

### C

**Catheter:** a thin, plastic straw placed in the patient's body

**Central line:** a straw or tube in a vein in the chest that can be used to take blood or give medicine

**CT scan:** a camera that looks like a big donut that takes pictures of the inside of the body

**Continuous Positive Airway Pressure Machine (C-PAP):** a mask that fits on the patient's face that helps give extra air to support the lungs

**Continuous Renal Replacement Therapy (CRRT):** a machine used to clean inside the patient's body by removing extra fluid and toxins from the blood

**Chest Tube:** a straw placed in the chest to remove fluid from the lungs to help the patient breathe better

### D

**Dialysis:** when the patient's blood needs a machine to help it remove water, waste, and germs

**Dressing:** a special clean bandage used to cover a part of the body while it heals

### E

**Echocardiogram (Echo):** a way to look at the patient's heart using a wand that is moved over the skin. A gel is placed on the skin to make the wand slide easily.

**Electrocardiogram (EKG):** stickers with strings that connect to a machine with a computer screen. The stickers feel how the heart is beating and turn the beat into a picture that doctors can see on the screen.

**Endotracheal Tube (ETT):** a soft, bendable tube attached to a machine that is placed in the patient's mouth and down the throat to help them breathe

## GLOSSARY OF PICU TERMS

**Electroencephalogram (EEG):** a test to see how the brain is working. Stickers are placed on the patient's head that are connected to a machine with colored strings. These stickers capture what is going on in the brain and turn it into a picture that doctors can see.

### F

**Foley catheter:** a small, soft tube that goes into the bladder through the opening where the patient pees

**Flush:** water given through an IV

### H

**High flow:** air that is heated to body temperature and sent through the nasal cannula to help a patient breathe better

### I

**Internal jugular catheter (IJ):** a thin tube placed in a vein in the neck that can be used to take blood and give medicine

**Infection:** germs that attack the body

**Interventional Radiology (IR):** a place in the hospital where a doctor performs procedures using special cameras that see inside the patient's body

**IV:** a tiny plastic straw that is placed in the vein to get blood and give medicine

### L

**Lumbar puncture (LP):** a procedure performed by a doctor when they need to run tests on the fluid surrounding a patient's spine and brain (CSF) to help find out what is making a patient sick

### M

**Magnetic Resonance Imaging (MRI):** a large camera shaped like a tunnel that takes pictures of inside the body; it makes loud noises

**Monitor:** a machine that looks like a computer screen. It shows the doctors how different parts of the patient's body are working.

### N

**Nasal cannula:** a soft, plastic, bendable tube that rests under the patient's nose and gently blows fresh air into the nose

**Nasogastric tube (NG):** a soft, bendable straw that goes in the nose to the belly to give medicine, fluid, and formula

**NPO:** when the patient is not allowed to eat or drink

### O

**Occupational Therapist (OT):** these therapists help the patient with visual and cognitive skills and activities of daily living, such as dressing and grooming

**Oxygen mask:** a clear, plastic mask that goes over the nose and mouth to help with breathing

## GLOSSARY OF PICU TERMS

### P

**Pediatric Intensive Care Unit (PICU):** a special place in the hospital for the children who are very hurt or very sick and need the most care from doctors and nurses

**Pulse oximeter:** a sticker that goes on a finger or toe with a red light that tells how much oxygen is in the blood

**Peripherally Inserted Centralized Catheter (PICC):** a long, skinny tube that is placed in a larger vein to get blood, give medicine, and give fluids

**Physical Therapist (PT):** these therapists focus on helping to increase the patient's strength and flexibility. They help reduce risk during physical activities, such as getting your child out of bed.

### R

**Respiratory (Breathing) Therapists (RT):** these therapists use oxygen and breathing medicines to help the patient breathe. They also manage breathing machines.

### S

**Sedation:** medicine to help the patient fall calmly asleep so they do not feel anything, hear anything, or see anything during a procedure

**Scope:** a small, flexible camera that is used to look inside the body

**Social Worker:** they help provide emotional support and can guide you and your child to resources they need during their PICU stay

**Speech Therapist:** this therapist focuses on helping the patient eat, swallow, and communicate well during their illness

**Stethoscope:** what doctors and nurses use to listen to the heart and lungs

### T

**Total Parenteral Nutrition (TPN):** nutrition that is delivered through a central IV when a patient is unable to eat, drink, or use a feeding tube

**Tourniquet:** a rubber band that squeezes the patient's arm to help veins show up better

**Tracheostomy Tube:** a tube placed in the neck to help with breathing

### U

**Ultrasound:** a way to look inside a patient's body using a wand that is moved over the skin. A gel is placed on the skin to make the wand slide easier.

### V

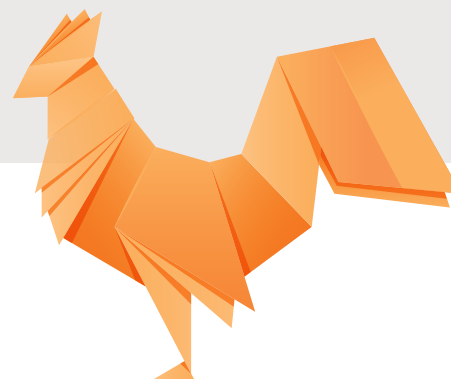
**Ventilator:** a machine that breathes for the body

**Versed:** a medicine that helps the patient relax and forget what happens during a procedure

**Virus:** a type of germ that gets inside the body and causes someone to be sick

### X

**X-ray:** a picture that lets doctors see the patient's bones



## ADDITIONAL RESOURCES

For more information on post-intensive care syndrome and your child's PICU stay, please visit:

[www.sccm.org/MyICUCare/](http://www.sccm.org/MyICUCare/)

- This website is designed by the Society of Critical Care Medicine to provide information and resources to patients and families following their critical illness. There are links to support groups and other information you may find helpful.

[www.afterpicu.com](http://www.afterpicu.com)

- This website contains information for parents, patients, and siblings who may need support after a PICU stay. There are stories and videos featuring real kids recovering after their illness.

[www.healthcaretoolbox.org](http://www.healthcaretoolbox.org)

- This website helps you to learn about and identify signs of post-traumatic stress in your child. It also has resources to address the social and emotional needs of children who struggle with this stress.

[www.experiencejournal.com](http://www.experiencejournal.com)

- This website features stories, videos, and personal experiences from real kids, teens, and families who are dealing with significant physical and emotional illnesses.

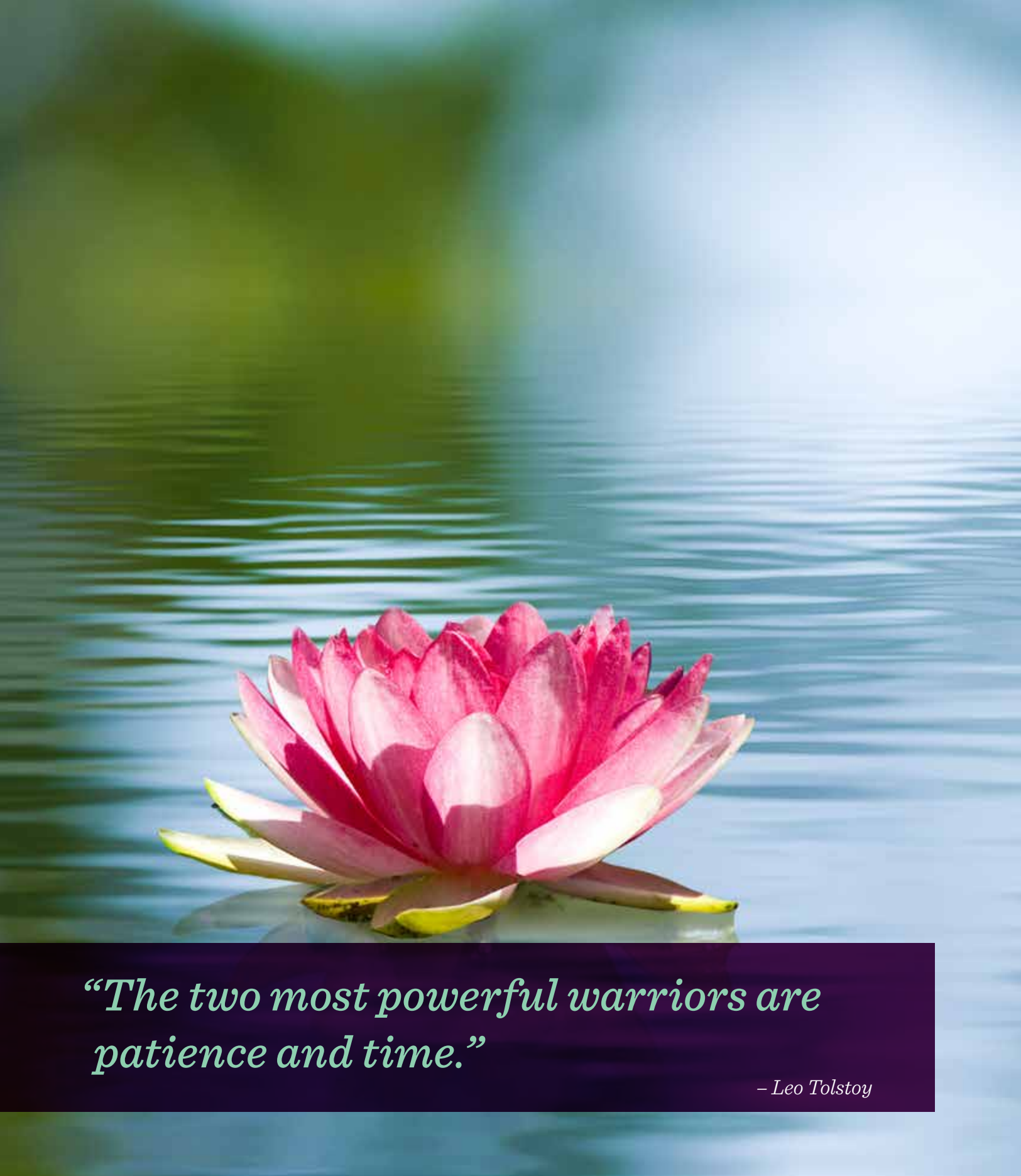
[www.picuparent.com](http://www.picuparent.com)

- This website has more in-depth information about people, machines, medicines, and procedures found in the PICU. It may be helpful if you are looking to dive into deeper understanding about your child's treatments.

These sources are provided solely as a convenience to you and not as an endorsement of the content on such sites. UPMC is not responsible for the content of third-party sites.

[www.chp.edu/our-services/circle](http://www.chp.edu/our-services/circle)

The Critical Illness Recovery for ChiLdrEn (CIRCLE) program helps your child safely shift from hospital to home. It also provides ongoing care over the months to come.



*“The two most powerful warriors are  
patience and time.”*

*– Leo Tolstoy*

## PEDIATRIC POST-INTENSIVE CARE SYNDROME

### Dear Primary Care Provider,

You are receiving this because your patient has recently been admitted to the pediatric intensive care unit (PICU) at UPMC Children’s Hospital of Pittsburgh. Critical illness is a life changing event for patients and families. Surviving children and caregivers may acquire new morbidities in physical, social, cognitive, and psychological functioning after they leave the PICU. The combination of these disorders is commonly referred to as pediatric post-intensive care syndrome (PICS-p). Data are accumulating that many children, siblings, and caregivers have new and persistent sequelae affecting quality of life and development long after PICU discharge. Improving long-term health outcomes among survivors is becoming a major focus in the PICU. This sheet was designed by the PICU Critical Illness Recovery in ChiLdrEn (CIRCLE) team at UPMC Children’s Hospital of Pittsburgh to bring awareness of the signs and symptoms of PICS-p to the doctors caring for our patients after their critical illness. The CIRCLE team aims to address the post-intensive care needs of critically ill children treated in the PICU at the UPMC Children’s Hospital of Pittsburgh.

### PICS-p Facts

Functional disabilities persist in many PICU survivors for years after leaving the hospital.

- 10% of previously healthy children require help for daily care 3 years after critical illness
- Poor adaptive behavior functioning is found in 28% of children 1 month after they leave the PICU
- 72% of children experience sleep difficulty 5 months after leaving the PICU
- Nearly 1/3 of parents have post-traumatic stress disorder (PTSD) after a child’s critical illness
- 4 years after leaving the PICU, patients score significantly worse than healthy controls on neuro cognitive testing

PTSD symptoms occur in up to 60% of children after PICU admission:

- Children with baseline normal function experience greater functional decline but recover more quickly than those with baseline impairment
- Longer PICU stays are related with worse PICS-p
- Trauma, cardiac arrest, neurologic, and oncologic disorders are risk factors for PICS-p

### Signs of PICS-p:

- Feeding difficulties
- Trouble sleeping
- Poor concentration
- Anxious
- Sad or withdrawn
- School difficulties
- Clumsiness or weakness
- Breathing issues
- Behavioral regression

### Suggested Therapies:

Services that may be recommended for PICS-p recovery:

- Rehabilitation therapies for mobility and activities of daily living
- Speech and language therapy for feeding and communication
- Behavioral therapy for family therapy and emotional health concerns
- Child Life interventions to promote coping with medical trauma if former ICU patients return for follow-up clinic visits or return to the hospital

Herrup EA, Wieczorek B, Kudchadkar SR. Characteristics of postintensive care syndrome in survivors of pediatric critical illness: A systematic review. *World Journal of Critical Care Medicine*. 2017;6(2):124

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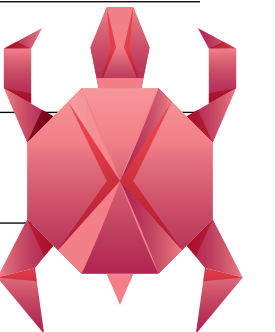
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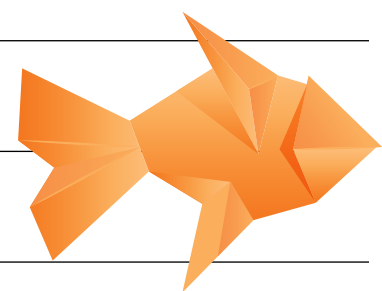
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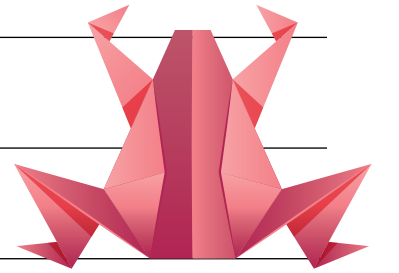
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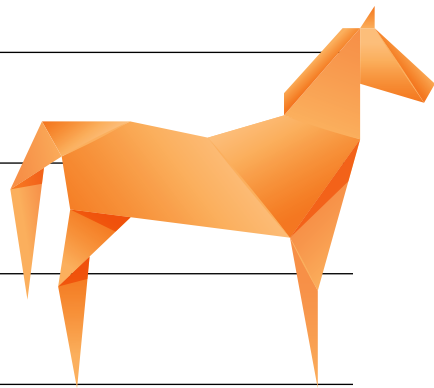
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