STRATEGIES

For Responding To Physical Changes In Your Child

Safety

It is important that your child follow all medical advice from their treating physicians, including any physical activity restrictions. If your child was in the hospital for a head injury, then it is recommended that they avoid activities that may cause another head injury such as wheeled activities (riding a bike, scooter, skateboard, etc.) and climbing on jungle gyms at this time. This may also be true for other areas of injury (arms, legs, abdomen) and your medical team can help you decide which activities are safe.

Pain Management

You likely received information about medications for managing pain in your discharge plan from the PICU healthcare providers. There are other methods for managing pain (including headaches) described below.

REST

It is often recommended that children begin some small exercises early to promote physical recovery and to avoid swelling, loss of motion, and decreased muscle strength. However, rest is also important for recovery and healing. Usually, you can treat your child's headache at home with rest, decreased noise, plenty of fluids, good sleep, and balanced meals.

POSITIONING

If your child has pain or swelling in one part of the body, it can be helpful to elevate (raise) the painful body part. For instance, while your child lies down, you can place their injured leg on a pillow. Your child may need extra pillows or help finding comfortable positions to sleep.

APPLYING COLD

Follow your doctor's instructions. Generally, though, it helps to apply cold (such as an ice pack) to an area with swelling or inflammation. Be careful to monitor the area closely and only apply cold packs for short periods (about 10 minutes on/10 minutes off) or less if your child finds it uncomfortable.

COPING SKILLS

If your child has acute pain, certain coping skills can be helpful. Refer to the **TEACHING COPING SKILLS (P. 11)** section to learn about distraction, breathing exercises, and guided imagery.

Healthy Sleep

10-12 hours of high quality sleep is important for recovery. For most children, sleep patterns become disrupted in the hospital because there are frequent check-ins, loud noises, and bright lights throughout the night. Several active steps can help restore your child's sleep:

ROUTINES

Try to maintain normal routines at bedtime as much as possible, while also making sure your child feels safe and comforted by you as they fall asleep. After first coming home from the hospital, it can be helpful to stay with your child a little longer than usual as they fall asleep.

Keep consistent bedtimes and wake times every day of the week. Late nights can throw off a sleep schedule for days.

To improve your child's ability to self-calm and fall asleep, set aside about an hour of "wind down" time before bed. Pick out low-energy activities that will help relax your child. Good options include reading a story, listening to calming music or podcasts, or coloring. Relaxation techniques such as performing deep, slow breaths or imagining positive scenes like being on a beach can help a child relax.

It is best to avoid loud play and screen-time in the hour before bed.

SECURITY OBJECTS

Security objects at bedtime are often helpful for children who need a transition to feel safe and secure when their caregiver is not present. Try to include a stuffed animal, toy, or blanket when you cuddle or comfort your child, as this may help them adopt the object.

CHECKS

When checking on a child at night, checks should be "brief and boring." The purpose is to reassure your child you are present and that they are OK. Spending too long on checks can keep your child awake longer and may also encourage them to seek out more checks at night.

PROVIDING COMFORT

If your child has a nightmare, provide comfort and cuddling for a short time and encourage them to go back to sleep in their own bed. Consider leaving the bedroom door open, reminding them you are close by, and providing a favorite soft toy or blanket for them to snuggle with for the rest of the night.

BEDROOM ENVIRONMENT

The bedroom should be cool, quiet, and comfortable.

STRATEGIES

For Responding To Emotional Changes In Your Child

Talk About Big Feelings

It is completely natural for your child to have an emotional reaction to their injury/illness, hospitalization experience, and recovery process. Oftentimes caregivers are not sure how to handle their children's feelings, especially as caregivers also have their own reactions.

NORMALIZE EMOTIONAL REACTIONS

If your child shares about their emotional experience, listen to them, tell them it is normal, expected, and okay for them to have big emotions about what happened to them. Try not to quickly shift the conversation to positives, but instead allow your child (and yourself) to appreciate how hard things have been. These conversations give children a chance to tell you whether they are troubled by memories from before or during the hospitalization and allows you to try to put their mind at rest about unnecessary concerns.

DON'T FORCE IT

Some children find it difficult to speak to their caregivers about their experiences and feelings because they do not want to upset them. Some children may talk to other people about these things. Still, other children do not want to talk about their experiences and feelings with anyone. Hesitancy to talk about scary experiences and big feelings is perfectly normal. Children should not be forced to talk about these things if they don't want to.

OTHER WAYS TO EXPRESS FEELINGS

Your family can work together to create a story, diary, or picture book that describes your child's illness before, during, and after their stay in the hospital. This is something you can look at with your family if and when you are all ready.

Teaching Coping Skills

You can help your child learn strategies to manage their big emotions. While their emotional reactions may be stronger or last longer since coming home from the hospital, the big emotions will decrease or fall away over time.

COPING THOUGHTS

It can be helpful to come up with short phrases or mantras that your child can repeat when they are feeling worried or overwhelmed. Examples include "I can do this," "This is not forever," "Things will be better soon."

COPING SPACE

Create a "calm down" space where your child can "take space" when they are beginning to get worked up, angry, or worried. This could be a pop-up tent or a corner where they have access to calming objects (e.g., pillows, blankets, music, calming reminders, etc.). Consider using a visual card or agreed upon hand signal to suggest they "take space," as instructing them with your words may be more upsetting for them.

DISTRACTION

If your child is feeling worried or overwhelmed, rather than focusing on a worry that you have already discussed (and therefore making it a bigger worry), it can be helpful to use distraction. The best types of distractions are talking, joking around, or doing a favorite activity, but watching TV or doing something else passive can help too.

BREATHING EXERCISES

Deep breathing helps your child relax by slowing down their breathing, heartbeat, and blood pressure. Encourage your child to take a few slow deep breaths into their belly, breathing in through their nose and out through their mouth. They can place their hands over their belly to check that it is rising with every in-breath and falling with every out-breath. Do this deep breathing for two minutes or more each time. With practice, you will be able to count slowly to 10 or higher with each breath.

EXTRA TIPS: For younger children, you can draw or print off pictures of flowers (to prompt inhales) and bubbles (to prompt exhales), or you could use physical objects such as bubbles or pinwheels to encourage kids to take deep breaths. Seeing a physical product of their breath sometimes helps. Children may also like the "Stop, Breathe, & Think Kids" app or Cosmic Kids Yoga YouTube.

GUIDED IMAGERY

Ask your child to imagine that they are in a calm, peaceful environment or to remember a pleasant experience from their past. If they have trouble thinking of a scene, they can imagine being on a calm beach. Encourage your child to describe what they see, as well as any smells, sounds, or other sensations. There are online scripts that you can print and read to your child. You can also access meditation and sleep stories that you can play for your child using a smartphone or other mobile device, for example: “New Horizon” on YouTube or in the App Store.

LEADING BY EXAMPLE

Let your child hear or see you successfully manage your emotions (even if this doesn’t always feel true!). By letting your child see that you also have big feelings and that you can handle them, you are showing them that it is possible to cope and that you can help them do so. For instance, "I have some worries too, but we do not want that to stop us from having fun and doing the things we need to do. We are safe. Let's take some deep breaths and do it together."

WORRY TIME

If worries are getting in the way of expected and preferred activities, you can try designating a 5-15 minute “worry time” when your child is encouraged to think about and discuss their worries with you. When your child brings up a worry outside of this time, assure them that there will be time to discuss it later. “Worry time” should be scheduled at the same time each day, so your child knows when to expect it. A visual timer may also be used to let your child know how long it will last. Avoid scheduling worry time near bedtime.

STRATEGIES

For Responding To Behavioral & Cognitive Changes In Your Child

Responding To Behavioral Outbursts Or Tantrums

Tantrum behaviors and increased irritability can be more common when first coming home from the hospital. If your child is in the midst of a tantrum, it can be hard to redirect them. Below are some things to try in those moments:

GIVE SPACE

Let your child calm down on their own and rejoin the group after they are calm. You may direct them to a designated coping space, if they have one.

TALK LESS

Reduce all verbal language and do not try to reason with your child. Instead, either give them time and space to calm down by themselves or direct them to coping strategies (e.g., breathing, etc.) using as little verbal language as possible. Wait until they have completely calmed down before discussing the trigger for the outburst.

STAY NEUTRAL

As much as possible, caregivers and siblings are encouraged to remain neutral during your child's outbursts. This decreased emotional response will help these incidents decrease over time.

Providing Comfort

After coming home from the hospital, your child may seek comfort from you more often.

SOCIAL SUPPORT

Increase time with family and friends. By staying involved with loved ones and in normal activities, you are communicating to your child that things are OK. You may have to switch up the types of activities your child does with friends based on their stage of recovery, but still having time with friends can help them feel less left out.

REASSURE SAFETY

Remind your child that they are safe – verbally and physically (giving extra hugs). Answer their questions in honest and simple, child-friendly terms.

STRUCTURE

Your child will respond best to a home environment that is structured, predictable, and routinized. As much as possible, try to keep items in the same place every day (i.e., have a special place for your child's belongings).

ROUTINES

Daily morning and evening routines should be developed to help make the day more predictable, Many children benefit from visual schedules outlining these daily routines and the child's responsibilities (e.g., put on clothes, eat breakfast, brush teeth). Visual schedules may include written lists or pictures. It may be helpful to create a tracking system so that your child can record and track which steps have been completed each day. For more information on creating a visual schedule, visit: https://do2learn.com/picturecards/howtouse/reminderstrips.htm

GIVING INSTRUCTIONS

Make sure your child is looking and listening to you before talking with them. Present new information at a slow pace and allow your child plenty of time to process what you said. Repeating yourself right away while they are still processing can actually interfere with their ability to process and respond effectively. However, if your child does not respond within 10-15 seconds, repeat yourself word-for-word first and then try rephrasing if they still do not seem to understand. Using gestures, demonstrations, and physical guidance when delivering an instruction will be helpful.

BREAKS

Your child may have lower stamina for schoolwork as they are healing. It may be helpful to have shorter work periods and longer breaks.

REMINDERS

Your child may need more repetition and review as they are healing. Whenever possible, provide visual cues and reminders, such as pictures or a checklist.

SCHOOL SUPPORT

Many families find it helpful to inform the school about their child's hospitalization and recovery process. Some children return to full-time school right away, while other children slowly work back up to attending school full time. Many children do best with temporary supports, such as additional breaks or opportunities to rest in a quiet area, extra time on tests and assignments, and reduced workload.

CARING FOR THE WHOLE FAMILY

Many families who have had children in the PICU tell us that hospitalization is an intense emotional experience for the whole family and can have an impact even after coming home from the hospital.

Taking Care Of Yourself

It is normal to feel overwhelmed and worried about your child's health after leaving the PICU. Taking care of yourself and your emotional needs will help your whole family adjust to life again after the hospital.

MAKE TIME FOR YOURSELF

Exercise, sleep, read, write, see friends- whatever you usually do to take care of yourself.

USE YOUR SUPPORT SYSTEM

Connect with friends, family, spiritual/religious leaders, and/or communities you belong to. Your support system can be there to help you talk about what your family has been through, find moments of joy, and offer a helping hand. Ask for help when and if you need it. This may mean help with meals, yard work, errands, babysitting, or a listening ear.

GIVE YOURSELF SOME GRACE

Note your own feelings or reactions. Be patient with yourself. Take small steps to cope. Many of the coping skills listed in the **EMOTIONAL STRATEGIES (P. 11)** section can also be useful for you!

SEEK HELP, IF NEEDED

Be aware of your own unhelpful coping or stress responses. Seek help from your doctor if you are having trouble reducing stress and getting back to normal routines, not getting enough sleep or food, and/or are using harmful coping mechanisms like drugs or alcohol.

Taking Care Of Siblings

Seeing or learning about a sibling's illness/injury and medical interventions can be scary for children during the hospital stay. Even after leaving the hospital, siblings can have worries about their siblings', caregivers' and their own health and safety.

CONSISTENCY

Keep normal routines as much as possible. Set normal limits and expectations for sibling behavior.

ATTENTION

Spend time with your children who were not hospitalized. Provide opportunities for them to have fun. Some families have challenges when siblings can engage in activities that are temporarily off-limits to the child who was in the PICU (like running, climbing). It can feel unfair to restrict siblings' activities, so instead try to find special ways for your recovering child to participate or play safely.

TALK OPENLY

Encourage, but do not force, your children to share their feelings and concerns with you. Give age-appropriate information and answer questions your child has about their sibling's illness/injury. Also share optimism with your family by highlighting signs of recovery and discussing how the doctors decided to have your hospitalized child go home because they are healing.

OTHER RESOURCES

Contact Us

If you have questions or need assistance/advocacy regarding any physical, neurological, emotional, behavioral, cognitive, or social aspects of your child's ongoing recovery, you should contact the Critical Care & Neurotrauma Recovery Program (**503-494-5522** for **Dr. Williams**, **503-418-2134** for **Dr. Hall**, or email **picubrains@ohsu.edu**). The team is available as a resource for your child whenever you might need them. More information about our team can be found at **https://www.ohsu.edu/pediatric-critical-care-neurotrauma-recovery-program.**

Contact Social Work

We acknowledge that some families may also be dealing with other priorities like securing stable transportation, housing, childcare, and food. The Information and Referral Line for Community Health and Human Services can be reached at **503-222-5555** (**www.211info.org**) for financial assistance with resources (e.g. food, health care, employment).

Doernbecher Children's Hospital also has social workers available to help families gain access to resources (such as transportation vouchers and a room at the Ronald McDonald House to ensure you can make your appointments). You can reach out to them while your family is still in the hospital by asking your inpatient team about a referral to Social Work for psychosocial support and referrals.

You can also reach out to **Alexis Black**, the PCCNRP social worker, at **503-494-6758** or blackale@ohsu.edu.

Online Resources Available At Any Time

- Websites with more information on supporting children and families after critical illness:
  - **www.afterpicu.com**
  - **https://www.aftertheinjury.org/**
  - **http://copingspace.org/**
- Websites with more information on brain injury:
  - Brain Injury Alliance of Oregon **https://www.biaoregon.org/**
  - Brain Injury Resource Center of Washington **https://www.biawa.org/**
- OHSU Oregon Family-to-Family Health Information Center **https://www.ohsu.edu/oregon-family-to-family-health-information-center**

Recommended Children's Books

Arnie's MRI

Arnie the armadillo falls off his bike. Since he wasn't wearing a helmet, he hurt his head and must undergo an MRI. Nervous about the whole process, Arnie overcomes his fears after the hospital staff turns the exam into an adventure. The end result? Arnie (and readers) learn why wearing a helmet is a must.

Access the book online here:
https://pdfslide.tips/documents/arnies-mri.html

I See You, Little Naomi

This book is about a survivor of pediatric stroke. Her story will introduce children to the world of special needs and that it's okay to be curious about others who may look or act differently.

Elvin the Elephant Who Forgets

After a tree limb falls on young Elvin the elephant's head, he has difficulty remembering how to count, is bothered by noise, and feels frustrated and sad. He sees a neuropsychologist and comes to understand his injury and to realize he is still special.

Access the book online here:
https://fb.watch/gFcI5NAR_3/

Mimi Learns to Walk

The "Mimi" Books are based on a mother's own experience helping her daughter. They feature a young girl who is just like everyone else except that as a baby she suffered a stroke.

Access the book online here:
https://pdfslide.tips/documents/arnies-mri.html

A Kid's Guide to Brain Injury

A resource designed to answer common questions children have about the brain and address common concerns and fears about brain injury. The content is geared for children ages 6 to 14. It may be helpful to read this book with your child, their siblings, other family members, or friends.

Access the book online here:
https://headway.ie/our-publications/kids-guide-brain-injury/

For Siblings & Other Family Members

The Road Ahead--Next Exit: Hope

Siblings also need help understanding their feelings when a family member has a brain injury, and this book does just that. Suited for kids ages 5 – 10, this book features puzzles, mazes, and other interactive tools to help children express themselves.

Access the book online here:
https://fvbia.org/the-road-ahead-next-exit-hope-2/

References

https://www.sccm.org/myicucare/resource-library

https://icusteps.org/assets/files/translations/english.pdf

http://www.afterpicu.com/

http://www.aftertheinjury.org

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