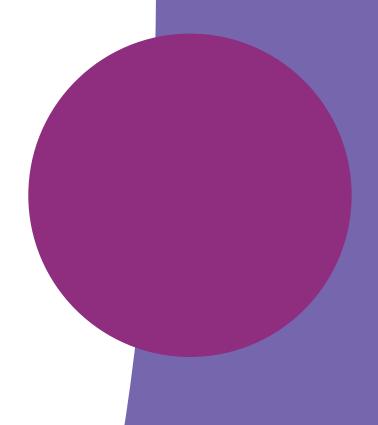


What's Inside:

| Common Hospital Challenges by Age | 4 |
|---|------|
| Common Questions | 8 |
| Creating a Connection Between Hospital and Home | 12 |
| Activities to Encourage Connection | . 13 |
| The Next Step | 15 |
| Glossary | 17 |
| Human Anatomy | . 18 |
| Taking Care of Yourself | . 19 |
| Additional Resources | . 19 |





Dear Caregivers,

Having a loved one stay at the hospital can be hard for everyone involved. We know families often worry about the best way to help their children during these times. It's common for children to ask questions that you may not be able to answer. They will also express their feelings in a lot of different ways.

At Intermountain Health, we want to provide the best care to our patients as well as their families. This guide will help your family find information on how to help your child when someone they love is in the hospital. Common questions adults and children ask are also answered.

This guide is written in sections to make it easy to use. Keep it close to look at when ideas are needed. We hope you will find it helpful as you find ways to best support your child

during this time.

Sincerely,

Your Medical Team



Common Hospital Challenges by Age

Every child is different and sees the world in their own way. Based on their age, children may show some common reactions to a loved one being in the hospital. For example, a baby may not know why their loved one is not at home, but they will still be aware that they are gone. Or, an older child who is feeling stress may act like a younger child. In this section, common responses are listed by age group along with ideas to help support each child's unique needs.

Infant to 2 years old

During this time, children form bonds with their family members. They trust that their needs will be met. Any change in routine can challenge their sense of trust and safety. Your child may:

- Have more temper tantrums.
- · Stop using newly-learned skills.

What may help

- When possible, create a dependable schedule.
- Choose a regular caregiver for your child.
- Offer simple explanations in words they already know. Be specific. "He is hurt and is getting help."





2 to 6 years old

Children in this age group usually do not have the words to tell you how they feel. Instead, they may act out by crying, yelling, hitting, or having a temper tantrum. Watch for signs of how your child is feeling. Your child may:

- Respond strongly to being away from their family member.
- Think they caused their loved one's illness.
- Make up stories about why their loved one is in the hospital when they do not know the reason.
- · Worry that they can "catch" the illness.
- Feel angry when they are not able to do what they want to do. They like to do things by themselves.
- · Worry about who will care for them.
- Change their behavior. They may wet the bed or go back to "baby talk."
- · Give your child the time and space to play, create art, or act out stories. This can help them understand what has happened and share their feelings.

What may help

- Find time to focus on your child and spend one-onone time together.
- Remind them that they did not cause this to happen.
- Learn more about what your child knows by asking questions like, "What have you heard about _

Remind your child often that they did not cause this to happen.

Include your child in decisions that affect their life. When possible, let them decide when to participate, what to wear, and who to be around.

What may help

- Keep to your child's routine. For example, they may still want to go to soccer practice after school.
- Encourage your child to ask questions and be involved in their loved one's care.
- Talk with your child about their feelings. Listen without judgment. Explain that it's okay to feel unhappy, sad, or angry. If you share your own feelings, they will be more likely to share their own.
- · Give them a 'job' to do to help them feel a sense of control and accomplishment.



6 to 12 years old

Children in this age group value their independence. Having a loved one at the hospital may cause changes in their day-to-day life. This can bring about complicated feelings such as jealousy, fear, and anger. They may not know how to act or talk about these feelings. They may act silly or try to hide their emotions. Your child may:

- Feel guilty or responsible for their loved one's illness. They may think that their thoughts made this happen.
- Worry about:
 - Being "normal."
 - Becoming sick or injured themselves.
 - Who is going to take care of them.
 - Choose to not listen or follow through with requests.
 - Feel self-conscious. They may separate themselves from family and friends.
- Fear:
 - Losing their loved one.
 - For their own safety and that of other family members.

12 to 19 years old

Teenagers may appear to be handling this experience like an adult. Or, at times, they may act their age. Either way, they need to feel safe and that they have some control of their situation. Your teen may:

- Fear a loss of identity (for example, their role as a brother or sister).
- Be concerned about how this will affect themselves and their world.
- Feel angry when they cannot do the things they normally do.
- · Worry about being different and losing their friends.
- Hide their feelings.
- Seem overly upset about an unrelated problem.
- Feel pressure to act like an adult or take on more adult responsibilities.

What may help

 Help your child understand their feelings and what others are feeling. Explain that their emotions are normal and expected. Share your own feelings.

Include your teen in making decisions.

Listen to their concerns and answer questions.

• Encourage them to spend time with their friends.

· Help them find friends or adults they can talk to about what is happening.

Respect their independence and provide privacy.

· Don't expect them to act like an adult.



Common Questions

Many caregivers are concerned with how to talk about a loved one being in the hospital. Here are some general tips:

- Be open and honest. It is best for children to get this kind of information from an adult they trust, rather than hearing it from someone else. When talking with children, do not make promises you or the doctors cannot keep. Avoid using the phrase "everything will be fine" when a situation is unknown.
- Use simple language. Use wording that is easy for your child to understand. Ask what level of detail they would like to know. Some children want to know all the details. Others may only want to know general information. For instance, they might want to know whether it was a good day or bad day.
- Let the child guide the conversation. Some children will ask questions, while others will remain quiet. One child may appear unaffected by the conversation, while a different child may burst into tears. These are all normal reactions. Follow your child's pace.

"I hope I worry statements are a caring way to introduce hard topics.



Common questions parents ask

Q. Is it okay for a child to visit the loved one at the hospital?

- · Yes, it is okay and is often helpful for children to visit the patient. Before visiting, check with the medical staff regarding rules for visitors. If your child is not able to visit the hospital at this time, you could schedule a video chat with their loved one.
- If the hospital allows visitors, give your child the choice to see their loved one. If they do not want to visit, that is okay. Encourage them to express their feelings and ask them if they would like updates.

Q. How do I prepare a child for a hospital visit?

 Use simple and honest information. It can be helpful to show your child a picture of their loved one ahead of time. This helps them get ready for what they will see on their visit. You can use the glossary on page 22 to help explain the things that they may see in the photo. You can also ask if a child life specialist is available to help prepare them.

Q. How do I start a hard conversation?

 Start by asking your child questions. This will help you know how much they understand and correct any misunderstandings. "Do you remember why [NAME] is in the hospital? Can you tell me?"

O. How do I make it clear that the situation is or could become serious?

• Use "I hope but I worry" statements. For example, "I hope that the medicine helps their body get stronger, but I worry that they may continue to get worse."



Q. What if I don't know an answer to a question my child asks?

 It is okay to say, "I don't know." This helps children understand that adults do not know the answers to everything. You could say, "I do not know the answer to that, but I hope that happens." Or, "I do not know the answer. What do you think it is?" Or, "I do not know the answer to that, but the doctors are working to find the answer. I will let you know as soon as I know more."

Q. Should I express my emotions in front of my children?

 Yes, expressing your emotions in front of children will help them understand that it is okay for them to express their own feelings in front of you. You can discuss with them what you do when you feel a certain way. For example, "I am really sad that [NAME] is in the hospital. When I feel this way, I like to listen to my favorite song." Or, "I feel angry so I will take a few deep breaths."

Common questions children ask and suggestions for responses

Q. Why are they in the hospital?

 "They are in the hospital because their body is not working like it should and they need extra help from the doctors and nurses."

Q. When will they come home?

 "I don't know. The doctors and nurses are doing everything they can to help [NAME] come home as soon as possible. I will let you know when I find out."

Q. Can I see them?

• "Yes. There are a few things that I think you should know first..." Describe what they will see in the room and how their loved one will look. Talk with your hospital to see what the rules are for hospital visits. If children are not allowed to visit in person, you can schedule a video chat with their loved one.

Q. What are all the things on their body?

Refer to the glossary on page 22.

Q. Do you care about them more than me?

• "I do not care about them more than you, but right now, they are very sick and so I am with them more. Do you want to plan something for just you and me to do together?"

Q. Did I make this happen?

• "No, you did not make this happen. This happened because their body needs extra help." If your child is seeking more information, you can explain in more detail the specific reason that the person is in the hospital.



Q. Is this going to happen to me? Will this happen to someone else I love?

- "I hope that this will not happen to you or someone else you love."
- "This is not something you 'can catch' or get by touching or being in the same room with your loved one."
- Explain again why this happened to the loved one.

Q. Are they in pain?

 "The doctors and nurses are doing their best to keep [NAME] comfortable, so they are not in pain."

Q. Who is going to take care of me?

 Right now, [NAME] will take care of you. You can always call me when I am at the hospital if you would like to."

Q. Are they going to die?

- "It is okay to worry about that, but we don't think that will happen. The doctors and nurses are working very hard to keep it from happening."
- If there is a chance their loved one will die, you can say, "I hope not, but I do worry because they are very sick. The doctors and nurses are doing everything they can to help their body."

Talking about emotions

During times of change, children may feel angry, sad, happy, or afraid. They may worry about what is happening or feel stressed. Talking with your child about their feelings can be helpful. Consider the following:

- Listen without judgment. Give your child time to talk with you about how they feel. Let them know what they are feeling is normal and that change can be hard.
- Be honest about your own feelings. When you talk with your child about your own feelings, you help them know that it is okay to feel the way that they do.
- Create a safe space for expressing emotions. Help your child feel safe to express their feelings.
- Make time for play. It is important for children to have time to play and participate in activities. Children use play to learn, grow, and express feelings.

- Help your child express their emotions in a safe and healthy way using activities like writing in a journal, playing games, listening to music, or making artwork.
- Create a coping plan. Ask your child what would be most helpful for them at this time.
- Let your child know they are not alone and that you will be there to listen, answer questions and help them with whatever they need.



Creating a Connection Between Hospital and Home

Families often wonder how to help their child stay connected with their loved one while they are in the hospital. Ask your child what they think will be most helpful for them. Here are some ideas that have helped other families:

Activities for your child to do for their loved one

- Draw a picture or write a letter for your loved one.
- Collect items from home to bring to the hospital.
- Make an "All About Me" poster for your loved one. Include fun facts about them.
- Make a music playlist for your loved one to listen to at the hospital.
- Deliver a letter or package to the hospital.
- Record a video for their loved one to watch at the hospital.

Activities to do from home with their loved one

- Read the same book over the phone together before bedtime.
- Watch the same TV show or movie at the same time.
- Talk on the phone or video chat.
- Print out some of your favorite photos of the loved one.

Activities that your child can do while they are visiting their loved one

- Decorate their loved one's room with pictures, letters, cards, or drawings.
- Watch a TV show or movie, read a book, or play a game together.
- Tell your loved one your favorite memory with them.
- Hold their hand.
- · Paint your loved one's nails or brush their hair.

A few more ideas

- Find an item of the loved one for your child to borrow, sleep with, or take to school. It can be a piece of clothing, a photo, stuffed animal, or blanket.
- Create memory-making items at home and at the hospital (see activity ideas in guide).



Activities to Encourage Connection

Heart paper chain

Materials

- Construction paper
- Glue, staples, or tape
- Scissors
- Markers or crayons

Directions

- 1 Cut construction paper into strips.
- 2 Draw a picture or write a message to your loved one on each strip of paper.
- 3 Fold the paper together in a shape of a heart.
- **4** Staple, glue, or tape the bottom and the top of the papers together.
- 5 Repeat steps, attaching hearts to each other.

Thumbprint hearts

Materials

- Air dry clay or Model Magic
- Book or clipboard
- Paint and brushes

Directions

- 1 Form clay or Model Magic into a ball shape.
- 2 Use a book or clip board to flatten the clay into a circle.
- 3 Press thumbs into clay to form a heart.
- 4 Let clay dry for 24 hours. Once dry, you can paint the clay.









Handprint art

Materials

- Construction paper
- Washable paint and markers
- · Paint brush or foam brush

Directions

- 1 Put paint onto hand.
- 2 Place hand onto paper at an angle to make heart.
- 3 Repeat steps 1 and 2 with the other hand to complete the heart.
- 4 Draw a heart with markers around handprints.

Picture collage

Materials

- Construction paper
- Pictures or magazines
- Glue or mod podge, and paint brush

Directions

- 1 Look through magazines and find pictures that represent your loved one.
- 2 Cut pictures and organize them on paper.
- 3 Glue or mod podge pictures onto paper.



The Next Step

Families often ask, "What is the best way to help my child when their loved one leaves the hospital?" See the following steps to help make this transition easier.

Prepare your child for what to expect

Children often cope better if they know what to expect. When talking with your child about change, use simple explanations. Listen to what they have to say and answer questions openly and honestly.

 When possible, prepare your child for routine changes or a new schedule.

 Use simple words to explain new medicines and machines they may see in the home.

 Introduce your child to any new people who will be coming to your home. Let them know why they are there.

 Let your child know who will be caring for them if they need help.

 Explain that their loved one may look different and tell them what to expect.

 Discuss any rules that may be needed to keep your child and their loved one safe.

Allow your child to ask questions. They may ask questions right away or later, after they've had time to think things through. They may even ask the same questions again and again. Asking questions is how children make

sense of their world.



Give your child choices to help them

feel in control during

this time of change.

Adjusting to a new normal

Create a plan with your child. Children need a daily routine they can count on to help them cope with change. You can help your children adapt to new things by:

- Maintaining the same routines when possible.
- Scheduling activities your child enjoys.
- · Setting normal boundaries.
- Talking with teachers and counselors about what is happening in your family.

Other things you can do

- Help your child practice how they want to answer questions their friends may ask them.
- Make time for your child to see their family and friends.
- Give your child the choice to help plan the family's weekly schedule.

Although there may be a lot of changes going on, one thing has not changed. You know your child best. Together, you can find success as you make plans to help your family manage the





Coping with loss and grief

If your loved one is not coming home, there are things you can do to help your child with the loss and grief they are experiencing. Saying Goodbye is an Intermountain Health booklet that can help children and families during this difficult time. Please speak with your social worker, case manager, or child life specialist for a copy.

Glossary

When explaining medical terms to your child, use simple and easy to understand words.

Aneurysm: A small bubble that is formed on a patient's blood vessel. Blood vessels are like small tubes that move blood around our bodies. When the blood vessel is weak, it makes a bubble at the weak spot.

Cancer: Sick or unhealthy cells that grow quickly and take over healthy cells. Cells are a part of everybody's body. Doctors and nurses use medicine and treatments to fight the unhealthy cells.

Chest tube: A tube that takes away air or water around a patient's lungs or heart.

CT: A type of picture taken of a patient's body using a large circle camera.

ECMO: A machine that helps a patient breathe. It also pumps their blood when their body is very sick. Electrodes: Small stickers on a patient's chest record how the heart is beating.

Foley bag: A bag that helps catch pee when a patient is unable to get up and use the bathroom.

Incision: A small opening made during surgery. The opening is closed when the surgery is finished. Intubation/breathing tube: Soft tube that goes in the patient's mouth into their lungs that helps them breathe.

Isolation: Wearing gloves, masks, or gowns to keep a patient safe and healthy.

IV: A small straw that is placed inside a patient's vein that helps nurses give patients medicine quickly.

Monitor: A computer screen that shows how a patient's heart and lungs are doing.

MRI: A type of picture taken of a patient's body that shows more details.

NG tube: A soft tube that takes medicine and food directly to a patient's stomach.

Oxygen: Air to help a patient breathe better. This air comes through a soft tube or mask.

Pulse oximeter: A sticker or plastic clip placed on the patient's finger to show the nurses how much oxygen (air) is in the blood. The sticker or clip has a red light to show the nurses that it is working.

Restraints: Soft bracelets that keep a patient safe.

Surgery: When a patient is given anesthesia (medicine to fall asleep), the doctor will check or fix the part of the body that is injured or sick.

Stroke: When blood stops flowing to a part of the patient's brain.

Trach tube: A small tube in a patient's neck that helps their body breathe.

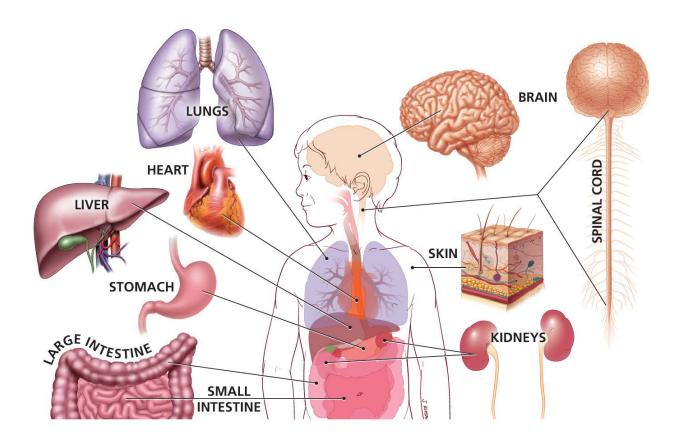
Traumatic brain injury (TBI): When a patient hurts their head very badly, it may change the way they move, think, and talk.

Ventilator: A machine that helps give a patient air to breathe through the breathing tube in their mouth, neck or nose.

PICC: A long soft tube that is placed inside a patient's vein that gives a patient medicine for a longer amount of time.

G Tube: A small tube that goes into a patient's stomach to give them food or medicine.

Human Anatomy



Brain: The brain controls how the body works. It's in charge of everything you do like breathing, digesting food, talking, and sleeping.

Spinal cord: The spinal cord sends messages from the brain to the rest of the body.

Lungs: The lungs bring air in and out of the body for breathing.

Heart: The heart moves blood throughout the body.

Liver: The liver cleans blood.

Stomach: The stomach breaks up food in the body.

Small intestine: The stomach sends food to the small intestine. The small intestines absorb the healthy parts of food.

Large intestine: The large intestines take water out of the food and make poop.

Kidney: The kidney takes out waste from the body and turns it into pee.

Bladder: The bladder stores pee until we use the bathroom.

Skin: The skin covers the entire body and protects it.

Taking Care of Yourself

Caring for a child while a loved one is in the hospital can be difficult. Remember to take care of yourself. When you manage your own stress, you'll have more energy and stability to offer your child. And you'll be a better role model for your child of how to cope. Here are some tips:

- As you provide care for your loved one, remember to take one step at a time.
 There are many unknowns in a Health journey. Taking time to recognize this and giving yourself grace will help you manage this hard time.
- Stay healthy. Eat as well as you can and get exercise.
- Make time to be alone.

- Ask your hospital staff about ways to stay connected that support your family.
- Ask for help from friends, family, and even professionals when needed. Reach out to your medical team to talk more about the topics discussed in this guide. We are all here for you and will support you through this experience.

Additional Resources

Books for caregivers

Caring for Well Siblings, Let's Talk About pamphlet available through Intermountain

How to Help Children Through a Parent's Serious Illness — Kathleen McCue

Helping Children Cope with Separation and Loss, Claudia Jew Jarratt

When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change, Marge Eaton Heegaard

Books for young children

Cuddle Bear, Claire Freedman and Gavin Scott
The Invisible String, Patrice Karst
The Kissing Hand, Audrey Penn

Books for children with ill siblings

When Molly Was in the Hospital: A book for Brothers and Sisters of Hospitalized Children, Debbie Duncan

What About Me? When Brothers and Sisters Get Sick, Allan Peterkin

Hi, My Name is Jack: (A Book for the Healthy Siblings of Chronically III Children), Christina Beall-Sullivan





