

Children Visiting the Intensive Care Unit

A Child Life Program Resource for Caregivers



Everyone in the family, including young children, will sense and be affected by the serious illness of a loved one.

Many times, parents' or caregivers' first instinct is to keep children at home to protect them from the situation. Adults may believe that children are too young to understand, or, adults may feel that they don't know how to share information with children about critical illness. If you are worried, under stress or anxious, chances are your children sense that and may worry or imagine the worst. If you are planning a visit, taking time to talk with children and prepare them prior to visiting a loved one has the potential to make a positive impact in a child's ability to cope.

Child Life Specialists are available, during business hours, to help in sharing information regarding what children might see and hear, offer additional developmentally appropriate descriptions of medical information, and provide assistance with coping and support.

For support, contact the Child Life Program at: 603.650.8831

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What children need during times of stress

- Contact with a parent or other close caregiver
- Simple, age-appropriate and honest explanations of what happened and what is happening, with frequent updates
- Reassurance and physical comfort
- Consistency in routine and limits
 - Bed time
 - Nap time
 - Attending school or daycare
 - Meal times and food choices
 - Maintain rules and expectations of behavior
- Special time set aside just for them
 - Read a book
 - Complete a project together
 - Do an art activity
 - Go for a walk
 - Have a meal together
- Time to talk about or play about their experiences
- Inclusion in family to help in feeling like they are a part of the process
 - Regular updates using words that are easy to understand
 - Planned and unplanned time to talk about questions or worries
 - Phone calls, Face time, Skype or other time planned for the family to connect

Sharing Information with children about the hospitalized person

Being honest does not necessarily mean telling children every detail – it does mean never sharing anything but the truth. Children can imagine worse things than the truth, often making up their own reasons for what happened, what is happening, and what will happen.

When you begin to share information, read the child's cues when a question may arise or if a break is needed.

Planning what to Say

- Tell them that the patient is ill or hurt
- Tell them the name of the illness or injury and what that name means or what the current injury or illness is (including what part of the body is affected)
- Tell them how the patient looks if it is different than the last time they were together (i.e. bruises, swelling)
- Tell them your best understanding of what may happen

Consider what to say when you are uncertain about the future

Talking about a loved one's illness to children may be particularly difficult when the illness or injury is life-threatening and the future is uncertain. How do you tell them your best understanding of what may happen when you don't know? Many parents and caregivers have found the following words helpful:

- 'We're really, really worried...the doctors and nurses are doing everything they can to take care of (the patient). We hope that...'
- For some parents, it may be easier to say: 'The doctors and nurses are very worried...they are doing everything possible to take care of (the patient)...they hope that...'

Be honest when you may be scared or uncertain about the future.

Questions to ask that can help children talk

Open-ended questions

- 'What kind of questions do you have?' is very different than 'Do you have any questions?'
- 'What do you think will happen?'
- 'What do you think is the best (or worst) thing that could happen?'
- 'What are you wondering about?'

When you are concerned about a specific behavior

- 'I've noticed that you're not eating much lately, and that's not like you. I think there is something on your mind...'
- 'Lately, you've been getting angry about things that don't usually bother you. Why do you think that is?'

Multiple choice

'I've heard lots of kids who have someone they love in the hospital worry that...' then offer several likely possibilities (such as, it could happen to them, they won't be able to do the things their friends are doing, etc.) Ask, 'What has this been like for you?'

Deciding if your child(ren) should visit

Visiting an Intensive Care Unit or even an Intensive Care Unit waiting area can be an overwhelming experience for an adult. Careful thought should be given to decide if it is appropriate for the child to visit.

Remember that a visit to the hospital can be many things

- Eating in the cafeteria with a loved one
- Being present in the waiting room with family
- A visit at the bedside
- Playing at the playground or at the Family Center (Molly's Place)

Questions to consider before a visit

- What is the goal of this visit?
- What are the ages of the visiting children?
- What do they know about the hospitalization? What do you think they understand?
- How does your child usually handle stress? (Are you seeing any of those signs right now?)
- What do you think your children's ideas are of what their loved one is like right now? Which do you think is worse – their ideas or reality?
- How did your children learn that their loved one was in the hospital? Did they witness anything difficult related to the hospitalization, such as their loved one becoming injured or ill or seeing their sibling leave in an ambulance or helicopter?

It is also important to consider your needs and how a visit to the hospital may affect you. Some families have shared the feeling of being conflicted in trying to balance the attention of the child (ren) visiting and the attention of the person who is hospitalized. The reaction of the child (ren) at the visit may also impact your own emotions.

What to consider before planning a visit

Check with the nursing staff before a visit

Never force a child to visit

If a child does not want to visit, offer alternatives for visiting:

- Making a card or poster for the patient's room
- Drawing a picture
- Writing a letter or recording a message to the patient
- Helping to make a Care Page
- Creating a music playlist

Prepare the patient for the visit

Consider using photos in this preparation.

Photographs can aide in preparing a child for what they might see, giving time to talk about what they see in the picture and ask questions before going into the hospital room. Pictures can also help children (and adults) be less sensitive to the changes in the patient's appearance and the medical equipment when going into the hospital room if they know what to expect.

Help the child know in advance the things they might see and hear

- Describe what the child might see in the hallway (example: other patients and families visiting, people in wheelchairs, doctors, nurses...)
- Describe changes in the patient's appearance from the last time they may have seen them
- Describe equipment
 - Machines
 - Tubing
- Describe the different sounds they might hear in the patient room (alarm beeping, blood pressure cuff inflating, etc.)
- Describe people they may meet or see in the patient's room

Remember that the visit is for the child – be there to support and guide the child and answer any questions as they come up.

Developmental Considerations

Children's development plays a part in how they understand and process events and information. The following section includes information about thoughts, fears, and feelings common in children of various age ranges, as well as possible responses or ideas to address these developmental needs.

Preschool Children

Believe that their thoughts, actions or wishes caused the accident or illness.

Learn from children what they believe made their loved one sick or injured, then address any basis for unnecessary guilt... 'Lots of kids think that, but it rarely happens that way.'

Fear that this will happen to them too

- Help the child understand that this will not happen to them, if that is accurate
- If the patient was involved in a trauma, ask what can be done to prevent that kind of accident
- Feel anger and/or a sense of abandonment with separation from parents or caregivers during stressful times. They may believe that they deserve punishment or that further abandonment will result.
- Ask, 'How has it been for you while your family spends time here at the hospital?' Acknowledge and accept their feelings
- 'If you were in the hospital, where do you think your parents would be? What do you think your parents would do?'

Believe that staff members are hurting their loved one

- Say, 'The nurses' and doctors' job is to help stop the hurting, or keep it from getting worse.'
- 'Here is how the nurses and doctors help...'

Have a limited understanding of internal bodies and how they work

- Use pictures of children's body books
- Ask the children to draw what they think or imagine

Are prone to invent their own explanations when there are gaps in communication. Their explanation of the illness or injury may have nothing to do with reality.

Provide honest, accurate information, updating as necessary due to changes in patient's condition or due to child's needs

School-age Children

Wonder if something they did caused the illness or injury. 'If I had done something differently, this wouldn't have happened.'

- Ask, 'What makes you think that?'
- Explain, 'Lots of children think that, but it rarely happens that way.'
- Give concrete examples: 'If you wished this object to fall, could you make it happen?'

Worry, 'Can I catch it?' and may not want to touch or go near the patient

- Ask, 'Do you think that you can catch this from touching?'
- Explain, 'We wouldn't let you touch him or her if that would happen. We know that it doesn't happen that way with this.'

Wonder, 'Will the patient be the same?'

- Possible responses:
 - 'We hope so.'
 - 'The nurses and doctors have seen some (or many) people who have been sick (or hurt) like this and who have gotten better.'
 - 'He (she) needs lots of help to get better.'
 - 'It may take a long time.'
 - 'We are not sure that all of the parts of his (her) body will work the same way. We can hope that they will.'
 - 'We are very worried and the doctors and nurses are doing everything they can to take care of him (her).'

Adolescents

It is likely that there are things on their mind even if they don't tell you

- Offer times to ask questions or share what they are wondering

Likely to have a sense that they are being watched

- Provide privacy, as appropriate. Ask if they prefer to be alone or have family or staff close by

Help the adolescent visitor share what they know about the patient.
Learn from them what the patient likes or dislikes

May talk in medical jargon without fully understanding meanings

- Ask what they understand about what is going on. Reassure them that there are adults who don't understand many parts.
- Ask, 'What does that mean to you?' if they use big words or medical words

Preparation for a child's visit to the hospital

The patient's condition should be explained in an honest and simple way to the child so that the interpretation is not left up to the child's imagination (Examples: 'The patient is not able to breathe on his or her own right now, he/she has a tube that is helping to breathe for him/her'; 'The patient is getting a lot of medication to help with _____')

Show a recent picture of the patient outside of the hospital and talk about what might look different during the visit

When possible, use a photograph (taken in the hospital room) to aid in preparing children for what they will see and experience at the bedside.

Briefly describe only the medical equipment that children will see and/or hear

- Talk about the monitor alarm bells and sounds during your descriptions
- Think about how tall the child is and what the child might see when walking through the hallway to visit their loved one

Encourage brief visits.

Tell children in advance the length of the visit and what they will do when they leave. (Short visits in the patient room of 3-5 minutes are recommended, to start, particularly in critical care settings). The visit can be extended for the benefit of the child visiting.

Help children plan what they will do during the visit.

Prepare with the child what they can do at the bedside. Having a concrete task to do during the visit will help ease possible discomfort of wondering what to do once they get to the bedside and will give children a focus if being at the bedside seems to become too much.

Examples of possible tasks for children to choose to do during the visit:

- Hold the patient's hands
- Rub lotion on the patient's hands/feet
- Hang pictures, drawings or cards
- Brush the patient's hair
- Play the patient's favorite music
- Have a planned transition – make a plan for what to do after leaving the hospital
- Tell the patient a story
- Talk to the patient
- Read a short book to the patient
- Sing a song/tell a joke

Before bringing a child into the patient room

- Plan the visit with nursing staff to help identify the best time of day
- Cover as much of the patient as possible with a blanket for when the child first comes into the room
- Consider the child's line of vision (remember, young children are at a lower height than most adults and will have a different view point)
- Encourage the child to ask questions and share what they are wondering about
 - If they see medical equipment they would like more information about, encourage the child to ask questions when in the patient room (it is okay not to have an answer or to ask staff to help in giving you more information)

During the visit

Give the child time to decide how close they would like to get to the bedside after walking into the patient room. Please do not force children to do anything that they are not comfortable doing. Be aware of the child's cues and body language in addition to what they say during the visit to see if they are uncomfortable and might want to make the visit short or end the visit.

Take a picture during the visit

- A photo of the visit can be something the child takes home with them as he or she is processing and thinking about the visit
- A photo of the visit can also help in extending the child's sense of being together with the loved one and help in making a transition after the visit
- Placing another picture at the patient's bedside can be a statement of the importance of the child's visit

Transition objects (Examples: Photograph, picture, stuffed animal, hand written letter, etc...)

- A transition object can help for the child to trade something with the loved one
- A transition object gives the child something to hold
- A transition object can help a child in feeling closeness to the loved one who is in the hospital

After the visit

Take time to talk with the child about the experience after the visit

- Was visiting the patient easier or harder than he or she thought it would be?
- Was the patient room/hospital the way he/she imagined?
- Was the patient the way he/she thought?
 - If not, what was different?
- Would they like to visit again? If so, what would he or she like to do the same or different than during this visit?

Talk about reasons people come to the hospital

- Scheduled surgery
- Treatment
- Unexpected injury
- Doctor's appointment

Suggestions for explaining medical equipment to children

Bite Block:

Soft, wide 'straw' that rests on the tongue and between the teeth to make sure the patient doesn't bite the breathing tube or her tongue by accident while she is in such a very deep sleep.

Bolt:

Intracranial pressure monitor (commonly called a 'bolt' by staff). Clarify the child's understanding of the patient's condition (head injury or bleed inside the brain) and use comparisons to explain swelling (like when you hurt your leg and a bump comes up, the bump is swelling); 'when someone's head is injured (or there's bleeding inside) like (the patient) , the tube helps the doctors and nurses know if there is any swelling inside (or how much), then they can decide the best way to take care of (the patient)'.

Sometimes it can help to also explain that it doesn't hurt while it's in and the patient was sedated (asleep with medicine) for placement. The outside part is big to help stabilize; the actual tube is quite small.

Central Line:

A small tube that is placed in a large vein (usually in the neck or near the heart). This tube is another way to give fluids, medicine or withdraw blood.

Chest Tube:

A straw placed in the chest to remove collection of air or fluid from the lungs to help the patient breathe better.

Dialysis Machine:

A machine to help take away waste (things that your body doesn't need to be healthy), what your pee normally does.

Electrodes for Electrocardiogram (EKG):

Like band aids or stickers with 'strings' that go to the machine. Together they can feel exactly how a heart is beating and turn it into a 'picture' on the monitor screen.

Electroencephalogram (EEG):

Doctors use electroencephalograms to find out how a brain is working. This machine helps to measure brain waves. Band aids or stickers are placed on the head and connected to a machine using different colored 'strings'.

Extracorporeal Membrane Oxygenation (ECMO):

A machine that helps to support the heart and lungs.

Foley bag:

Collect and measures 'pee' (or other word used as a family). Inside there is a very soft small tube that helps the 'pee' come out. The tiny soft tube connects to the bigger tube that you see. This also helps to keep the bladder empty.

IV pumps and fluids:

IV means 'into the vein'. An IV is a tiny plastic 'straw'. "Food" (nutrients) and medicine go right where the blood travels through with an IV. Through the IV is the fastest and strongest way to help someone get many medicines.

Monitor:

A machine that looks similar to a television – this machine helps the nurses and the doctors see how the patient's body is working. There are lines and numbers on the screen that show what the patient's oxygen level is, how fast his or her heart is beating and other information that will be helpful for the doctors and nurses to know when taking care of the patient.

NG Tube:

This is like a very soft straw that goes in the nose and down the patient's throat to the stomach; to help the stomach stay empty and resting while the body is working to get better; or to give the body tiny bits of food a drip at a time, so the body won't have to work hard.

Oscillator:

A machine that helps to keep the lungs open.

Restraints:

Soft bracelets that will help make sure that the patient doesn't grab or pull a tube by accident, while the patient is so sleepy (or until he/she is more awake).

Rectal Bag/Stool Containment Device:

A place to collect 'poop'. Inside there is a very soft small tube that helps to collect the 'poop'.

Tracheostomy (Trach):

A tube in the neck that helps a person breathe in a different way. An opening is made in the trachea (a long tube in your neck and chest that carries air in and out of your lungs) to allow the passage of air.

Ventilator/Respirator/Breathing Tube:

This helps the patient get enough air in and out; helps the patient take good, deep breaths and get plenty of air while they are asleep or very sore or while the patient's body is working to get better.

REFERENCES:

Adaptations, with permission, from the Harriet Lane Compassionate Care Program at the Johns Hopkins Children's Center

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