



### Supporting Children When Siblings Are Sick

MAYO CLINIC CHILDREN'S CENTER





#### Mayo Clinic Children's Center

For more than 100 years, teams of physicians have cared for children at Mayo Clinic.

### T. DENNY SANFORD PEDIATRIC CENTER MAYO EUGENIO LITTA CHILDREN'S HOSPITAL

#### Pediatric Sub-Specialties in the following areas:

Allergy and Immunology
Anesthesiology
Cardiology
Cardiovascular Surgery
Child and Family
Advocacy Program
Community Pediatrics and
Adolescent Medicine
Critical Care
Dermatology
Developmental and
Behavioral Pediatrics
Emergency Medicine

General Pediatric and
Adolescent Medicine
Gynecology, Adolescent
Hematology and Oncology
Infectious Diseases
Medical Genetics
Neonatal Medicine
Nephrology
Neurology
Neurosurgery
Ophthalmology
Oral and Maxillofacial Surge

Ophthalmology
Oral and Maxillofacial Surgery
Orthopedic Surgery
Otorhinolaryngology (ENT)
Physical Medicine and Rehabilitation

Plastic and Reconstructive Surgery Psychiatry and Psychology Pulmonology Radiation Oncology

Radiology Regional (Health System)

Pediatrics Research Rheumatology Sleep Medicine Center

Metabolic Bone Clinic

Speech Pathology Surgery Urology

#### Pediatric Specialty Clinics:

**Endocrinology and Metabolism** 

Gastroenterology and Hepatology

Adrenoleukodystrophy Clinic **Aerodigestive Clinic** Anxiety Disorders Clinic and Intensive Therapy Program Arrhythmia and Device Placement Clinic Asthma Center Attention Deficit Hyperactivity Disorders (ADHD) Clinic **Bariatric Surgery Clinic Brain Injury Program Brain Tumor Clinic** Cerebral Palsy Clinic Chemotherapy/Radiation Long-Term Effects Clinic Child and Adolescent Intensive Mood Program (CAIMP) Childhood Sarcoma Clinic ComPASS (Palliative Care and Integrative Medicine) Congenital Heart Clinic **Constraint Induced Movement** Therapy Program Craniofacial Clinic

Cystic Fibrosis Center

Dana Child Developmental and Learning Disorders Program **Dermatology Genetics Clinic Diabetes Clinic Eating Disorders Clinic** Eosinophilic Esophagitis Clinic **Epilepsy Clinic** Erythromelalgia Clinic Facial Paralysis and Reanimation Clinic Feeding Program **Fertility Preservation Fetal Surgery Program** Friedreich's Ataxia Clinic **Functional Movement** Disorder Program **Heart Failure Clinic** Hemophilia/Coagulopathy Clinic Hyperlipidemia Program Immunodeficiency Disorders Clinic Inflammatory Bowel Disease Clinic Learning Disorders

Assessment Clinic

Long QT Syndrome Clinic

Marfan Syndrome Clinic

Mood Disorders Clinic Neonatal Follow-Up Clinic Neuromuscular Clinic Pain Clinic Pain Rehabilitation Center Pediatric Diagnostic Referral Clinic Pediatric Level 1 Trauma Center Plagiocephaly Program Pulmonary Hypertension Program Renal Stone Clinic Spina Bifida Clinic Spinal Deformities Clinic Sports Medicine Center Thyroid Nodule/Cancer Clinic Transgender Clinic **Transitions Program** Transplant Center Travel Clinic Vascular Malformations Velo-Pharyngeal Insufficiency Clinic **Voiding Clinic** Weight Management Clinic

## Sibling Illness or Hospitalization Affects the Whole Family

When your child has an illness or needs to stay in the hospital, it affects the family. Priorities and routines likely change. Not knowing what will happen and for how long affects both your child who is ill and your child's siblings.

Siblings try to understand and cope with changes in family life and their daily routines. This brings different responses and emotions. These big changes may affect siblings':

- Emotions and behaviors.
- Communication.
- Relationships.
- Sense of stability and routine.

Be aware of the many different possible reactions. Talk openly about feelings and thoughts that happen when life changes. This is an important way to offer support to siblings.

A wide range of responses is normal. And it is OK for these feelings or responses to change from day to day or minute to minute. Work with members of your child's healthcare team, including a child life specialist, to find the best ways for siblings to cope.

#### Common reactions to sibling illness or hospitalization

Children react in different ways to the illness or hospitalization of a sibling. Common reactions from siblings of a sick child may include the following:

- **Grief.** Siblings may be sad or grieve the change in daily routine that comes with illness or hospitalization.
- Loneliness. Siblings may feel left out. They may miss the attention that was given before the illness. They may feel like there is not as much of it as before. They also may miss a sibling not being home. And they may miss you, the caregiver, not being at home.
- **Fear.** Siblings may fear something bad may happen to an ill or hospitalized sibling. They also may fear they too may become ill or hurt.
- Guilt. Depending on age, siblings may believe they played a role in what is happening.
- **Jealousy or anger.** Siblings may be jealous or angry about the attention, focus or gifts their sibling receives in the hospital.
- Neutrality. Some siblings may seem as though the illness or hospitalization does not affect them.

Talk to siblings about how they feel. Support them and their feelings. Let them know that it is OK to have them. Be clear that they are not required to feel anything specific.

This is an essential part of communicating and processing what is happening. Let siblings know they can come to you with any questions or concerns.

#### How children may show stress

It is common for children of any age to show stress in the way they act. You may notice behavior changes in the following ways:

- **Being more reactive.** Behavior may become more aggressive. Children may be more short-tempered than usual. They may not be as flexible. Boundaries or limits may be pushed more than before.
- **Being quieter.** Children may be less interested in relating with others. A child may become clingy and want to be around you or be held more often.
- **Changing habits.** Sleeping or eating habits may change. There may be less or more of an appetite. Or they may wake up more often throughout the night.
- **Reverting to less mature behaviors.** In spite of being potty trained, bed wetting may begin again. Children may start to suck their thumbs again. They may start carrying a comfort item such as a blanket or stuffed animal once more.
- **Complaining about sickness.** Siblings may say they feel sick, complain about headaches, stomach aches or other feelings that come with illness.
- Caretaking. A child may start to try to take care of a sibling, parent or other family members. The child's focus may be on the care of others. A child may strive to be "perfect" at school or at home.



Figure 1. Children may start using comfort items again.

# Supporting Children While Their Sibling Is III or in the Hospital

#### Share information in a way siblings can understand

Siblings often do not completely understand what is happening to their hospitalized sibling. They do not understand what caused the illness or hospitalization. Share with them any information that is suitable for their age. Help them understand what is going on.

Sharing information builds trust and lessens distress for children. The healthcare team and child life specialist can help you discuss your child's illness or hospitalization in ways that siblings can understand.

#### Infant and toddler: Ages birth to 2

Very young children react to a change in routine. They may not be concerned with the "what" or "why" of their sibling's illness. But they notice when their sibling or caregiver is not there. You can let a toddler know that the healthcare team helps sick children.

#### Preschool: Ages 2 to 5

At this age, children can understand simple explanations. They benefit from preparing for new events and communicating about feelings. They may have a hard time with routine changes.

Children this age may worry they caused their sibling's illness because of something they did. Or they may believe that the illness is contagious. They may fear they will get it. When an illness is not contagious, let siblings know it was not caused by anyone else. They will not get sick too.

#### School age: Ages 5 to 12

Children at this age start to understand more about how an injury or illness affects the body. They may have many questions, and they may repeat questions. Answer questions as honestly as you can. You may not know the answer. It is OK to let them know that. But let them know you will help find the answer. Assure children that they may ask any question. Come back to a question when you have an answer.

Kids this age may benefit from peer support. It also can be helpful to let other supportive adults, such as teachers and coaches, know what is going on. They can help provide support and answer questions that might come up.

#### Teens: Ages 12 to 18

At this age, children know more about how illness or hospitalization can affect the body. They benefit from open and honest discussions to learn and process information. Children this age may begin to think about mortality and the meaning of life. Share as much information as possible.

Respect their need for space and peer connection to process information. At times, teens may appear as though they do not want to talk. But as a caregiver, it is important to check in with them. Let them know you are there when they are ready.

#### Prepare siblings to visit the hospital

Before you take siblings to visit the child in the hospital, prepare them for what they may experience. It may be helpful to take a picture of the hospital room and the medical equipment in the hospital room.

Show siblings the picture. Talk about what they see. Prepare them for what they will see in the hospital room. Talk to them about how the medical equipment in the picture helps their sibling.

Before siblings visit the hospital, talk about any changes they might notice in the way their sibling looks. You also may prepare them to see gifts your child has received in the hospital.

Do what you can to keep siblings included in the healthcare experience as much as they want to be. Remind them that it is always OK to ask questions.

#### Support the relationship between siblings at the hospital and at home

The relationship between the ill sibling and siblings who are not ill is important for the well-being of both. Find ways for them to connect and spend time together. Consider the following:

- When appropriate, encourage children to do activities together. These may include puzzles, board games, video games and crafts. Siblings can read or watch movies together. They can make a music playlist together. They can find ways to decorate the hospital room with photos and art to make the room feel more comfortable.
- If the ill sibling is sedated, the other siblings can still engage. For example, they can read a book aloud or sing a song. They can decorate the hospital room for their sibling. Or they can hold their brother or sister's hand.
- Create a play space in the hospital room for a sibling to play. This invites the sibling to be present in the space.
- When you call your child in the hospital, make sure siblings have a chance to be part of the call too. Help siblings stay in touch as much as they would like. You also may have your children send video or audio messages to your child in the hospital.
- If siblings cannot be present at the hospital, they can mail letters. You can help
  with this. Take physical pictures or notes back and forth between the siblings.
  While digital photos and texts are nice, having something concrete may be helpful.
  You also can send a special care package in the mail.

### More Ways to Support Siblings

#### **Emotional processing**

Children may benefit from seeing a counselor or therapist to help them process their responses. You also can help siblings process difficult emotions. Consider the following:

- **Art.** Siblings can draw or paint pictures to show how they feel about their sibling's illness.
- **Movement.** Suggest siblings dance or move to show how they feel. This gives them the chance to let out their emotions.
- **Crying.** Give siblings space to cry, yell or scream in a safe and controlled setting. It is also OK for you to show emotion in front of your child. Letting children see you react honestly to difficult things shows that your feelings are like theirs.
- **Writing.** Suggest keeping a journal to record thoughts and emotions. Be clear that this journal is private. They can safely write about their feelings.
- Let children take the lead. Ask open-ended questions rather than yes or no questions. Do not push them to talk about emotions if they don't want to. The most important thing is for siblings to know it is OK to talk when they want to. Let them talk to you when they feel ready.

#### **Medical play**

Play gives young children a way to work through their emotions. Through play, they can express themselves in a way that is familiar to them.

Medical play is a hands-on opportunity for siblings to use pretend or real medical equipment to work through feelings. It helps them show their understanding of a sibling's illness or injury.

Medical play also helps teach siblings about diagnosis or injury. Stuffed animals can be used as patients during play. Child life specialists are trained to plan medical play sessions.

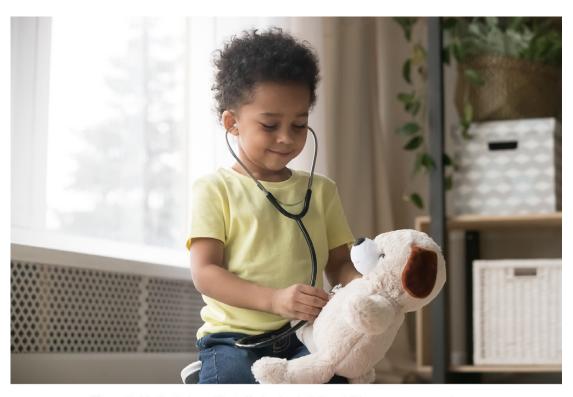


Figure 2. Medical play with stuffed animals helps children process experiences.

#### Interest in medicine

Older siblings may have interest in, or questions about, biology and medicine. It is common for siblings to connect their experience to their daily life. Siblings may make connections to a science class or an experience about visiting a grandparent in the hospital. Or they may have seen something on TV or a movie about medical situations. If your child wants more information, talk to your care team about resources they suggest for your child's interest.

#### How to give support at school

Once children start school, much of their time is spent around teachers, counselors and other staff. These adults may help children cope. Talk about what your family wants to share with the school. Help siblings talk about what they want to share with friends or teachers. Find out how they may want to do this.

You may find it helpful to let teachers and school staff know what is going on in your family. They may be able to make accommodations for your child. They may be able to give extra support if needed.

Teachers and school counselors or psychologists can help by talking about the situation. They may help with talking about emotions and how to stay on schedule at school. And they may be able to suggest additional resources. If needed, a child life specialist can work with the school on ways to discuss questions or concerns.

#### Ways to support siblings as they cope and adjust

- Spend time together. As possible, set time aside for each of your children. Quality time together helps nurture relationships. It lets your children know each one is important. Be realistic about the time you can spend and what you can do together. For example, you may spend 10 minutes alone together. You can play, read a book, eat a snack or talk about the day. The important thing is focusing your attention fully on the sibling during this time.
- Create clear expectations at home. Once your child returns home from the hospital, it is important to get back to normal chores, expectations and routines. It is OK if responsibilities are not the same as they were before. But it may be helpful to discuss how each family member can help around the house. Be open about why you may have different expectations for each child. Communication about responsibilities and roles helps create a positive environment for all your children.
- Be flexible and communicate about schedules. Children who have chronic conditions may have frequent outpatient healthcare visits. Siblings and parents or guardians may miss siblings' events, practices or competitions because of a child who must be at the hospital or is frequently ill. Talk to your family about these situations. Find ways to help siblings get to events even when you cannot attend. You also may ask friends or family to record special events. You then can watch those events as a family.
  - Be sure to share with siblings why appointments continue to take time away. Help them understand the care that is still needed. When a sibling has no other commitments, invite the sibling to come along for one of the clinic visits. This helps them understand what happens during these visits.
- Think about unplanned hospital admissions. Make plans for unexpected hospitalization or illness. Talk to family and friends about caring for your other children. The type and amount of care siblings may need depends on their ages and individual needs. Older siblings may help you make these plans. They need to know what to do if their sibling needs help but you are not there. Assure siblings that they will be kept up to date about care and appointments.

#### Other resources

Your child's healthcare team may include the following professionals. You may find their support helpful for your family.

- **Child life specialists.** These professionals support the emotional care and education of children and families.
- **Social work professionals.** They provide support, resources and assistance through your child's treatment and beyond.
- **Psychologist.** They can help your children cope with the trauma of an illness or injury.
- **Chaplain.** This religious or spiritual person can offer support to your family.
- **SibShops.** This is a national program that provides support for siblings. Children can meet other siblings going through situations like they are. Find more information about a SibShops event near you at the SibShops website.

#### **Going forward**

A child's illness or hospitalization affects your whole family. You may feel overwhelmed and anxious. Ask your care team about resources for parents. You may find support groups or online forums helpful.

Your healthcare team is ready to help answer your questions and give you resources. Team members want to help your child get better. They want your child to live well. And they want to support you and your family too.



This information is for your education only. It does not replace medical advice, diagnosis, or treatment. New medical research or practices may change this information. If you have questions about a medical condition, talk with a member of your healthcare team.

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#### BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal Mayo Clinic patient of more than 40 years and a self-made business leader who significantly expanded her family's activities in oil, gas and ranching. Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic. By naming the Barbara Woodward Lips Patient Education Center, Mayo honors her generosity, her love of learning, her belief in patient empowerment and her dedication to high-quality care.

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