



Super Siblings Support Guide

A resource for adults who provide support to children with siblings with complex medical needs



Support for Super Siblings

At Kennedy Krieger Institute, your child's interdisciplinary team is here to care for your entire family. We know that when a child has complex medical needs, their siblings are affected. They want to support their sibling with complex medical needs, but they also have their own unique experiences, thoughts, emotions and needs.

This guide offers suggestions and ideas for each age group of siblings of children with complex medical needs, including:

- Descriptions of siblings' common challenges and reactions
- Strategies that family members and caregivers can use to support siblings

The age groups of siblings covered in this guide are:

- Infants
- Toddlers
- Preschoolers
- Elementary and middle school-age children
- Adolescents

Members of your care team can connect you with additional resources, as needed.

Email ChildLifePrograms@KennedyKrieger.org to connect with a child life specialist at Kennedy Krieger.



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Infants (Birth–1 Year Old)

Infants are trying to figure out their world. They are quickly learning that their caregivers are here to nurture and love them, and that their actions have an impact on the world around them. Infants gather information about the world through their senses: sight, smell, taste, touch and hearing.

Challenges

- Separation from caregivers due to a sibling's hospital stays, appointments and/or other care needs
- Loss of routine due to a sibling's care needs

Reactions

- Increased fussiness, as shown by clinginess and difficulty separating from caregivers during transitions

Strategies for Caregivers

- Develop a consistent routine as much as possible. This helps build a trusting relationship with your child.
- Lean on the support of family and friends.



DURING YOUR OUTPATIENT VISITS

- Share any concerns you may have, including about any behavioral changes you may have observed, with your child's care team to be connected with a child life specialist.
- Inform your care team if you need privacy to pump or breastfeed during your appointment.

DURING YOUR HOSPITAL STAY

- A child life specialist can coordinate sibling playtime with infant mats and toys.
- Door signs and/or private spaces are available for breastfeeding and pumping.

Toddlers (1–3 Years Old)

Toddlers are constantly on the go, exploring and learning about their environment. Their desire for independence is growing, as are their vocabulary and their ability to communicate thoughts and emotions. They have a limited understanding of other people's points of view and are generally unsure of new people who come into their world.

Challenges

- Separation from caregivers due to a sibling's hospital stays, appointments and/or other care needs
- Loss of routine due to a sibling's care needs
- Loss of sense of control—for example, they don't understand why playtime may be cut short due to a sibling's care needs
- Missing their absent caregiver or sibling with complex medical needs

Reactions

- Setback in previously acquired skills (for example, potty-training) in response to a sibling's hospitalization or from separation from caregivers
- Increased tantrums or clinginess to caregivers after a caregiver's extended absence

Strategies for Caregivers

- Develop a consistent routine as much as possible. This helps build a trusting relationship with your child.
- Read books with your child about emotions and feelings. (Ask your child life specialist to recommend titles.)
- Dedicate one-on-one time with your child as much as possible. For example, spend 15 minutes together taking a walk or reading a book.
- Record a video of you reading a favorite story to your child that can be replayed in your absence, or plan a time to read a book to them via video chat.



DURING YOUR OUTPATIENT VISITS

- Please feel free to ask the clinic staff to bring toys and/or other distracting or engaging activities to the exam room for the appointment.

DURING YOUR HOSPITAL STAY

- Your child may sign out toys from the Rec Room to use in hospital rooms.
- A child life specialist can coordinate sibling playtime, visits and/or other sibling support needs.

Preschoolers (3–5 Years Old)

Preschoolers are on the move! They are spending more time with peers, through day care or school, for example. As a result, they are building friendships and slowly becoming aware of the emotions of others. Preschoolers constantly attempt to do things by themselves.

Challenges

- Separation from caregivers due to a sibling's hospital stays, appointments and/or other care needs
- Loss of routine due to a sibling's care needs
- Fear of the unknown—for example, they may wonder, "Where is my sibling going?"
- Limited understanding of sibling's diagnosis and needs, but a gradual understanding that their sibling is different

Reactions

- Jealous of the attention given to their sibling with complex needs
- Increased tantrums or clinginess to caregivers after a caregiver's extended absence
- Wants to help—attempts to be involved in their sibling's care and/or shows curiosity about medical equipment (wheelchair, G-tube, etc.) in the home

Strategies for Caregivers

- Develop a consistent routine as much as possible. This helps build a trusting relationship with your child.
- Read books with your child that focus on the sibling experience. (Ask your child life specialist to recommend titles.)
- Dedicate one-on-one time with your child as much as possible. For example, spend 15 minutes together taking a walk or reading a book.
- Model appropriate ways siblings can play together.
- Give your child a job or a way to be involved in their sibling's care, such as gathering supplies like wipes, diapers or toys. Give positive praise for helpful behaviors.
- Provide developmentally appropriate information about their sibling's diagnosis. Assure them that their sibling's diagnosis is not their fault.



DURING YOUR OUTPATIENT VISITS

- Please feel free to ask the clinic staff to bring toys and/or other distracting or engaging activities to the exam room for the appointment.
- A child life specialist is available to help talk about medical concepts with your child during the appointment, or via phone and/or email.
- Check with clinic staff to see if the patient's siblings can use the outpatient playroom during the appointment.

DURING YOUR HOSPITAL STAY

- Your child may sign out toys from the Rec Room to use in hospital rooms.
- A child life specialist can coordinate sibling playtime, visits and/or other sibling support needs.
- The child life team can provide patient- and sibling-specific resources, such as children's books, about their sibling's illness or injury.

Elementary and Middle School-Age Children (6–12 Years Old)

Children ages 6 through 12 are exploring their own hobbies and interests. Their self-confidence grows as they develop new skills and receive praise from others.

Challenges

- Fear of the unknown—for example, they may wonder, “Where is my sibling going?”
- Increased understanding that their sibling is different from others
- Reduced time and attention from other family members due to their sibling’s complex needs
- Feeling isolated from peers due to their unique experiences

Reactions

- Jealous of the attention given to their sibling with complex needs
- Wants to be “the good kid” or a perfectionist
- Wants to help—attempts to be involved in their sibling’s care and/or shows curiosity about medical equipment (wheelchair, G-tube, etc.) in the home
- Wants to protect or defend their sibling from insensitive comments and teasing from peers

Strategies for Caregivers

- Dedicate one-on-one time with your child as much as possible. For example, spend 15 minutes together taking a walk or reading a book.
- Give your child a job or a way to be involved in their sibling’s care, such as gathering supplies like wipes, diapers or toys. Give positive praise for helpful behaviors.
- Remind your child that they don’t have to be perfect. Help them set realistic expectations.
- Provide developmentally appropriate information about their sibling’s diagnosis. Assure them that their sibling’s diagnosis is not their fault.
- Remind your child that it is OK to feel frustrated or embarrassed by their sibling, at times. Assure them that they may express these emotions to you and can ask you questions if they don’t have an understanding of their sibling’s needs.



DURING YOUR OUTPATIENT VISITS

- Please feel free to ask the clinic staff to bring toys and/or other distracting or engaging activities to the exam room for the appointment.
- A child life specialist is available to help talk about medical concepts with your child during the appointment, or via phone and/or email.
- Check with clinic staff to see if the patient’s siblings can use the outpatient playroom during the appointment.

DURING YOUR HOSPITAL STAY

- Your child may sign out toys from the Rec Room to use in hospital rooms.
- A child life specialist can coordinate sibling playtime, visits and/or other sibling support needs.
- The child life team can provide patient- and sibling-specific resources, such as children’s books, about their sibling’s illness or injury.
- The child life team can provide one-on-one educational and therapeutic interventions for your child—in person or virtually—during their sibling’s admission.

Adolescents (12 Years Old and Up)

Teenagers are developing their own values and sense of self, and identifying what is most important to them. They are starting to think about their future and how their decisions impact those around them.

Challenges

- Reduced time and attention from other family members due to their sibling's complex needs
- Feeling isolated from peers due to their unique experiences
- Concerns about how their decisions might affect their sibling and caregivers—they may wonder, “What if I want to move away one day?”

Reactions

- Jealous of the attention given to their sibling with complex needs
- Wants to be “the good kid” or a perfectionist
- Wants to protect or defend their sibling from insensitive comments and teasing from peers
- Increased capacity for empathy and tolerance of others
- Takes on the caregiver role

Strategies for Caregivers

- Consider having your child join a support group to meet other kids with similar experiences.
- Dedicate one-on-one time with your child as much as possible. For example, take a 15-minute walk together or talk about their interests and hobbies.
- Remind your child that they do not have to be perfect. Help them set realistic expectations.
- Provide developmentally appropriate information about their sibling's diagnosis. Assure them that their sibling's diagnosis is not their fault.
- Tell your child that it is OK to feel frustrated or embarrassed by their sibling, at times. Assure them that they may express these emotions to you and can ask you questions if they have concerns about the future.



DURING YOUR OUTPATIENT VISITS

- Please feel free to ask the clinic staff to bring books and/or other distracting or engaging activities to the exam room for the appointment.
- A child life specialist is available to help talk about medical concepts with your child during the appointment, or via phone and/or email.
- Check with clinic staff to see if the patient's siblings can use the outpatient playroom during the appointment.

DURING YOUR HOSPITAL STAY

- Adolescents may accompany caregivers to the playroom for sibling playtime.
- A child life specialist can coordinate sibling playtime, visits and/or other sibling support needs.
- The child life team can provide patient- and sibling-specific resources, such as books or other resources, about their sibling's illness or injury.
- The child life team can provide one-on-one educational and therapeutic interventions for your child—in person or virtually—during their sibling's admission.
- For additional support or specific requests, a child life specialist is available to speak with your child about their sibling's diagnosis.