

SIBLING INFORMATION NEEDS

What information should you be sharing with your child about their sibling's disability? What information is appropriate to share with them at what age?



Preschoolers and School-age Children

Children in this age group should know what their sibling's disability is. Even if you think they will not understand what the disability is. For example, explaining to a five-year old that their brother has Cerebral Palsy and may have mobility difficulties, rather than telling the five-year old Sibling that their brother is sick can lead to less misconceptions about the disability.



Adults

If they want to be involved, adult Siblings should be involved with any applicable decision making and support.

They should understand their brother or sister's disability or illness and understand the responsibilities that may come upon them in the future.

Parents should provide information regarding the sibling with a disability or illness' care and services. An organized way to track all of this information is the Care Notebook from the Medical Home Portal.

<https://bit.ly/MHPCareNoteBook>



Teens and Young Adults

For teens, the topic of the child with a disability, specifically the disability and care, should be an open and honest topic at all times. Teens are beginning to understand the world around them and question it. Keeping information about them could result in emotional events, distrust and resentment.

"Why was his hair falling out? Why was he going to the hospital all the time? Why was he getting bone marrows all the time? It never occurred to me that he might die. What was happening? I didn't get to go to the hospital to see him. What was leukemia? Why was he getting so many presents?"

Teens are also planning for the future. Both for themselves and possibly their Sibling. Ask your teen if they want to be involved in decision making, discussions, doctor's appointments, or school meetings could be beneficial.

Tips for Parents

- Keep the sibling's disability or illness an open topic
- Answer the Sibling's questions
- Ask them if they want to be included in decision making and provider visits
- Respect their feelings, even if they hurt your feelings
- Respect their boundaries
- Prepare information regarding your child's disability or illness in case of emergency