

*Learn how to  
talk about your  
child's diagnosis  
with their  
sibling(s) in a  
way that is both  
age-appropriate  
and productive.*

## Sibling Support Fact Sheet for Parents

Siblings of children with special needs and disabilities experience many of the same emotions as their parents/caregivers, but they are often left out of family support services. Learn more about how you can support your other child(ren) and help them to adapt to their sibling's diagnosis.

### **Why is it important to talk to Siblings about diagnoses and special health needs conditions?**

Though it is rarely the intention, it can be easy to overlook siblings of children with special health care needs or disabilities. This is because many siblings work overtime to ensure they are not serving as an additional burden or stressor to their parents. You may see certain qualities, such as perfectionism, in siblings as they are trying to do the best they can.



Many emotions lie stagnant under the surface. Because the sibling is trying to overachieve and succeed

independently, sometimes parents think they do not need to worry about that child as much, resulting in self-isolation and feelings of resentment.

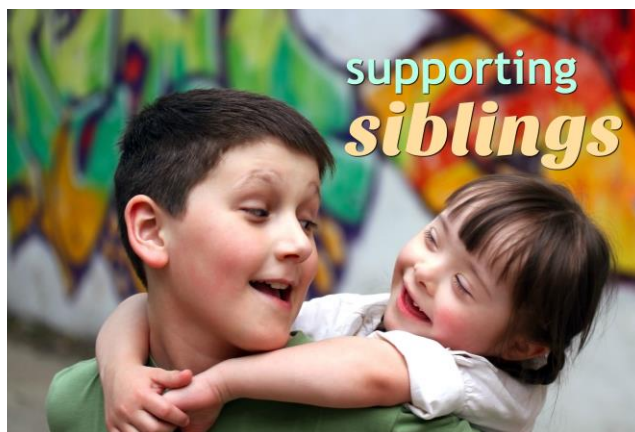
To understand how to talk and appropriately involve siblings in caring for their brother or sister, this fact sheet addresses several questions that will help parents initiate conversations with siblings and provides tips for supporting each other through life's daily obstacles.

### **When is the right time to talk to a sibling about an illness/condition?**

No time will ever feel like the "right" time to talk to your child about a sibling's diagnosis or condition. However, it is important to understand how critical and necessary these conversations are for siblings.

Think about all the information you receive from your child's care provider or team. During this time, is anyone talking to the sibling(s)? If not, this is information that is important for them to hear too. They are also searching for answers and trying to navigate what is happening with their brother/sister.

Though it may seem early, it is reasonable to have these conversations with siblings as early as the preschool age, considering accessible and age-appropriate language. This will, and should, change over time as the siblings get older and they can understand more about the disability or special health need.



### How do you explain an illness or condition?

As is with finding a time to talk, finding the words to say to a sibling can be equally, if not more, challenging. Here are several considerations when initiating or continuing the conversation with your child:

- **Delivery:** using accessible and age-appropriate language is key to ensuring proper understanding and knowledge regarding an illness or condition.
- **Name it:** it is important to use the name of the condition or disability. This will help avoid confusion and any negative

connotations or feelings (e.g., it's a "bad word") when talking about or explaining the situation.

- **Inquire:** consider asking what the sibling already knows about their brother/sister's condition or illness. Children are incredibly observant, so if you can focus on what they have seen and what their experiences have been like so far, you can offer the opportunity to affirm or revise their perspectives as needed and provide an opportunity for them to ask questions.
- **Validation:** In these conversations, it is important to actively ensure the words and feelings the sibling(s) are expressing are both heard and validated. This will help build a stronger relationship and the ability to communicate about the illness or conditions for future encounters.
- **Honesty:** As in any situation, honesty is the best policy. Though this can be challenging, it is important information that siblings should be receiving too. Help them understand that this may be an ongoing dialogue. Acknowledge that you may not always have the answers and it is okay to say that you don't know something. It is also okay to show and feel emotions with your child.





### How do you talk about death?

The biggest consideration when discussing death and dying is, again, to be honest, and openly communicate with your child. Though it may seem instinctual to avoid sharing information to protect the sibling and their feelings, it generally results in more feelings of isolation and frustration.

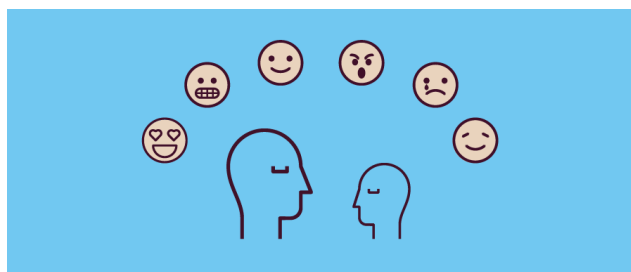
When initiating conversations, it is important to acknowledge and support any and all emotions. Some wonderful advice from the National Center for Grieving Children and Families, otherwise known as the Dougy Center, says “start with a short, simple explanation about the death, in language they can understand, and then let their questions guide what else to share.”

### Are feelings like anger, frustration, and jealousy normal?

The short answer: yes! Though it may not be intentional, more attention is typically given to the sibling with the disability or illness because of their additional baseline needs. This can manifest feelings of both resentment and guilt among siblings and can be a constant mental battle that occurs within their minds. This can create an additional internal dilemma that causes stress for siblings.

Again, acknowledging the situation and validating your child’s feelings is key to helping them move forward. Be open and honest, agree that certain situations are difficult, and confirm that you are experiencing similar emotions. Do your best

to provide them a voice within a safe, open container for discussion.



### How do you address behavioral issues?

Though it can be difficult, patience is key. Continue not to tolerate behaviors that you would not have tolerated before a diagnosis, but integrate open and honest conversations about the behaviors, while working to pinpoint the root cause. This will help your child process emotions and provide you with an opportunity to acknowledge and validate their feelings.

Some examples of acknowledging and validating feelings might include:

“Tell me more about your frustrations.”

“That must be/I know it is really hard.”

“I can see why you would feel that way.”

It is important to try to avoid including “but’s.” Efforts to create equal expectations for all members of the family will help promote fairness and ultimately minimize common frustrations that siblings experience.

An additional tip to help support your child with a special health need/disability’s sibling is to find something that brings the family together—something that is not related to the disability. This could be as simple as bowling, a dinner night out, or even just some routine one-on-one time with your child. Small, consistent gestures



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**1 802-876-5315**

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like these are invaluable to siblings. By simply listening and making yourself available to them means more than any action and goes a long way.



### Resources

VFN SibShops are a great tool for your child to connect with other siblings of children with special needs/disabilities, while doing a fun, supervised activity. VFN holds these events monthly for siblings ages 6 and up! For more information about Sibshops, visit <http://www.vermontfamilynetwork.org/get-support> and click the "Sibshops" drop-down.

*"My child just appreciated knowing that there were other kids out there 'like her'. I appreciated that she had that time to just be herself and not worry about what was going on with her brother."*

### Dougy Center

Support, resources, and connection before and after a death.  
503-775-5683

### Sibling Support Project

Books and publications, online communities for teen and adult siblings, and workshops and training.

### Organization for Autism Research: Sibling Support

Print resources for parents, young children, and teenage siblings.  
866-366-9710

### **Books:**

*Rules*, by Cynthia Lord

*Siblings Without Rivalry*, by Adele Faber and Elaine Mazlish

*Sibshops: Workshops for Siblings of Children with Special Needs*, by Don Meyer, M.Ed & Patricia Vadasy, PhD.

*Thicker than Water: Essays by Adult Siblings of People with Disabilities*, by Don Meyer (Editor)

*Views From Our Shoes: Growing up with a Brother or Sister with Special Needs*, by Don Meyer (Editor)

*What About Me? Growing Up with a Developmentally Disabled Sibling*, by Bryna Siegel and Stuart Silverstein

The following books are published by the Organization for Autism Research:

**For Parents:** *Brothers, Sisters, and Autism: A Parent's Guide to Supporting Siblings*

**For Teenage Siblings:** *Life as an Autism Sibling: A Guide for Teens*

**For Young Children:** *Autism, My Sibling, and Me*