Special Siblings

A Guide To Being a Brother or Sister To Someone Affected By a Genetic Disease

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NTSAD

National Tay-Sachs &
Allied Diseases Association
www.NTSAD.org

Congratulations! You have one of the most important jobs in the whole world. You are a sibling - a brother or a sister of someone who really needs you and all of your special gifts.

You are more than just someone to play with to your brother or sister. You are a bedtime story reader, bed tucker-inner, diaper changer, and care giver. Your job is hard sometimes, especially since your brother or sister needs some extra attention or care. It might seem unfair that your sibling gets so much attention or that they can't do all of the things that you can do. They can't play ball or tag, they can't walk or say all of the words that you can. These differences don't make them any less special, or any less exciting to be around. There are lots of ways that you can interact with your brother or sister that are perfect just for them.

As a brother or sister of someone who is sick, lots of questions come up and may be confusing. When friends come over and ask about your sister or brother, sometimes it's hard to know what to say. You might have your own concerns about what is happening to your sibling, and it's hard to understand the explanations. This booklet will help answer some of those questions and concerns, and will give you lots of stories of other siblings just like you who are going through the same kinds of things you are!

Read this with a family member, and remember that even though your job might seem awfully hard, it's one of the best and most rewarding ones there is!

Every person in the world is born with genes. Genes are what give you the color of your eyes, your hair, and they even determine if you are going to be tall or short! In addition to having information about what we look like, genes can also make us healthy and strong. Very rarely genes cause disease. There are several different kinds of diseases that result from genes that don't work properly. When you are a brother or sister to someone with a disease, often times you have lots of questions about what is going on with your sibling and how you can interact with them. In this booklet you'll read about your brother or sister's disease as well as find lots of questions that siblings have and the answers to them, as well as fun ways to play with your sibling and spend time with them.

Tay-Sachs

What is Tay-Sachs?

The disease called Tay-Sachs is when a person's genes are different than most people. A person with Tay-Sachs can't walk or talk. A person with Tay-Sachs can't get rid of the bad stuff in the body that can limit a person's ability to walk and talk. Because of this yucky disease your sibling will need special doctors, medical equipment, medicine and lots of extra attention but remember your parents and family **love you** just as much as your sibling – more than you can ever possibly imagine!

Can I catch it?

Tay-Sachs is not contagious, so you can't catch it, and it is very different from the common cold or flu. It is something your brother or sister was born with, just like hair or eye color. It isn't anyone's fault. It just is.

What can I do with my sibling who has Tay-Sachs?

Because of their disease, a person with Tay-Sachs may look different, act different, and not be able to do the same things that you can do. Just because they have this disease doesn't mean they are any less fun to be around or exciting to play with, they just have to play and do things in a different way. Reading to them, listening to music, and making up games to play, drawing pictures to put up next to their bed, or decorating their stroller for the holidays are all ways to interact and spend time with your sibling! Tell your brother or sister anything and know that it won't be repeated! Sometimes they can smile and laugh too!

Canavan

What is Canavan Disease?

Canavan disease is another kind of disease that has to do with genes. In your brain, there is something called "white matter," which tells your body to move, speak, and work in the right ways. A person with Canavan disease doesn't have enough white matter to do those things, so they also might look different and act different than you. Because of this yucky disease your sibling will need special doctors, medical equipment, medicine and lots of extra attention but remember your parents and family love you just as much as your sibling – more than you can ever possibly imagine!

Can I catch it?

It is not contagious, so you can't catch it, and it is very different from the common cold or flu. It is something your brother or sister was born with, just like hair or eye color. It isn't anyone's fault. It just is.

What can I do with my sibling who has Canavan?

Because of their disease, a person with Canavan may look different, act different, and not be able to do the same things that you can do. Just because they have this disease doesn't mean they are any less fun to be around or exciting to play with, they just have to play and do things in a different way. Reading to them, listening to music, and making up games to play, drawing pictures to put up next to their bed, or decorating their stroller for the holidays are all ways to interact and spend time with your sibling! Tell your brother or sister anything and know that it won't be repeated! Sometimes they can smile and laugh too! People with Canavan can smile and laugh and they love to be around people!

Liliana with her sister

Sandhoff and GM1

What is Sandhoff Disease?

The disease called Sandhoff is when a person's genes are different than most people. A person with Sandhoff can't walk or talk. A person with Sandhoff can't get rid of the bad stuff in the body that can limit a person's ability to walk and talk. Because of this yucky disease your sibling will need special doctors, medical equipment, medicine and lots of extra attention but remember your parents and family love you just as much as your sibling – more than you can ever possibly imagine!

What is GM-1?

The disease called GM-1 is when a person's genes are different than most people. A person with GM-1 can't walk or talk. A person with GM-1 can't get rid of the bad stuff in the body that can limit a person's ability to walk and talk. Because of this yucky disease your sibling will need special doctors, medical equipment, medicine and lots of extra attention but remember your parents and family love you just as much as your sibling – more than you can ever possibly imagine!

Can I catch it?

Sandhoff and GM1 are not contagious, so you can't catch it, and it is very different from the common cold or flu. It is something your brother or sister was born with, just like hair or eye color. It isn't anyone's fault. It just is.

What can I do with my sibling who has Sandhoff or GM1?

Because of their disease, a person with Sandhoff may look different, act different, and not be able to do the same things that you can do. Just because they have this disease doesn't mean they are any less fun to be around or exciting to play with, they just have to play and do things in a different way. Reading to them, listening to music, and making up games to play, drawing pictures to put up next to their bed, or decorating their stroller for the holidays are all ways to interact and spend time with your sibling! Tell your brother or sister anything and know that it won't be repeated! Sometimes they can smile and laugh too!

Frequently Asked Questions (5-8 years old)

1. How can I interact and play with my sibling when they are so severely disabled?

There are lots of ways that you can play with your sibling. Reading to them, listening to music, and making up games to play, drawing pictures to put up next to their bed, or decorating their stroller for the holidays are all ways to interact and spend time with your sibling! Tell your brother or sister anything and know that it won’t be repeated! Sometimes they can smile and laugh too!

“The only time that he only sorta talked was when he laughed when I told him jokes and I also read to him. I read some books that I had when I was young like the same books that my mom read to me when I was his age.” -Nicholas, age 11

2. How many siblings should I say I have?

This is totally up to you. You can tell your friends about your sibling if you want to, but you don’t have to. It is OK to tell and it is OK not to tell. It is OK to tell some people but not everyone. Do what feels right for you. You can also explain to them about your brother or sister’s disease if you want to--you can even show them this booklet!

3. How should I explain what my sister or brother has to my friends?

You don’t have to tell your friends about your sibling if you don’t want to; it all depends on what you want to do. If you decide you want to tell your friends about your brother or sister, then you can share details about the disease or you can just tell them that they are extra special, and they can’t do everything that you or your friends can do, but that they are really fun to be around!

4. Sometimes I feel angry, sad, frustrated, lonely, jealous or hurt because my sibling has a disease; is it OK?

Yes, any feeling you have towards your sibling is okay. It’s hard having a sibling with a disability, and it can make you feel lots of different confusing emotions. It’s important that you talk to your parents about your feelings instead of misbehaving or acting out.

5. How can I help my parents take care of my sibling?

It is great you want to help take care of your sibling but don’t feel like you have to. All that matters is your sibling knows how much you love him/her. If you want to help, ask your parents if you can help with feedings, picking out clothes and keeping your brother or sister comfortable. Just tell your parents what you want to do and they will help you do it!

6. Do I always have to tell my friends about my sibling?

No. You can tell your friends about your brother or sister if you want to, but you don’t have to. It’s important to make sure you feel comfortable talking about it, and if you don’t want to then its okay. Introducing your sibling to your friends is a great way for them to understand more about your brother or sister. You can also show them this booklet!

7. Is it okay to sometimes wish my sibling was normal?

Yes! It’s okay to feel sad that your brother or sister can’t do all of the things that you can do, and it’s okay to wish that they were different. But it’s also important to focus on all of the things that your brother and sister can do, and to learn about the different ways that you can spend time together.

8. My parents give my sibling a lot of attention, how can I remind them that I need attention too?

Talking to your parents is important. If you feel like you need more attention then talk to them about spending time together just you and them--without your sibling. Go to a fun movie or out to dinner with your parents and talk to them about how you are feeling. Sometimes having a boy or girl with a disability can be hard, and parents spend a lot of time taking care of them. You deserve and need attention too--you might just have to remind your parents that you want to spend time with them alone.

9. I don’t have a lot of privacy at home with all of the nurses or staff members coming to help take care of my sibling--how can I get more privacy and a space that is all mine?

Make sure to talk to your parents about privacy. It’s important to let them know how you feel! You can put a sign up on your door saying “privacy please” when you want to be alone, and talk with your parents about when the nurses or staff members are coming so that you can be prepared.

10. Where can I meet other siblings my age who have brother or sisters with genetic diseases?

The family conference that NTSAD has every year is a great way to meet other siblings who are going through the same things you are! If you can't make it to the conference, you can ask your parents to call NTSAD and find out about other boys and girls in your area that might be around to talk to you.

11. What do I say to my friends if they ask me if my brother or sister is contagious?

You can tell them that your brother or sister doesn't have a cold or the flu and its not something that you can catch. The disease has to do with the brain inside of the body, and it doesn't spread to different people. If they are still worried, you can show them this booklet!

12. What is a seizure?

A seizure is caused by abnormal activity in the brain, usually caused by electrical signals not working the way they should. It's like a light switch being turned on and off really fast. There are different kinds of seizures, but the symptoms are generally shaking, eyes rolling, and the person losing control of his or her body. If your brother or sister has a seizure, it's important to tell your parents. You can hold your brother or sister's hand and stay with them until it's over, or you can give them a big hug when it stops!

13. What is a G-Tube?

A G-Tube is a tube that helps your brother or sister eat. Not all kids who have a genetic disease have G Tubes, but some do. The tube goes in through the stomach and helps your sibling get all the foods that keep them healthy even if they can't swallow well.

14. What is a suction machine?

Sometimes your sibling might not be able to cough or spit out their saliva, so a suction machine helps pull it out like a little vacuum.

For more resources, please visit:

www.NTSAD.org
www.RareSiblingsProject.org