

FASTEN YOUR SEATBELT

**a crash course on Down syndrome
for brothers and sisters**



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Just published by Woodbine House in February 2009, *Fasten Your Seatbelt* is a new book for siblings who have a brother or sister with Down syndrome. The authors, Brian Skotko and Sue Levine, met with more than 3,000 siblings in workshops across the country, collecting and answering their questions about Down syndrome. Those questions became the focus of this book, which gives kids the green light to explore their own feelings and concerns. The following excerpt highlights just a few of the questions found in the book:

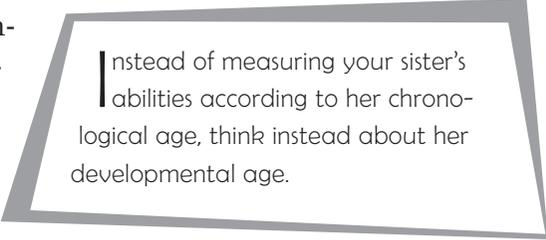
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Fasten Your Seatbelt costs \$18.95 and is available from barnesandnoble.com and amazon.com

**For more information about the book, go to
www.woodbinehouse.com**

Should I treat my sister like any other kid, or should I give her more of a break because she has Down syndrome?

Because she has Down syndrome, your sister is different in some ways from other people her age. She might have difficulty with following directions or understanding more complicated conversations. Consequently, thinking of her as slightly younger than her actual age might be helpful. Instead of measuring her abilities according to her chronological age (how old she actually is according to her birth date), think instead about her developmental age (the age at which she seems to be learning and understanding).



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In contrast to your other siblings or friends of her age, your sister might need to be repeatedly reminded of the rules or chores that need to be done. She might need to be shown how to do something several times before she successfully masters it. Your sister might need extra time to catch onto things. However, you and your parents should expect that she can follow the rules, behave reasonably, and have responsibilities around the house appropriate to her developmental age.

How do you figure out her developmental age? Your parents might be helpful with this. You can have a discussion about how much your sister understands and how you can best help her learn the rules. Your sister is certainly more like any other person than she is different. So treating her like one of the gang, who is just a bit younger, is often a good approach.

I'm always asked to help my sister. What about my own time?

Certain responsibilities and expectations come with living in any family that has more than one child. Brothers and sisters are asked to share everything from toys to bedrooms to Mom's or Dad's attention. They are asked to help each other out, protect each other in dangerous situations, work together, and clean up, just to name a few. And, of course, siblings are supposed to be nice to each other!

Helping each other is expected of all family members, especially if you are one of the oldest. But, there might be a time when you feel you are asked to do too much. Let's examine two different possible situations:

1. YOU HAVE ALWAYS BEEN AGREEABLE WHEN ASKED TO HELP YOUR SISTER.

If this is the case, your parents might think that you are fine with helping out. They might have fallen into the habit of expecting you to pitch in for many different situations. Sometimes parents fail to realize just how much they are depending on you!

To solve this problem, you need to speak up. Find a good time to have a conversation with your parents—when everyone is in a good mood, and your sister is in bed or busy with another activity. Explain that you need a break! Try to give clear examples of when you are okay with helping out and when you are not. Perhaps your parents can remember to *ask* you first rather than just expecting that you will help in every situation. You deserve your own time; so don't feel bad about looking for some time off!

In some situations, parents almost come to depend on you to be your sister's best friend. This might make you feel extra guilty. When you talk with your parents about what you are okay with and what is difficult for you, they can begin to plan ahead for times when you are not available to occupy your sister. They

can plan play dates, go to the park, or get your sister involved in helping to make dinner. With your parents' help, you'll find a good balance between the time you spend with and without your sister. Then you'll enjoy your time together so much more. You and your sister will both be happier as a result.

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2. YOU DON'T REALLY LIKE HELPING YOUR SISTER; YOU'D RATHER BE WITH YOUR FRIENDS OR DOING YOUR OWN THING.

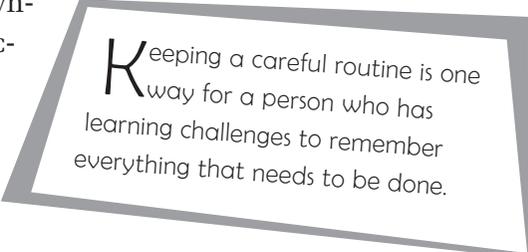
If this is the case, you might want to think about how much you do with your sister. Next, remind yourself that assisting brothers and sisters is expected in any family. Then, sit down with a piece of paper and draw a line down the middle. On one side of the line, list the kinds of things you wouldn't mind doing for your sister. On the other side, write down things you'd rather not be part of. Try to have at least five items on either side of the line. Share your list with your parents. Again, try to pick a time to talk about this when everyone is happy. Is there anything your parents want to add to the list? Discuss each item with them. Then, you and your parents can use your list as a guide for when they can expect you to help.

Your list might change from time to time. As you get older, you might find that you no longer need to use the list. You'll feel better about helping out whenever the mood strikes!

On certain days, you may find that you don't mind being with your sister. But if you've had a bad day or have a lot of homework weighing on your mind, you might feel like you really need your own time. Take advantage of the good days to spend time helping, and then your parents will be more likely to allow you to do your own thing when you need a break.

My brother is a perfectionist— everything has to be “just so.” Why does he have to be so stubborn?

Some people with Down syndrome might seem like perfectionists because they like to do their favorite activities or regular chores the same way every time. For example, your brother might take a long time to get ready for school in the morning because he combs his hair “just so” and follows the same routine, in the same way, every single day!



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Keeping a careful routine is one way for a person who has learning challenges to remember everything that needs to be done. Routines actually help the person cope with a world that moves more quickly than he does. A schedule can also be comforting and can help the person feel less anxious, especially at stressful times (like on a busy morning when everyone is rushing to get out of the house). So routines can be very helpful to someone with a learning difference; it's not that they are simply stubborn.

While you can understand why a routine can be helpful to your brother, these careful ways of doing things can get frustrating for other family members, especially when you are late and need to get somewhere quickly! You might think that it's almost impossible for some people with Down syndrome to hurry along or do something a little bit differently.

If a routine needs to be changed because it no longer works well for others in the family, it's best to begin that change one little step at a time. Your parents or a teacher may need to be part of changing a routine that is important to your brother with Down syndrome. If you think something needs to change, talk to your parents about how they can make that happen.

If your brother's routine generally works fine, but something needs to be changed every once in a while, give him a lot of notice to help prepare him. For example, when you know a few weeks in advance that baseball practice will be cancelled on a certain day, you can let your brother know ahead of time and write it into the schedule. An unexpected change in a routine can be harder to deal with. For example, your brother knows he has baseball practice every Tuesday after school. Practice gets cancelled, though, when it rains, and it's pretty hard to plan days in advance for weather! Checking the weather the night before and warning him of the possibility of rain might help somewhat. But be prepared for a little grumpy behavior!

How do you deal with people who use the word “retard”?

In many middle schools and high schools throughout the country, it's quite common to hear students use the word “retard.” The word is often used as a substitute for “stupid” or “dumb” in everyday conversation. Adults even use the word, often in relation to themselves, when they have forgotten something or have had a problem. Even some popular song lyrics include the word.

The “r” word, as we will call it from now on, is not always used for the purpose of insulting someone with a disability. In fact, some people don't even think about the negative connection between the word and people with disabilities. However, because you are close to a person with Down syndrome, chances are you are offended by the use of the word. We have heard this over and over again from many brothers and sisters. So, if it bothers you, you have lots of company!

Some brothers and sisters have even heard others using the terms “Down syndrome” and “autistic” as a substitute for the “r” word. For example, one brother caught a conversation at school where a classmate said, “Do you have Down syndrome or something?” And, on the sidelines of a soccer game, a sister heard a teammate say, “That's so autistic.” If the “r” word gets you angry, using “Down syndrome” probably really gets your blood boiling because the negative connection to disabilities is very clear here.

WHAT CAN YOU DO ABOUT IT?

The most successful way brothers and sisters have dealt with the “r” word is by sharing how the word makes them feel. You might be thinking, “The word makes me so angry, I just want to scream at the person!” But the most effective and long-lasting strategy is to calmly share your feelings.

Imagine the following: You are at the water fountain with your teammates during the halftime of your basketball game.

Someone makes a joke, and a teammate says, “That’s so r ____.” After the game is over, you go up to your buddy and tell him what a great game that was. You then tell him that you wanted to let him know that earlier, during halftime, one of the words that he used really had an effect on you. You know he probably didn’t use the word intentionally, but you just wanted to point out that the word really hurt you because you have a brother with Down syndrome. Unless the person is just downright cruel or insensitive, you can better believe that he will think twice about saying the word again!

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Telling your closest friends that the “r” word is uncomfortable for you and your family makes them more sensitive to their use of the word. As your closest friends begin to eliminate the word from their own vocabularies, you might find that they start correcting others. Before you know it, the people closest to you will use the word less and less. When an occasional student uses it to your face to annoy you, your friends might even jump in and stick up for you so you don’t have to do all the work.

Depending on your comfort level, you might try some of these other ideas that brothers and sisters across the country have used:

- Ask one of your teachers if you could give a quick report on Down syndrome. As part of the report, explain how hurtful the “r” word can be.
- Ask your coach if you or he could speak to the team about keeping the word out of the group’s vocabulary.
- Write a letter to the editor when the word is used inappropriately in a newspaper or magazine.
- Write an article for your own school newspaper.

While you can’t change the whole world, you’ll find it feels good to at least change a small part of your school and your neighborhood.

How do I explain Down syndrome to my friends?

Your friends are probably curious about Down syndrome, and some of them may not know very much about it at all. Meeting your brother or sister and finding out about his or her abilities



Providing the facts is a great first start in having a conversation with your friends.

and personal qualities will help to educate your friends. But, if they still have some questions, you can always share some additional information:

- Chapter 1 includes many facts about Down syndrome, including how it occurs and some of the common characteristics. Your friends might have a few other questions that are listed in that chapter. Providing the facts is a great way to start having a conversation with your friends. You can keep your answer short and sweet and change the subject if you don't feel overly comfortable with the discussion. As you get older and have more practice, you might find that you're more relaxed and at ease with any question.
- In addition to giving general facts, you might want to talk about your sibling's abilities and expectations for the future. Describe a few of his or her recent accomplishments or things that make you proud. Once you begin a conversation about Down syndrome with your friends, they will hopefully be more comfortable asking you other questions whenever they want to know more.

If you have **never** brought up the subject of Down syndrome with your friends, and now don't know where to start, take a closer look at the last question in Chapter 5 (page 118) for more ideas on how to start the conversation.

Will my brother be able to live on his own when he is an adult?

Adults with Down syndrome have many different options for living arrangements. Some might choose to live with family members. Others might live in a “group home” with roommates who might or might not have disabilities, and some might choose to live independently in their own apartment or house. Regardless of where they choose to live, most adults with Down syndrome will require some assistance with daily activities.

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Many communities have resources available to help adults with disabilities live independently. Some adults who live in group homes have aides or workers who visit on a regular basis to provide assistance with cooking, money management, taking medications, and transportation. Other times, family members might choose to pay for such services in order to allow a person with Down syndrome to live as independently as possible. How much support adults with Down syndrome need depends on how much they are able to do on their own.

You might be asking yourself: will my brother with Down syndrome need to live with me when my parents are older or no longer living? In some families, everyone agrees that the best living arrangement for a person with Down syndrome is with a close relation such as a brother, sister, or cousin. This kind of a decision is not usually made until all the siblings are adults. However, as we pointed out above, this certainly is not the only option for your brother as he gets older. If you are concerned about this situation, consider thinking about the following:

- If your brother is a teenager or older, your parents will probably have a discussion with him about his goals for the future.

He might or might not have an idea about where he would like to live—in fact, he may never have thought about living anywhere other than home. But, you might very well be surprised that he has his own opinions about the matter!

- Have a conversation with your parents about their expectations for your brother as he gets older. Have they made plans for his future? Where do they envision him living as they get older or are no longer living? They might already have some plans in place that they can share with you. When parents have plans arranged well in advance, siblings are often relieved that they don't have to make all the future decisions.

- If living independently with or without a support system is not an option for your brother, ask your parents what expectations they have for you in your brother's future. Share with them your honest feelings about whether you can see your brother moving in with you one day (and it is okay if you can't). You might find that your feelings change as you get older, but expressing your honest opinions with your parents can help them make practical plans for your brother's future. Many parents hope that siblings remain involved enough that they will, at least, make sure that their brother with Down syndrome is happy, safe, and has enough money. This does not necessarily mean you need to live with him or take care of all his needs.