

CAREGIVER GUIDE TO CONVERSATIONS AT HOME



THIS WAS CREATED TO HELP GUIDE CAREGIVERS IN HAVING CONVERSATIONS AT HOME ABOUT AUTISM. IT INCLUDES TOPICS DISCUSSED IN SIBSCONNECT, THINGS TO CONSIDER, PROMPTING QUESTIONS AND RESOURCES.

IT'S IMPORTANT TO HAVE THESE CONVERSATIONS FOR BOTH YOU AND YOUR CHILD. FOR YOU, IT HELPS YOU TO UNDERSTAND EXACTLY WHAT YOUR CHILD'S QUESTIONS, CONCERNS AND CURIOSITIES ARE AS A SIBLING. FOR YOUR CHILD, IT SHOWS THAT THEY HAVE A SAFE SPACE AT HOME TO ASK QUESTIONS AND VOICE THEIR THOUGHTS.

RATHER THAN WAITING FOR THE CONVERSATION TO HAPPEN NATURALLY, WE ARE ENCOURAGING CAREGIVERS TO START THEM AT HOME!

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TOPIC 1: WHAT IS AUTISM?

Autism Spectrum Disorder is a disorder of the brain that affects everyone who has it differently. We say that autism is a spectrum because it can present differences and challenges in a variety of ways for everyone. Someone with autism could have difficulties with social communication and interactions in different settings and may have restricted (very little) or repetitive behaviours, interests or activities (American Psychological Association, 2013). It is estimated that 1 in 68 people in Canada have autism.

Things to Consider:

There is never a "perfect" time to start talking about autism with your children, both with those who are autistic and those who are not, but it should be taken into consideration that the earlier these conversations start, the more normalized and comfortable they will feel. Having these conversations with you at home will set your children up for success when having these conversations outside of the home (at school, for example). Kids are smart! The sooner they understand their sibling's autism, the sooner they can help others understand!

Prompting Questions:

1. Do you know what "autism" means?
2. Do you have any questions about autism?
3. If you could know one thing about autism/your sibling, what would you like that to be?
4. Do you know why your sibling acts like this sometimes?

Resources

Helping Siblings Understand Autism and
Encouraging Positive Relationships

Reference #10

TOPIC 2: THE ROLE OF THE SIBLING

Siblings grow up together, play together, and share a lot with each other. They know a lot of stuff about each other, and even sometimes have their own method of communication. Siblings can sometimes know what the other one wants or needs before you do. Many siblings will have a lifelong bond that will outlast any other family relationship, and those who have a sibling with autism are likely to be there for every challenge they may face in their life.

Things to Consider:

It's important to address any questions or concerns they may have about something that their autistic sibling is doing or something that is happening to them in a way that is easy to understand for someone their age. It's also important to initiate these conversations as well to show your children that having open and honest discussions are welcomed. Having autism will provide different challenges throughout your child's lifespan, and their needs may change over time. Having your other children know that they can be there to help and support their autistic sibling every step of the way will help them feel secure in their role as a sibling. However, as a caregiver, it's also important to recognize that not all siblings feel secure and content in their role, and there is a chance they may never. Again, having open and honest communication about the thoughts and feelings of everyone involved can be beneficial in creating a long-lasting relationship between the siblings.



TOPIC 2: THE ROLE OF THE SIBLING

Prompting Questions:

1. Are there times when we're asked questions about your sibling's autism that you think you could also answer?
2. Are there times where you have been worried about something involving you or your sibling that you felt should have been addressed?
3. Would you like to be included in more conversations about your sibling's autism?
4. Do you have any questions about how you can support your sibling?
5. Are you worried about having to support your sibling?
6. How does being a sibling make you feel?



Resources

What Siblings Would Like Parents and Service Providers to Know

Reference #14

TOPIC 3: COPING STRATEGIES

As a caregiver, you have likely experienced a lot of emotions around your child's autism diagnosis. Did you know that your other children have likely experienced a lot, if not all, of those same emotions? The difference is that children do not have the same ability to cope as an adult would. Let your child know that it's okay to feel stressed out, anxious, and even angry, and teach them that there are some things they can do to cope with their feelings. Talking to someone, like a friend (or even a counselor); talking about their situation with other children their age who also have siblings with autism; taking a break from the situation they're in, like leaving the house or going to their room; or physical exercise, like walking, running, and biking; are all strategies that could help them cope with hard and/or big feelings.

Things to Consider:

No pair or group of siblings gets along 100% of the time, and autism siblings are no exception. They may disagree, argue, and sometimes even get angry at each other. It's important to let your child know that it's okay and normal to get mad at their sibling if they've done something they didn't like to them, their stuff, or their space. Make sure that they know that they're allowed to have boundaries and that their sibling is still required to follow them regardless of disability. The autistic sibling may require more time or explanation to understand what their sibling is asking of them, but you can work on setting boundaries together as a family.

It could also be beneficial for caregivers to model both talking about their feelings and using coping strategies in order to teach their children how to use them. Seeing that someone they love and look up to, such as yourself, will help siblings normalize how to express themselves as well as using these strategies as needed.



TOPIC 3: COPING STRATEGIES

Prompting Questions:

1. What are some things that you've felt about your sibling, or about autism? I have felt...
2. Is there a time where you experienced guilt, or became upset at yourself, for having big feelings towards your sibling?
3. Do you feel comfortable talking to me when you're experiencing big feelings towards your sibling?
4. What are some things that you like to do that help to make you feel better? I like to do...



Resources

(1) I Am Stronger Than Anger: Picture Book About Anger Management and Dealing with Kids Emotions and Feelings (Preschool Feelings Book, Self-Regulation Skills); **(2)** "I'm Constantly Thinking About Bev and her Future"; Siblings Speaking About Aging

Reference #3 and #12

TOPIC 4: STRENGTHS AND WEAKNESSES

Everyone has different strengths and weaknesses, and it's important that your children know that everyone has them, including them and their sibling. At SibsCONNECT, we use superheroes and villains to talk about our strengths and weaknesses! As a caregiver, you can help your children learn about their strengths and weaknesses in terms of what they like to do and what they're good at, as well as what they don't like doing and feel they're not-so-good at. Doing this together with all your children will help them learn about each other's at the same time.

Things to Consider:

Being aware of these strengths and weaknesses will help your child become better advocates for themselves and their sibling. For example, if there is a presentation at school and your child knows that their autistic sibling is sensitive to flashing lights, they can let a teacher know to hold off on anything that would have flashing lights in order to allow their sibling to enjoy the presentation just as much as everyone else in the auditorium and they'll be less likely to exhibit behaviours linked with light sensitivity. This skill will also come in handy for your other children when advocating for themselves. For example, your child may realize that they need some extra help in math but may feel too guilty to ask as they do not want to put anything else on your plate (a common bad for individuals who have a sibling with different needs). Having these self-advocacy skills, as well as knowing that they can talk about it either to you or a teacher would help them receive the supports they need sooner.



TOPIC 4: STRENGTHS AND WEAKNESSES

It is also important to consider talking about your strengths and weaknesses as well. When children see that all people, including their caregivers, have things they're good at and not-so-good at, it helps to normalize their thoughts and emotions towards themselves and others!

Prompting Questions:

1. What is something that you like to do or something that you're good at? I think you're good at...
2. What is something that you don't like to do or something that you feel you're not so good at?
3. How can we change your weaknesses into strengths?
4. What is something your sibling likes to do or something they're good at?
5. What is something that your sibling doesn't like to do or something that you think they may struggle with?
6. How can we turn their weaknesses into strengths?
7. What do you think I'm good or not good at? What do you think I can do differently?

Resources

(1) How to Let Young Siblings Know You Care;

(2) Ask for Help

Reference #15 and #2

TOPIC 5: ADVOCACY

Being an advocate for yourself and others is an important part of life. As mentioned earlier, siblings typically have the longest lasting relationship within a family, and your child may be their autistic siblings' caregiver at some point in time. Because of this, they are likely going to be in situations that require advocacy just as often as you are. Your child cares about what's right for their sibling and will likely do whatever they can to make sure they aren't being discriminated against or treated unfairly. It's also just as important to make sure that they are able to stand up for themselves. Teaching them what to say in situations where they feel they are being treated unfairly (for example, "you asked me to do _____ but you never ask my sibling to do it, even though they're capable of doing it"), will help them become more confident self-advocates.

Things to Consider:

Teaching your child ways in which they can advocate for themselves and others will ensure that they are more likely to know what to say not only when they see unfair treatment of others, like their sibling, or when they experience it themselves. It's also important to let your child know that they can even talk to you about something that may be bothering them, even if it is you they feel has treated them or their sibling unfairly. Being open and welcoming to these conversations and helping your child to know that they can advocate for themselves and their sibling, even to you, will help them become more confident in their role as a sibling and as a person.

TOPIC 5: ADVOCACY

Prompting Questions:

1. Have you ever been in a situation where you thought your sibling was being treated unfairly? Did you know what to say or do you wish you had said something different?
2. Have you ever been in a situation where you thought there was a way that your sibling could have succeeded with better support?
3. Have you ever noticed a time where your sibling could have done something that was done for them?
4. Have you ever been in a situation where you thought that you were being treated unfairly? Did you know what to say or do you wish you had said something different?
5. Have you ever been in a situation where you thought you could have been more successful had you had the help you needed? Did you know how to ask for it?



Resources

(1) Autistic Kids: The sibling problem; (2) Supporting Siblings at School: Small Ways to Make a Big Difference for Siblings of Children with Disabilities

Reference #7 and #16

TOPIC 6: BEING TREATED DIFFERENTLY

An autism diagnosis can come with a lot of stress, confusion, and anxiety, and it will often be at the forefront of both the caregivers' and the siblings' minds. When they have a sibling with autism, your child will likely grow up knowing that their sibling will sometimes require extra help, support, or care. However, there may be times that your child will feel that the way they're being treated is unfair compared to the treatment of their autistic siblings. For example, your child may feel that their sibling gets more recognition for their achievements, or that their sibling may not get in as much, or any trouble, in the same way that they would. Alternatively, they may feel that unfair expectations have been placed on them that are not placed on their autistic siblings.

Things to Consider:

While it is likely not your intention to put additional expectations on your other children, it's important to let them know that their feelings and/or frustrations are valid and to reassure them that they can talk to you any time they feel this way. Also, it's important to reflect on times you may be unintentionally treating your children different from one another and to have a conversation on their thoughts and feelings on the matter. Having an honest conversation on the expectations of each sibling is important, especially when you may need to explain why they may have more, or different, responsibilities than their siblings. For example, if your child is frustrated with the chores they are expected to do, is there room for you and them to have a conversation on what chores they would like to do at that time? Let's use cleaning up after dinner as a concrete example: Do you want to dry the dishes or take out the garbage? Allowing your children to have some choice and control over the things they are expected of may help to make those expectations feel more reasonable to them.

TOPIC 6: BEING TREATED DIFFERENTLY

Prompting Questions:

1. Has there ever been a time when you felt that we didn't pay as much attention to you or the things you are doing like we do for your sibling?
2. Has there ever been a time when you felt there were unfair expectations placed on you, or extra things that we wanted you to do, that weren't placed on your sibling?
3. Do you know why there are some things that you are asked to do that your sibling isn't?
4. Has there ever been a time when you were asked to do something that you feel your sibling also could have done? If so, what are they? Do you think there is a way we could divide up that task between you more often?



Resources

Life as an Autism Sibling: A Guide for Teens

Reference #19

TOPIC 7: FOSTERING RELATIONSHIPS BETWEEN THE SIBLINGS

Every sibling relationship is unique, and a relationship between siblings where one has autism and the other does not can come with unique differences and even challenges. Individuals with autism may have different ways of communicating their needs and emotions, and the way they show affection to those they love may look different than one would expect. As a result, other siblings may have a harder time knowing what your child with autism may be feeling.

This can also shine through on their playful interactions. While play between your children may not always look the same as it does for other siblings you may know, there are still ways to foster a good and healthy relationship between the two. Strategies include helping them find subjects, activities, games and more that are of common interest to each of them. You could then encourage types of play that involve those interests (sensory play, arts and crafts, songs, chase games, playing with toys, reading stories, building with blocks or other materials, etc.). Another way to ensure that play goes smoothly is to make sure they know helpful communication strategies for the type of play they're participating in, so they can all enjoy it just as much.



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TOPIC 7: FOSTERING RELATIONSHIPS BETWEEN THE SIBLINGS

Things to Consider:

As much as spending time together and working with the above strategies is important in fostering the relationship between your children, spending time apart from each other is just as important. This allows for your children to explore their own interests, have time to decompress and have full control over how they are playing or interacting with their things. Having this space to be alone and do other things of interest helps your children to come together in a content and relaxed state to have fun with each other at a later time! It's important for your child to know that they're allowed to have separate interests that are just for them, and some things they can do separately from each other.

Prompting Questions:

1. What are some things you enjoy doing with your sibling? Do you think you would enjoy doing more things together? What might that be?
2. Is there something about your sibling's interest that you would like to know more about?
3. What is something that your sibling does not like doing, but you would still like to do?
4. What are some things you like to do in your alone time, when you are playing or doing activities by yourself?
5. Do you feel you get enough alone time? Or do you feel you get too little or too much alone time?

Resources

Brother's, Sister's and Autism: A Parent's Guide to
Supporting Siblings

Reference #18

TOPIC 8: THE W'S OF AUTISM TALK

As mentioned earlier, your child will most likely be a lifelong advocate for their sibling with autism. This will likely include having to explain or talk about their sibling's autism to many people in their lives, such as friends, teachers, employers, and more. Some siblings may want as many people as possible to understand their sibling's autism; some siblings may not want to talk about autism at all; and some may only want to talk about it in certain situations with certain people. At SibsCONNECT, we discuss that your answer, if you even have to or want to answer other's questions or respond to their comments, will depend on who they're talking to. For example, when talking to medical professionals about their sibling, they will likely require information about their autism. However, when it comes to personal relationships, they can use their own discretion on how much information they want to give and to whom.

Questions and/or comments that your child may hear are:

- What is wrong with your sibling?
- Why is your sibling acting like that?
- I would be so embarrassed if they were my sibling.
- They probably just do that for attention.

As you can see, some of these questions/comments can be said in many different contexts, and it'll depend on who is asking, why they're asking and how they're asking that will determine if your child (or even you) want to answer or respond to them!



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TOPIC 8: THE W'S OF AUTISM TALK

Things to Consider:

Preparing your children for questions or comments like that will make them more able to answer (or not answer) in a way that makes them feel better about the situation. We can teach to identify how, why and when questions are asked or comments are made in order to determine whether they want to answer or not. At SibbsCONNECT, we often do this through role play where one person will ask a question or make a comment in a certain way, and the other person will practice their response, if they choose to respond at all! We also take the time to practice our coping strategies if these questions or comments give us being feelings.

Questions or comments like these could be coming from friends or people in their lives who just don't know and are not educated in autism, in which case your child may want to help them understand their sibling's autism by answering their questions. It's important for them to know that they don't have to explain autism to anyone who may be being disrespectful towards them or their sibling or if they just don't want to. As mentioned earlier, in situations such as when information is being asked by doctors or teachers, it would be important for those questions to be answered. However, if someone is just being disrespectful comments or if your child just doesn't feel like talking about it, it's also important for them to know that they don't have to answer.



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TOPIC 8: THE W'S OF AUTISM TALK

Prompting Questions:

1. Have you ever been asked a question about autism/your sibling's autism from a (teacher, friend, doctor, neighbor, stranger, therapist)? If so, did you feel comfortable answering? Do you feel like you would need to answer?
2. What types of questions have you been asked? What types of answers did you provide, if any? Do you want to practice your answers with me?
3. Do you think you would be able to tell the difference between someone asking a question because they don't know anything about autism, and someone asking a question because they wanted to be mean?
4. What if someone makes a comment about autism/your sibling's autism that doesn't seem very kind. What do you think you would do? (If the answer is them engaging with the person in a way that may get them in trouble, maybe talk about the coping strategies they have learned and how they could use these in this moment!)



Resources

Autism, My Sibling, and Me

Reference #17

TOPIC 9: FAMILY TIME

There are times when caregiver(s) spend a lot of one-on-one time with their autistic child as there are a lot of appointments, therapies, extra needs, etc. Spending time as a family can be helpful in including everyone in fun and meaningful ways. While some family activities may look different for your family, any time spent together will be beneficial to everyone. It may also be helpful to find some time to spend alone time with your other child (in SibsCONNECT, we call this “Special Time”!). Finding a time where you can be alone with your child without their autistic sibling present, for example cooking or shopping for groceries together, could be beneficial to your relationship, and can provide a feeling of importance and one of being special, too, for your other child.

Things to Consider:

Family public outings may look a bit different when you have a child with autism, and their needs may cause staring or other forms of unsolicited attention in public. In situations like these, it's important to remind yourself and your children that most people don't pay attention to others' behaviours and needs, and of those who do, a lot of people are very understanding and kind! If your child is afraid of being embarrassed in front of their friends, it may be a good idea to remind them that their feelings and worries are valid, and that their friends are likely to be understanding and kind, and will not make fun of you or your sibling for their behaviours. Another strategy your child could use is humour. Something that may have seemed embarrassing at the time can be turned into a funny story later.



TOPIC 9: FAMILY TIME

Prompting Questions:

1. Have you ever felt embarrassed/upset/angry/worried by your sibling's behaviour in public? Do you know/want to know about coping with embarrassment in public?
2. Have you ever felt embarrassed/upset/angry/worried by your sibling's behaviour in front of your friends? How did they respond? Did they try to make you feel better about it?
3. Can you think of any times where in the moment you felt embarrassed/upset/angry/worried, but now looking back you can find something funny about it? I remember...



Resources

Positive Relationships in Families with Autistic Children

Reference #23

RESOURCES

Please note: This resource list includes resources used in creating this guide as well as additional resources that may be helpful for you and your child.

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