

Helping Your Child Understand Spina Bifida



The following information should be seen as a guide. It offers simple answers to questions young child may ask and activities which can be used to help your child better understand Spina Bifida and explore new ways to enrich their lives. The information and activities can be used to help you open and guide discussion with your child about issues such as movement, bathroom routines, exercise, physical activity, diet and scars all of which are important for your child's sense of self.

Talking to your child about Spina Bifida

When talking to your child about Spina Bifida remember:

- It's OK to say "I don't know" to a question from your child. Reassure them that their question is important and that you will get help to find the answer.
- It's OK if you can't find the words to use, you will have more than one chance to talk about these things
- It's OK if your child asks the same question a few times. Most children need to do this before they understand a complex condition like Spina Bifida.
- It's OK and encourage for you and your family to seek support from others, such as Spina Bifida Hydrocephalus Ireland (SBHI), your SBHI Family Support Worker, other parents, others with Spina Bifida, doctors, therapist etc.

Typical questions, complaints and concerns your child may raise and suggested replies may include:

What is Spina Bifida?

"Spina Bifida is a medical condition you were born with. When you were in Mummy's tummy, part of your back didn't grow the way it should have. This can make it hard for you to go to the toilet and to use your legs. Nothing that you, Mummy or Daddy did caused Spina Bifida. No one knows exactly how it is caused".

Will I always have Spina Bifida?

"Yes, you will have Spina Bifida all your life. This means you may need to use something to help you get around like your wheelchair or your walker or crutches and you will need to pay attention to how you use the bathroom."

Will people love me?

"That is a very good questions and easy to answer. Yes! They already do!"



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Movement

Young children have a strong natural curiosity about visible differences. Your child may ask why their movement, legs and feet may be different than other children. After providing answers, explore how your child's moves can have hidden gifts.

Online Worksheet:

Equipment I Use

http://www.myspinabifidabook.org/Activities/Activity_Eng_1.html

Why can't I walk like other children?

Your back was made differently, so you may not feel your legs and feet the way they do. This can make it difficult for you to walk. You may use a wheelchair, walker, crutches or calipers to move around.

Why do I move differently than other children with Spina Bifida?

Just as children can have different colour eyes, they can have different kinds of Spina Bifida. There are many types of Spina Bifida. The kind you have determines how you move and what equipment you use to get where you want to go.

Why are my legs and feet small?

Legs and feet need to move a lot to grow. Because you only move yours a little they stay small.

Bathroom Routines

Your child may be self-conscious that they use the bathroom differently than other children do. To help address this concern, explain why particular supplies and routines are needed and together develop playful ways of coping.

Online Worksheet:

Bathroom Equipment I Use

http://www.myspinabifidabook.org/Activities/Activity_Eng_2.html

Why do I use the bathroom differently?

Because your body didn't grow the way it should, it can't tell you when it's time to wee or poo. So you use other ways to go to the bathroom. You wear pads and catheterise. This is how you help you body to not have accidents.

I don't want to wear pads. My friends don't. It's not fair.

It sounds like you are feeling mad and sad. That's okay. I'm glad you told me. Your friends don't wear pads because their bodies can tell them when to wee or poo. You may be



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able to wear only underwear, when you are older. Would you like to wear underwear over you pads right now?

I want to hide when I have to ask for help to go to the bathroom.

I'm glad you told me how you're feeling. Let's try and change how you're feeling together. There are different ways you can let grown-ups know it's time for you to go to the bathroom. You can say 'I need help', use a secret code or make a hand signal, like waving or do a thumbs up.

Exercises

Your child will need support to do stretches and wheelchair push-ups regularly. To help establish a routine, explain why exercises are important and make them fun.

Online Worksheet:

Exercises I Use

http://www.myspinabifidabook.org/Activities/Activity_Eng_3.html

Why do I have to do my exercises?

Exercises can make it easier for you to move and wheelchair push-ups will help protect your skin from sores when you sit too much. Exercising is very important!

I don't want to do my exercises!

I know it's hard, but exercises need to be done every day. Let's make this a special time! You can colour, do a jigsaw or play a game. What favourite things would you like to do while you exercise.

Physical Activities

All children need physical activity. Encourage your child by explaining how this makes their body stronger, going to the bathroom easier and offers new ways to play with friends. Then, ask your child to choose which of the following they would like to try first.

Suggested Activities To Help Your Child:

Indoor

- Ask your child to draw themselves playing their favourite sport
- Use magnetic letters to form words **high** up on your fridge door
- Stretch up to "draw" on the bathroom mirror with shaving cream
- Creating treasure hunts around your home
- Finger painting or colouring on paper taped to the wall



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Outdoor

- Taking a dog (a neighbour's if your family doesn't have one) for a walk – supervised by an adult
- Flying a kite
- Watering the garden
- Playing Tag
- Creating an obstacle course

A suggested obstacle course for your child and their friends could include weaving between three empty 2 litre milk containers, going under a towel hung between a window sill and a chair and tossing a Frisbee into a cardboard box.

Diet Tips

Healthy eating is important for children. Your child will also need to learn what foods and drinks help prevent constipation. To help your child make better decisions when choosing food and drink, explain why these are important, acknowledge their cooperation and have fun with food presentation.

Online Worksheet:

Foods that help me poo

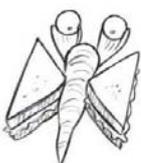
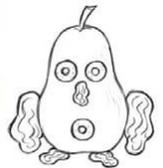
http://www.myspinabifidabook.org/Activities/Activity_Eng_4.html

Why do I have to eat so many fruit and vegetables?

Eating fruits and vegetables and drinking lots of water helps your body poo. Without these you get constipated. Being constipated is when your poo is hard and can make you feel sick and have tummy aches.

Try the following food sculptures, or make up some of your own

To make a **robot**, cut a pear in half, from top to bottom. Use raisins for feet and nose, whole wheat cheerios for the eyes and mouth and dates for the arms.



To create a **butterfly**, cut a low-fat cheese or chicken sandwich on whole grain bread into two triangles. Add a carrot for a body and celery sticks and tomatoes for the antennae.

To make a **spider**, spread low-fat peanut butter on a whole wheat cracker for the body, add eight pretzel sticks for the legs and two raisins for the eyes.



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Scars

Children don't like to be different. When a child has a scar and it's noticeable, it may attract unwanted attention and comment. Support your child by helping them to recognise and express their feelings about having scars.

Online Worksheet:

Scars are my medals

http://www.myspinabifidabook.org/Activities/Activity_Eng_5.html

"Scars are medals made of skin that show you have been very brave"

Ask your child how they feel about their scars. Remember you do not always need to respond or discuss. You can simply listen and then repeat, in your own words, what your child has just said. This will encourage your child to continue to talk freely and openly.

Ask your child to think of other people who might also have scars. Realising that professional athletes, teachers and garda may have scars from accidents or operations may help him understand that it is quite common to have a scar.

Sew "scars" onto your child's favourite stuffed toy. It can help provide comfort, self-acceptance and discussion about looking different and having scars.e skin's elasticity.