

Keeping Children with Spina Bifida Safe from Sexual Abuse

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What Families Need to Know

Introduction

Children with Spina Bifida, like all children, go through sexual development. As they get older, they share the same interests as their peers in making friends, dating, and having families of their own.

It is important for children with Spina Bifida to learn about their sexual and reproductive health, but these conversations do not happen enough. Some people wrongly believe that people with disabilities are not interested in dating or relationships. Healthcare providers often say they haven't had the training or support to feel comfortable talking about sexual and reproductive health with their patients. Because of this, only 5% of adults with Spina Bifida say they have talked about sexual health with their healthcare providers.

This gap can leave young people less prepared for healthy relationships and at a higher risk of abuse. Families, healthcare providers, and the whole community need to work together to prevent abuse and promote healthy sexuality for people with Spina Bifida.

Why this Matters

Children with disabilities are **2 to 4 times more likely** to be sexually abused than children without disabilities. Some children with Spina Bifida may have an even greater risk because of their daily care needs:

- **Early urinary catheterization.** Some children begin using catheters when they are very young. Because they become used to adults helping with private parts of their body, it can be harder to know when a touch is okay and when it is not.
- **Precocious puberty.** Some children with Spina Bifida, especially girls with hydrocephalus, go through puberty early—early as 8 years old. Their bodies may change before they are emotionally ready.

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- **Personal care needs.** Some children need extra help with bathing, dressing, using the bathroom, or other personal care. This means more people may need to help them with private parts of their body.
- **Social isolation.** Some children have fewer chances to spend time with friends or learn about healthy relationships. This can make it harder to recognize unsafe situations or know how to ask for help.

These challenges make it especially important to start teaching children about body safety at an early age. Open conversations, clear rules about personal boundaries, and regular practice speaking up can help children stay safe.

Who Might Abuse a Child?

About 93% of children who are sexually abused are **hurt by someone they know**, not by a stranger. This person could be a family member (34%) or acquaintance (59%) which could include a family friend, neighbor, caregiver, or someone the child knows through school, church, sports, or other activities.

Children with Spina Bifida may have a harder time protecting themselves if they:

- Depend on others for daily care, such as bathing, dressing, or using the bathroom.
- Have trouble speaking or communicating
- Do not fully understand relationships or personal safety
- Are used to adults touching private parts of their body during medical or personal care.

This is why it is so important to teach children about body safety, personal boundaries, and trusted adults.

What Abuse Can Look Like:

Sometimes children tell someone they have been hurt. Other times, the signs are harder to see. Watch for changes such as:

- Being afraid of a certain person or not wanting to be around them.
- Acting differently than usual, such as becoming very quiet, angry, or having more tantrums.

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- Showing sexual behaviors or using sexual words that are not right for their age.
- Complaining about stomach pain, pain when using the bathroom, or pain in their private areas.
- Bruises, bleeding, sores, or other injuries around the private parts of the body.
- A sexually transmitted infection (STI) or other symptoms that a healthcare provider cannot easily explain.
- Saying things like, “Something bad happened,” even if they do not share many details.

Trust your instincts. If something does not seem right, take your concerns seriously and ask for help.

What Can Families Do?

You are your child’s first and most important teacher and protector. You can help your child stay safe by talking openly about their body, feelings, and relationships from an early age. Research shows that over 90% of adults with Spina Bifida want a healthy romantic and sexual life, including dating. So, it’s especially important that children and teens learn about healthy relationships, personal boundaries, and how to stay safe. These conversations should happen early and often, not just once.

Here are ways you can support and protect your child:

- **Start early:** Teach your child the correct names for all body parts, including private parts. Explain that some parts of the body are private and should be treated with respect. Talking about these topics in a calm, natural way helps your child feel comfortable asking questions.
- **Teach the difference between safe and unsafe touch:** Help your child understand that no one should touch their private parts unless it is for personal care, like bathing, or for medical care, and only when they understand why. When teaching catheterization, explain which touches are okay and which are not. Let them help in age-appropriate ways and encourage them to speak up if something feels different or wrong.

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- **Make talking about these topics normal:** Talk about body changes, feelings, and relationships as your child grows. Let them know it's okay to be curious and to ask questions. These talks help them build confidence and reduce shame.
- **Remember that most abuse is by someone the child knows:** Many children are abused by someone they already know and trust. This is why regular conversations at home are so important. Remind your child that they can always tell you if anyone makes them feel uncomfortable, even if it is someone they know or like.
- **Practice speaking up:** Teach and practice phrases like “stop,” “no,” or “I don’t like that.” Let your child know they have the right to say no if something feels uncomfortable or unsafe. For medical care like catheterization, explain that sometimes it may feel uncomfortable, but it should always be done in a respectful, safe way. Teach them to tell you or another trusted adult right away if something feels *different than usual* or makes them feel worried.
- **Keep communication open:** Tell your child often that they can come to you with any question or concern. Listen calmly and thank them for telling you. Remind them that safe adults do not ask children to keep secrets about touching or anything that makes them feel unsafe.
- **Talk about photos and online safety:** Teach your child never to take or send pictures of their private body parts. Explain that if anyone asks for these pictures online, through text messages, or on social media, they should tell a trusted adult right away.
- **Ask about abuse policies:** If your child receives personal care, therapy, or attends outside programs, ask if staff have had background checks and what training they receive to prevent abuse. Don’t be afraid to ask questions. You are your child’s advocate.

What If You Think Your Child Has Been Abused?

- Under age 18: Report to Child Protective Services
- Age 18 or older: Report to Adult Protective Services
- You can also talk to trusted professionals at your child’s medical office or school. Doctors, nurses, therapists, and teachers are mandated reporters. This means they are required by law to report suspected child abuse so it can be investigated. Most children’s hospitals also

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have child protection or sexual abuse teams who are trained to support families and guide next steps.

- Write down your concerns: If something feels wrong, write it down and report it immediately.

How to Empower Your Child

Every child deserves:

- Respectful education about their bodies, relationships, and boundaries
- The chance to explore safe, age-appropriate activities
- Knowledge and skills to advocate for themselves and speak up when something is wrong

You can help your child by:

- Giving them many chances to make friends and practice social interaction
- Helping them learn to say what they need, what they like and don't like, and when something feels wrong
- Teaching the difference between affection, care, and abuse
- Reminding them how and to whom they can report harmful behavior

How Can Healthcare Providers Help?

Healthcare professionals are important partners in protecting and empowering children with Spina Bifida. As mandated reporters, they are required to report any suspected abuse, but their role doesn't stop there.

Providers can:

- Recognize that patients with Spina Bifida are not asexual and deserve full, respectful conversations about puberty, privacy, safety, and relationships.
- Start and normalize sexual and reproductive health discussions early, including body changes, consent, STI prevention, contraception, and healthy relationships.
- Screen for signs of abuse or coercion.
- Seek out training or tools to build skills and comfort in having these conversations.
- Refer to adolescent medicine, gynecology, or other specialists when appropriate.

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When providers speak openly and confidently about sexual reproductive health, they help create a safe space for families and help prevent harm before it starts.

Conclusion

Protecting children with Spina Bifida from sexual abuse takes more than just watching for it. It also means teaching skills, building confidence, and having open conversations. When families, providers, and communities work together, we can reduce risk and empower youth with Spina Bifida to recognize unsafe situations, speak up, and stay safe.

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This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.

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