Spina Bifida: Your Guide to a Healthy Life

Integument (Skin)
For ages 0-18+

Adapted from Guidelines for the Care of People with Spina Bifida, 2018
Skin-related issues have a significant impact on health, activities of daily living, and quality of life among people with Spina Bifida.

Complications related to wounds, also known as pressure injuries or skin breakdown, are the second most common problem seen in Spina Bifida clinics. Over one quarter of patients on the National Spina Bifida Patient Registry report having had a pressure injury.

These guidelines are aimed at preventing skin breakdown from happening in the first place.
Guidelines for Integument (Skin) Care

0-11 Months

1. Learn which parts of your baby’s skin appear to lack sensation. Your child’s health care provider can assist with this.

2. Regularly inspect these areas of skin for changes in how the skin looks and feels, as well as changes in temperature.

3. Always check bath water temperature before placing your baby in the bath, and if possible, use a bath water thermometer with a temperature of no more than 37-38º C/100º F.

4. Before placing your baby anywhere, check for hot surfaces that have been exposed to the sun, such as car seats and playground equipment.

5. Use barrier diaper creams (creams with zinc oxide) to protect the skin from diaper rash.

1-2 Years

1. Regularly inspect for changes in how the skin looks and feels, particularly areas of skin that lack sensation and places where your child is bearing weight (such as feet, knees if your child is a crawler, and buttocks if your child uses a wheelchair). Also check for changes in the temperature of the skin of the infant.

2. Always check bath water temperature before placing your child in the bath, and if possible, use a bath water thermometer with a temperature of no more than 37-38º C/100º F.

3. Before placing your child anywhere, check for hot surfaces that have been exposed to the sun, such as car seats and playground equipment.

4. Use barrier diaper creams (creams with zinc oxide) to protect skin from diaper rash.

5. If your child wears braces, always check to make sure they fit well. Your child’s physical therapist or orthotist can teach you what to watch for. After removing the braces, red areas should be watched to make sure they disappear within 15 – 20 minutes. Pressure sores or pressure injuries often start as a dark red area that eventually gets darker and darker until the area is purple or black. This is caused by continual pressure on the skin and will become a sore if the pressure persists. Your child’s braces may need to be refitted if they cause red areas, which may especially occur as your child grows.

6. Make sure your child wears protective clothing or shoes on the areas of the body that lack sensation. Water shoes should be worn at the beach or pool.

7. Immediately seek treatment if your child develops a pressure injury or a break in the skin in the areas that lack sensation.

3-5 Years

1. Regularly inspect areas of skin that lack sensation or where your child is bearing weight (feet; knees if your child is a crawler; buttocks if your child uses a wheelchair) for changes in how the skin looks and feels, as well as changes in the temperature of the skin of the infant.

2. Help your child learn which areas of their skin lack sensation and how to inspect those areas. Teach your child to use a mirror to examine the skin of the buttocks and genital area.

3. Keep in mind that heat, moisture, and pressure on areas of skin that lack sensation can quickly lead to pressure injuries or skin breakdown. Pressure sores or pressure injuries often start as a dark red area that eventually gets darker and darker until the area is purple or black. This is caused by continual pressure on the skin and will become a sore if the pressure persists.

4. Always check bath water temperature before placing your child in the bath, and if possible, use a bath water thermometer with a temperature of no more than 37-38°C/100°F.

5. Before placing your child anywhere, check for hot surfaces that have been exposed to the sun, such as car seats and playground equipment.

6. Use barrier diaper creams (creams with zinc oxide) to protect skin from diaper rash.

7. If your child wears braces, always check to make sure they fit well. Your child’s physical therapist or orthotist can teach you what to watch for. After removing the braces, red areas should be watched to make sure they disappear within 15 - 20 minutes. Pressure sores or pressure injuries often start as a dark red area that eventually gets darker and darker until the area is purple or black. This is caused by continual pressure on the skin and will become a sore if the pressure persists. Your child’s braces may need to be refitted if they cause red areas, especially as your child grows.

8. Make sure your child wears protective clothing or shoes on the areas of the body that lack sensation (including water shoes at the beach, in a pool, or on a pool deck).

9. Immediately seek treatment if your child develops a pressure injury or a break in the skin in the areas that lack sensation.

10. Check out the “Did You Look?” brochure for more details on how to protect your child.
6-12 Years

1. Regularly inspect areas of skin that lack sensation or where your child is bearing weight for changes in how the skin looks and feels, as well as changes in temperature.

2. If your child uses a wheelchair, ask your provider about using a pressure-relieving cushion and check it daily for wear or damage.

3. Help your child learn which area of their skin lack sensation and how to inspect those areas.

4. Keep in mind that heat, moisture, and pressure on areas of skin that lack sensation can quickly lead to pressure injuries or skin breakdown. Pressure sores or pressure injuries often start as a dark red area that eventually gets darker and darker until the area is purple or black. This is caused by continual pressure on the skin and will become a sore if the pressure persists.

5. If your child wears braces, always check to make sure they fit well. Your child’s physical therapist or orthotist can teach you what to watch for. After removing the braces, red areas should be watched to make sure they disappear within 15 – 20 minutes. Pressure sores or pressure injuries often start as a dark red area that eventually gets darker and darker until the area is purple or black. This is caused by continual pressure on the skin and will become a sore if the pressure persists. Your child’s braces may need to be refitted if they cause red areas.

6. Make sure your child wears protective clothing or shoes on the areas of the body that lack sensation (including water shoes at the beach, in a pool, or on a pool deck). Wearing clean and dry socks is also important to protect the skin.

7. Using antiperspirant can help keep skin dry, especially on the feet and anywhere the skin rubs together.

8. Always check bath water temperature, and if possible, use a bath water thermometer with a temperature of no more than 37-38º C/100º F.

9. Check for hot surfaces that have been exposed to the sun, such as car seats and playground equipment.

10. Encourage your child to drink plenty of water and eat healthy foods for healthy skin.

11. Immediately seek treatment if your child develops a pressure injury or a break in the skin in the areas that lack sensation.

12. If your child is a full-time wheelchair user, teach them to move to relieve pressure every 15 minutes. Moving can include wiggling, leaning forward, pushing up off the surface, etc.

13. Check out the “Did You Look?” brochure for more details on how to protect your child.
13+ Years

1. Inspect your skin daily for signs of pressure injuries. Pressure sores or pressure injuries often start as a dark red area that eventually gets darker and darker until the area is purple or black. This is caused by continual pressure on the skin and will become a sore if the pressure persists. You may need to use a mirror to check some areas of your skin.

2. If you use a wheelchair, talk to your provider about using a pressure-relieving cushion and check it daily for wear or damage.

3. Keep in mind the factors that can put you at greater risk for developing a pressure injury: wheelchair use, a recent surgery, a shunt, a higher level of lesion, and bladder incontinence. Males are also at greater risk of skin breakdown.

4. Keep in mind that heat, moisture, and pressure on areas of skin that lack sensation can quickly lead to pressure injuries. Check the “Did You Look?” brochure for more details on how to protect your skin.

5. If you wear braces, always check to make sure they fit well. Your physical therapist or orthotist can teach you what to watch for.

6. Always check bath water temperature, and if possible, use a bath water thermometer with a temperature of no more than 37-38° C/100° F.

7. Check for hot surfaces that have been exposed to the sun before the parts of your body that lack sensation come into contact with them (for example, hot sand at the beach or other items that might be hot such as electric blankets, space heaters, etc.)

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8. Drink plenty of water and eat healthy foods for healthy skin.

9. Wearing clean and dry socks is important to protect the skin. Seamless socks are recommended.

10. Using antiperspirant can help keep skin dry, especially on the feet and anywhere the skin rubs together.

11. Immediately seek treatment if you develop a pressure injury or a break in the skin in the areas that lack sensation. You may need to see a wound clinic for any severe pressure injury.

12. If you are a full-time wheelchair user, change position to relieve pressure every 15 minutes.

13. Learn safe transfer skills. Your physical or occupational therapist can help with this.