



Spina Bifida:

*Your Guide to
a Healthy Life*

Health Promotion and Preventive Health Care Services

For ages 0-18+

***Adapted from Guidelines for the Care of People
with Spina Bifida, 2018***



**SPINA BIFIDA
ASSOCIATION**

Introduction



Routine, preventive health care is key to maintaining health and overall quality of life for people with Spina Bifida. Spina Bifida is often a complex condition to manage, affecting multiple systems in the body. For this reason, people with Spina Bifida have specific life-long medical and social needs when compared to the general population. These include:

- **Chronic pain**
- **Bowel and bladder issues. Routine monitoring is very important to keep kidneys healthy and avoid kidney failure and dialysis.**
- **Hypertension (high blood pressure).**
- **Hydrocephalus, which occurs in about 85% of people with Spina Bifida (myelomeningocele), requires life-long management whether or not the person has a shunt.**
- **Self-management of personal medical care by adults with Spina Bifida, which can be a challenge due to the complexity of this care and possible cognitive impairment.**

Challenges within medical systems also make it difficult for people with Spina Bifida to receive preventive health care. Many medical offices are not accessible. Examination rooms may be far from the reception area and/or otherwise inaccessible; examination tables may be too high or not be adjustable; scales may not be wheelchair accessible or safe for people with limited balance.

In addition, medical professionals sometimes lack knowledge of Spina Bifida. Providers must be willing and able to take the time needed to communicate with the individual or family and manage the complex needs. Medical professionals who do not routinely care for people with Spina Bifida are less likely to recognize these unique situations and address them appropriately.

These guidelines offer a road map to help parents, caregivers, and individuals manage these multiple and complex issues throughout the lifespan.

0-11 Months

1. Make sure your baby receives routine (well-baby) check-ups with a pediatrician, including immunizations and vision and hearing screenings.
2. Ask your pediatrician how your baby is progressing towards developmental milestones and what additional services your baby may need.
3. Follow your pediatrician's guidance about the health and safety of your baby, such as using car seats, water safety, and nutrition.
4. Follow the guidance of your baby's providers on the care and management of issues your baby may experience currently or in the future, such as:
 - **Having a shunt**
 - **Mobility**
 - **Orthopedic issues**
 - **Developmental delays**
 - **Bowel and bladder management**
 - **Latex allergies**
 - **Promoting inclusion of your child**





1-2 Years

1. Make sure your child receives routine (well-child) check-ups with a pediatrician, including immunizations and vision and hearing screenings.
2. Ask your pediatrician how your child is progressing towards developmental milestones and what additional services your child may need.
3. Follow your pediatrician's guidance about the health and safety of your child, such as using car seats, water safety, and nutrition.
4. Follow the guidance of your child's providers on the care and management of issues your child may experience currently or in the future, such as:
 - **Having a shunt**
 - **Bowel and bladder management**
 - **Mobility**
 - **Orthopedic issues**
 - **Developmental delays**
 - **Latex allergies**
 - **Promoting inclusion of your child**
 - **Risk of becoming overweight**
 - **Importance of physical and recreational activity**
 - **Keeping track of unexpected changes in your child**
 - **Keeping up with regular medical appointments**
 - **Recognizing signs of pain and what to do in response**

3-5 Years

1. Make sure your child receives routine (well-child) check-ups with a pediatrician, including immunizations and vision and hearing screenings.
2. Ask your pediatrician how your child is progressing towards developmental milestones and what additional services your child may need.
3. Follow your pediatrician's guidance about the health and safety of your child, such as using car seats, water safety, and nutrition.
4. Follow the guidance of your child's providers on the care and management of issues your child may experience currently or in the future, such as:

- **Having a shunt**
- **Bowel and bladder management**
- **Mobility impairments**
- **Orthopedic problems**
- **Developmental delays**
- **Latex allergies**
- **Promoting inclusion of your child**
- **Risks of becoming overweight**
- **Importance of physical and recreational activity**
- **Keeping track of unexpected changes in your child**
- **Keeping up with regular medical appointments**
- **Managing pain**
- **Recognizing signs of pain and what to do in response**



6-12 Years

1. Make sure your child receives routine (well-child) check-ups with a primary care provider (PCP), including age-appropriate screenings for:

- **Hypertension (high blood pressure)**
- **Iron deficiency**
- **Lipid disorders (high cholesterol)**
- **Overweight/obesity**
- **Abuse, neglect, and/or violence**
- **Social isolation, anxiety, and depression**
- **Motor vehicle and wheelchair safety**

2. Talk with your child's PCP about common conditions that children with Spina Bifida experience, such as:

- **Shunt concerns**
- **Sleep apnea. Note if your child's sleeping is restful and if there are snoring or breathing pauses during sleep.**
- **Skeletal and limb issues**
- **Constipation, urinary tract infections (UTIs), kidney function, and problems with bowel and bladder regimens.**
- **Skin breakdown and pressure injury, including ways to prevent skin breakdown prevention**
- **Pain. In particular, pain that is new, happens during specific activities, or limits the ability to do things.**
- **Adaptive equipment needs, including braces, crutches, walkers, and wheelchairs.**
- **Dental care**
- **Falls prevention, including equipment checks to limit the risk of fractures.**

3. Speak with your child's PCP and specialists about how to best coordinate your child's care between multiple providers.

4. Ask your providers about adaptive and accessible physical and recreational activities in the community.

5. Ask your providers about protecting your child's skin from sun exposure, particularly on areas of skin that don't have feeling.

6. If you are concerned about alcohol or drug use, ask your provider about treatment options.

13-17 Years

1. Your teen should receive routine care from a primary care provider (PCP), including age-appropriate screenings for:
 - **Hypertension (high blood pressure)**
 - **Iron deficiency**
 - **Lipid disorders (high cholesterol)**
 - **Overweight/obesity**
 - **Abuse, neglect, and/or violence**
 - **Social isolation, anxiety, and depression**
 - **Motor vehicle and wheelchair safety**
 - **Contraceptive use, pregnancy, and sexually transmitted diseases. (as age appropriate)**
2. Your teen's healthcare providers may monitor for conditions that are specific to teens with Spina Bifida both during routine and specialist visits:
 - **Shunt concerns**
 - **Sleep apnea. Note if your child's sleeping is restful and if there are snoring or breathing pauses during sleep.**
 - **Skeletal and limb issues**
 - **Constipation, urinary tract infections (UTIs), kidney function, and problems with bowel and bladder regimens.**
 - **Skin breakdown and pressure injury, including ways to prevent skin breakdown prevention**
 - **Pain. In particular, pain that is new, happens during specific activities, or limits the ability to do things.**
 - **Adaptive equipment needs, including braces, crutches, walkers, and wheelchairs.**
 - **Dental care**
 - **Falls prevention, including equipment checks to limit the risk of fractures.**
3. Speak with your teen's PCP and Spina Bifida-specific specialists on how to best coordinate your teen's care between multiple providers.
4. Ask your providers about adaptive and accessible physical and recreational activities in the community.
5. Ask your teen's PCP about skin cancer prevention, which is especially important on insensate skin.
6. If you are concerned about alcohol or drug use, ask your provider about treatment options.

18+ Years

1. You should receive routine, preventive care from primary care provider (PCP) appropriate for your age, including screenings or counseling for:

- **Hypertension (high blood pressure)**
- **Iron deficiency**
- **Lipid disorders (high cholesterol)**
- **Overweight/obesity**
- **Abuse, neglect, and/or violence**
- **Social isolation, anxiety, and depression**
- **Motor vehicle and wheelchair safety**
- **Contraceptive use, pregnancy, and sexually transmitted diseases. (as age appropriate)**
- **Smoking and illicit drug use**
- **Hearing and vision**
- **Immunizations, depending on additional health conditions (e.g., flu vaccine)**
- **Dental care and hygiene**

2. Your PCP and specialists may monitor you for conditions specific to adults with Spina Bifida both during routine and specialist visits:

- **Shunt concerns**
- **Sleep apnea. Note if your child's sleeping is restful and if there are snoring or breathing pauses during sleep.**
- **Skeletal and limb issues**
- **Constipation, urinary tract infections (UTIs), kidney function, and problems with bowel and bladder regimens.**
- **Skin breakdown and pressure injury, including ways to prevent skin breakdown prevention**
- **Pain. In particular, pain that is new, happens during specific activities, or limits the ability to do things.**
- **Adaptive equipment needs, including braces, crutches, walkers, and wheelchairs.**
- **Dental care**
- **Falls prevention, including equipment checks to limit the risk of fractures.**

18+ Years *contd.*

3. Speak with your primary care providers and specialists on how to best coordinate your care between multiple providers.
4. Your providers can give you information about sexually transmitted infections, use of different types of contraceptives, and violence among intimate partners.
5. If you are interested in becoming pregnant, ask your providers about family planning and possible fertility and genetic counseling.
6. Your providers can speak with you about managing your routine care, including bowel and bladder routines, skin-check procedures, and how to monitor changes in your health status.

