

Spina Bifida:

*Your Guide to
a Healthy Life*



Urologic Care

For ages 0-18+

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



SPINA BIFIDA
ASSOCIATION



Why does urologic health matter for children and adults with Spina Bifida?

The nerves that control our bladder and bowels are found very low in the spinal cord. For that reason, most people with myelomeningocele will likely have a bladder and/or bowel that doesn't function properly.

Historically, problems with the urinary tract have led to disease and death for people with Spina Bifida. After neurological issues, kidney problems have been the most common cause of death in people with Spina Bifida. However, recent medical advances have contributed to increased life spans.

There are two main reasons to begin urologic care in infancy and continue throughout life:

- 1. To protect the kidneys from damage** caused by urinary tract infections (UTIs), high bladder pressures, and reflux of urine from the bladder to the kidneys (known as vesicoureteral reflux). Research has shown that if problems in the urinary tract are not addressed, 50 percent of children will end up with kidney damage. This can lead to the need for dialysis and/or kidney transplants later in life.
- 2. To achieve urinary continence**, which has been reported as a major factor in the quality of life for people with Spina Bifida beginning at school age.

What can we do to maintain urologic health?

Urologists around the country have taken two different approaches to maintaining urologic health in children with Spina Bifida: a proactive and a reactive approach.

A proactive approach means performing studies such as renal ultrasounds early in life and regularly to identify children at risk for kidney damage and beginning treatment early in life, before any potential problems occur. This treatment can include medication and clean intermittent catheterization (“in and out” catheterization) and medication.

The reactive approach means following a child closely with studies to monitor any potential or actual changes to urologic health, and only treating once problems emerge.

The guidelines below blend the best practices from both methods. The Centers for Disease Control and Prevention (CDC) are conducting research to determine the best standardized protocol for managing urologic health in newborns through age 5.

Guidelines

0-11 Months



Within three months of birth, it is recommended that your child have the following:

1. Renal/bladder ultrasound (repeat at 6 months).
2. Voiding cystourethrogram (VCUG)¹ (this may be combined with urodynamic testing).
3. Urodynamic testing² (using x-rays to monitor the child's bladder pressure).
4. A blood test to check kidney function.

Note: babies less than a month old with failure to thrive and dehydration should be checked for urinary tract infections (UTIs).

Based on these tests, your urologist may recommend a catheterization regimen which could include medication to decrease bladder pressures and prevent kidney damage.

Urinary Tract Infections (UTIs)

Discuss UTIs with your child's urologist. If you suspect a UTI, see your child's healthcare provider to obtain a catheterized urine specimen (a catheterized specimen is more accurate in diagnosing a UTI than urine obtained from voiding or a collection bag).

UTIs are usually diagnosed by:

1. A positive urine analysis,
2. A positive urine culture on a catheterized sample, AND
3. 100.4 degree fever or higher

Diagnosing a UTI can be complicated in children that are catheterized because they typically always have some bacteria in their urine (known as "colonization"). If the child does not have a fever, any bacteria in a urine sample may just be due to colonization and not require treatment.

If your child is not catheterized, a UTI may indicate the need for additional testing and possibly the need to begin catheterization and medication.

¹ Avoiding cystourethrogram (VCUG) is a minimally invasive test that uses a special x-ray technology called fluoroscopy to visualize your child's urinary tract and bladder.

² Urodynamics is used to measure nerve and muscle function, pressure around and in the bladder, flow rates, and other factors.



1-2 Years

The following steps are recommended for a child in this age group:

1. A renal/bladder ultrasound every six months up to age two. After that, a renal ultrasound may be done once a year as long as your child has no UTIs or changes in the results of the ultrasound.
2. Additional renal/bladder ultrasounds if your child has UTIs or changes in ultrasound results, or if a urodynamics test indicates increased bladder pressures which may be damaging to the kidneys.
3. A yearly urodynamic test through age 3, and repeated as needed if the test shows:
 - **Increased bladder pressures that may be damaging to the kidneys**
 - **Changes in the upper urinary tract**
 - **Recurrent symptomatic UTIs**
4. A blood test to check the kidneys if there has been a change in the upper urinary tract.
5. If you think your child has a UTI, obtain a urine specimen from catheterization for analysis.

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UTIs are usually diagnosed by:

1. A positive urine analysis,
2. A positive urine culture on a catheterized sample, AND
3. 100.4 degree fever or higher

If your child is not catheterized, a UTI may indicate the need for additional testing and possibly the need to begin catheterization and medication.

3-5 Years

The following steps are recommended for a child in this age group:

1. A yearly renal/bladder ultrasound and additional ultrasounds if there have been recurrent, symptomatic UTIs or if a urodynamics test finds increased bladder pressure that may be damaging to the kidneys.
2. A yearly urodynamic test if:
 - **There have been changes in the kidneys**
 - **Your child has had recurrent symptomatic UTIs**
 - **You and your child are interested in beginning a urinary continence program**
3. A yearly blood test to check kidney function at age 5 and more frequently if there are changes in the kidneys.
4. If your child is catheterized, begin involving them in the process of self-catheterization (Self-Management and Independence Guideline).
5. Your urologist will discuss interest in and options for beginning a urinary continence program.
6. Because of the large role that bowel function plays in urologic health and overall well-being, ask your healthcare provider (usually a urologist or urology nurse, or clinic nurse) about a bowel management program (Bowel Function and Care Guideline).

Urinary Tract Infections (UTIs)

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Discuss UTIs with your child's urologist. If you suspect a UTI, see your child's healthcare provider to obtain a catheterized urine specimen (a catheterized specimen is more accurate in diagnosing a UTI than urine obtained from voiding or a collection bag).

UTIs are usually diagnosed by:

1. A positive urine analysis,
2. A positive urine culture on a catheterized sample,
3. Change in leakage between catheterizations,
4. Pelvic or back pain, AND
5. 100.4 degree fever or higher

If your child is not catheterized, a UTI may indicate the need for additional testing and possibly the need to begin catheterization and medication.

6-12 Years

The following steps are recommended for a child in this age group:

1. A yearly renal/bladder ultrasound and additional ultrasounds if there have been recurrent, symptomatic UTIs or if a urodynamics test finds high bladder pressure that may be damaging to the kidneys.
2. A urodynamic test if:
 - **There have been changes in the upper urinary tract**
 - **Your child has had recurrent symptomatic UTI**
 - **There have been changes in urinary continence status (i.e. more leakage than expected)**
3. A yearly blood test to check kidney function.
4. If not already on a program, ask your urologist about beginning a urinary continence program.
5. Because of the large role that bowel function plays in urologic health and overall well-being, ask your healthcare provider (usually a urologist or urology nurse, or clinic nurse) about a bowel management program (Bowel Function and Care Guideline).





13-17 Years

The following steps are recommended for a teen in this age group:

1. A yearly renal/bladder ultrasound and additional ultrasounds if there have been recurrent, symptomatic UTIs or if a urodynamics test finds high bladder pressure that may be damaging to the kidneys.
2. A yearly blood test to check kidney function.
3. Begin self-management of urologic care, if your child is able to do so (Self-Management and Independence Guideline).
4. Begin self-management of bowel program, if your child is able to do so. (Bowel Function and Care Guideline).

18+ Years

The following steps are recommended for this age group:

1. A yearly renal/bladder ultrasound and additional ultrasounds if you have had recurrent, symptomatic UTIs or if a urodynamics test finds increased bladder pressures that may be damaging to the kidneys.
2. A yearly serum creatinine test. If you have low muscle mass, a different test of kidney function may be used.
3. A yearly serum chemistry blood test including B12 if you've had major surgery in the urinary tract.
4. A cystoscopy to examine the lining of your bladder and a renal ultrasound if you have had a bladder augmentation and you have any of the following:
 - **Changes in urinary tract that appear on ultrasounds or other tests**
 - **Blood in the urine (hematuria)**
 - **Recurrent symptomatic UTIs**
 - **Increasing incontinence**
 - **Pelvic pain**
 - **A kidney transplant complicated by BK/polyomavirus bladder infection**

Ask your healthcare provider about continence issues and how to address them. Be sure to discuss the amount (volume) of incontinence as well as the frequency.

Ask your healthcare providers for assistance in achieving self-management of your urologic health and your independent living.