CONDITION

Epispadias

Epispadias is a birth difference in which the urethra does not form or close in the usual position.

WHAT IT IS
Congenital difference affecting the urethra and external genitals

BODY SYSTEM
Urinary and reproductive systems

MAIN SYMPTOMS
Unusual urethral opening, urine leakage, altered stream, penile curvature

WHAT CAUSES IT
Early fetal development differences, usually unknown

HOW IT IS DIAGNOSED
Physical examination, plus urinary tract and bladder testing

MAIN TREATMENT
Reconstructive surgery and long-term urinary care

CAN IT BE CURED?
Sometimes - surgery can restore anatomy and continence

IS IT AN EMERGENCY?
Sometimes - inability to urinate or severe infection signs

LONG-TERM OUTLOOK
Often good, though urinary or sexual concerns may continue

Overview

Epispadias is a condition present from birth. The urethra-the tube that carries urine out of the body-does not form or close in its usual position.

In a child born with a penis, the urethral opening is on the upper surface rather than at the tip. The opening may be close to the tip, farther along the shaft, or near the pubic area. The penis may also be short, broad, or curved upward.

In a child born with a vulva, the urethra may be wider or split, and the clitoris and nearby tissues may not have joined in the usual way. These changes can be less obvious than penile epispadias.

Epispadias can occur by itself. It can also be part of the bladder exstrophy-epispadias complex.

In bladder exstrophy, the bladder and lower abdominal wall do not close normally, leaving the inner surface of the bladder exposed at birth.

Epispadias matters because it can affect urine control, bladder emptying, urinary infections, genital appearance, and later sexual function. Some people have a mild form with little leakage. Others have an affected bladder outlet and cannot stay dry without treatment.

Symptoms

Epispadias is often noticed during a newborn examination. The findings depend on where the urethra opens and whether the bladder neck-the ring of muscle controlling urine flow-is affected.

Possible features include:

Urine leakage is more likely when the opening is close to the base of the penis or when the bladder neck is underdeveloped. However, appearance alone does not always show how well the bladder stores urine.

Epispadias usually does not cause pain by itself. Pain, fever, burning during urination, or a sudden change in urine output may point to an infection or another problem and should be assessed separately.

- A urethral opening in an unusual position
- A spraying or misdirected urine stream
- Continuous or frequent urine leakage
- Difficulty becoming dry with toilet training
- A short, broad, or upward-curving penis
- A split-looking clitoris or unusually wide urethral opening
- Repeated urinary tract infections

Causes and risk factors

Epispadias begins early in pregnancy as the lower urinary tract, pelvis, abdominal wall, and external genitals develop. The tissues do not join in their usual way.

The exact cause is usually unknown. Researchers believe that several developmental and genetic factors may be involved, particularly when epispadias is part of the bladder exstrophy-epispadias complex. In most families, there is no single identified gene or event that

explains it.

Epispadias is not caused by anything a parent did or did not do during pregnancy. It is not an infection, and it cannot be passed from one person to another.

It is diagnosed more often in children born with a penis. A family history of bladder exstrophy or epispadias may raise the chance slightly, but most affected children do not have a close relative with the condition.

Diagnosis

A clinician usually confirms epispadias by examining the urethral opening, external genitals, lower abdomen, and pelvis. If bladder exstrophy is present, it is generally clear at birth.

Further tests help show how the bladder, ureters, and kidneys are working. The ureters are the tubes carrying urine from the kidneys to the bladder.

Testing may include:

A voiding cystourethrogram can also identify vesicoureteral reflux. This means urine flows backward from the bladder toward the kidneys.

Assessment is usually coordinated by a pediatric urology team. If the condition is part of bladder exstrophy, other specialists may be involved because the abdominal wall, pelvic bones, bowel, or reproductive organs can also be affected.

- Ultrasound of the kidneys and bladder
- Blood and urine tests
- A voiding cystourethrogram, which uses X-rays to follow urine leaving the bladder
- Bladder function testing to measure storage, pressure, and emptying
- Imaging of the pelvis or urinary tract when needed

Treatment and management

Treatment is planned around urinary control, safe bladder function, genital function, and appearance. The approach depends on the anatomy and whether epispadias occurs alone or with bladder exstrophy.

Reconstructive surgery is the main treatment. It is often performed during infancy or early childhood, although the timing and number of operations differ from one child to another.

For penile epispadias, surgery may:

For epispadias affecting the vulva, surgery may reconstruct the urethra, clitoris, and nearby tissues when this is expected to improve function or appearance.

If the bladder neck does not close well, a separate continence procedure may be considered. Some people need more than one operation to improve urine control. More complex bladder surgery is mainly used when bladder capacity, pressure, or emptying remains unsafe or difficult to manage.

After surgery, a catheter or small drainage tube may remain in place while tissues heal. Follow-up checks look for infection, urine leakage from the surgical repair, narrowing of the urethra, bladder emptying problems, and ongoing curvature.

Continence support may include planned toilet visits, pelvic floor work, bladder training, medicines, or catheterisation in selected cases. These measures are chosen according to bladder testing and the person's age and abilities.

Emotional support is also part of care. Age-appropriate explanations and privacy can help children take part in appointments without feeling that their body is shameful or secret.

- Move the urethral opening toward the tip
- Straighten the penis
- Reconstruct the urethra and surrounding tissues
- Improve the distribution of erectile tissue and skin

Complications

Not everyone with epispadias develops complications. The likelihood is influenced by the position of the urethral opening, bladder neck function, associated reflux, and whether bladder exstrophy is present.

Possible complications of the condition include:

Repeated infections, reflux, or high bladder pressure can sometimes affect kidney health. Regular monitoring is intended to identify these problems before lasting damage develops.

Surgery also has risks. These may include infection, bleeding, reopening of part of the repair, narrowing of the reconstructed urethra, or a fistula. A fistula is an unwanted channel that allows urine to leak through the skin. Residual penile curvature or urinary leakage may require further treatment.

Later concerns can include erections, ejaculation, vaginal comfort, fertility, and pregnancy. Many people can have sexual relationships and become parents, but individual anatomy and previous operations affect what is possible.

- Persistent urine leakage
- Urinary tract infections
- Backward urine flow toward the kidneys
- Difficulty emptying the bladder
- Skin irritation from regular urine contact
- Reduced bladder capacity or high bladder pressure
- Concerns about body image, relationships, or sexual function

Prevention

Epispadias cannot currently be prevented. It develops very early in fetal growth, and its exact cause is usually not known.

Routine pregnancy care supports general health but cannot guarantee that epispadias will not occur. Parents should not blame themselves for the condition.

Someone with epispadias, bladder exstrophy, or an affected close relative may choose genetic counselling before a pregnancy. A genetic counsellor can review the family history and explain what is known, while being clear that testing often does not identify a specific cause.

Living with it and what to expect

Treatment and follow-up often continue through childhood and adolescence. Even after a successful repair, the urinary system changes as the body grows. Periodic checks may include kidney and bladder ultrasound, urine tests, assessment of bladder emptying, and discussion of continence.

Some children become dry after reconstruction and toilet training. Others continue to leak or need bladder medicines, catheterisation, or additional surgery. A result that looks satisfactory soon after an operation does not always predict long-term bladder control.

School can usually continue normally. Practical planning may help if a child needs regular toilet access, catheterisation, spare clothing, or time away for appointments. These needs can often be included in a private school health plan.

As children get older, care gradually includes direct conversations with them about their anatomy, previous procedures, and health needs. Adolescents may want to discuss genital appearance, erections, periods, sexual activity, fertility, or pregnancy without a parent present.

Adult follow-up remains useful, especially for people with bladder exstrophy, ongoing leakage, repeated infections, catheter use, or several previous operations. Care may eventually move from a pediatric urologist to an adult urologist familiar with congenital urinary conditions.

Many people with repaired epispadias study, work, exercise, form relationships, and raise families. Some continue to manage urinary symptoms or need further procedures. The long-term course cannot be predicted from appearance alone.

When to get medical help

If a newborn appears to have an unusual urethral opening, arrange prompt medical assessment. This is usually not an emergency when the baby is comfortable and passing urine, but early referral helps with testing and treatment planning.

Contact the usual care team promptly for:

Seek urgent medical care for fever with urinary symptoms, particularly in a young baby or someone with known kidney or bladder problems.

Get emergency help for inability to pass urine, severe lower abdominal pain with a swollen bladder, heavy bleeding, or signs of serious illness such as marked drowsiness, breathing difficulty, or poor responsiveness. Follow the surgical team's emergency instructions after a recent operation.

Routine follow-up is still important when there are no urgent symptoms. These appointments monitor kidney health, bladder pressure, growth, continence, and the results of reconstruction.

- New leakage or a major change in the urine stream
- Pain or burning during urination
- Repeated wetting after a period of dryness
- Cloudy, bloody, or unusually strong-smelling urine
- Redness, discharge, or increasing swelling around a surgical site
- A catheter that is leaking, blocked, or not draining as expected

Common questions

Is epispadias the same as hypospadias?

No. In epispadias, the urethral opening is on the upper surface of the penis. In hypospadias, it is on the underside. Epispadias is also more likely to involve the bladder neck and urinary

continence. Both conditions need their own specialist assessment.

Can epispadias be fixed completely?

Surgery can often reconstruct the urethra and improve genital appearance and function. Some people achieve reliable urine control, while others need further operations or long-term bladder management. A complete correction cannot be guaranteed.

Will a child with epispadias be able to control their bladder?

Many children gain useful or complete continence, but the outcome mainly depends on bladder neck development, bladder capacity, pressure, and associated bladder exstrophy. Toilet training may take longer, and some children need additional treatment.

Can someone with epispadias have sex and children?

Many adults can have satisfying sexual relationships and biological children. Penile curvature, ejaculation, vaginal anatomy, fertility, or previous pelvic surgery may affect an individual's experience. Specialist review can address these concerns before sexual activity or pregnancy.

Does epispadias affect gender identity?

Epispadias is a difference in urinary and genital development. It does not determine a person's gender identity. Care should respect the person's privacy, preferred language, and developing understanding of their body.

Will another baby in the family have epispadias?

Most families have only one affected child. A family history may increase the chance, but the cause is usually not identified and exact recurrence cannot be predicted from general information. Genetic counselling can provide a family-specific review.

Sources

- European Association of Urology. EAU Guidelines on Paediatric Urology: Bladder Exstrophy and Epispadias . 2026 guideline edition.
- National Institute of Diabetes and Digestive and Kidney Diseases. Bladder Exstrophy . National Institutes of Health.
- Boston Children's Hospital. Epispadias: Symptoms, Diagnosis, and Treatment . Department of Urology.
- Children's Hospital of Philadelphia. Bladder Exstrophy and Epispadias Program . Division of Urology.

- Ebert AK, Reutter H, Ludwig M, Rösch WH. "The Exstrophy-Epispadias Complex." Orphanet Journal of Rare Diseases . 2009;4:23.
- Woodhouse CRJ. "The Sexual and Reproductive Consequences of Congenital Genitourinary Anomalies." Journal of Urology . 1994;152:645-651.