## Information for Patients

## English

## Neurourological Disorders



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## This information was produced by the European Association of Urology

This leaflet contains general information about neurourological conditions. If you have any specific questions about your individual medical situation you should consult your doctor or other professional healthcare provider.

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You can find this and other information on urological diseases at our website: http://patients.uroweb.org



## What is a neurourological disorder?

The nervous system connects the brain and spinal cord to all parts of the body through a network of nerves. A disturbance in that network can cause problems storing and passing urine. Urinary problems caused by the nervous system are called *neurourological disorders*.

## What is neurogenic lower urinary tract dysfunction?

The lower urinary tract consists of the bladder and urethra and includes the prostate in men (**Figure 1**). The bladder stores the urine produced by the kidneys. It is a hollow stretchy bag made of muscle tissue that sits on the pelvic floor muscles. Normally the bladder is able to store urine without building up high pressure. Below the bladder, the <u>urinary</u> <u>sphincter</u> helps store the urine and prevent leakage. It is composed of different parts and muscle layers. The urethra is the tube through which urine passes from the bladder out of the body.

The main functions of the lower urinary tract are storing and passing urine. Both functions are regulated by the nervous system, which coordinates interaction of the bladder and the sphincter. For normal storage, the bladder muscle should be relaxed and the sphincter muscles tense. For urination, the bladder muscle should contract to build up pressure and to press the urine out, and the sphincter should relax to allow for easy and complete emptying without resistance.

These functions involve many parts of the nervous system, including the brain, the spinal cord, and the <u>peripheral nerves</u>. Any disturbance of these parts can lead to malfunction of normal storage and voiding and cause many symptoms. This disturbance is called neurogenic lower urinary tract dysfunction.

You may have a neurogenic lower urinary tract dysfunction if you also have one or more of the following conditions:

- A neurologic disease such as dementia, stroke, or multiple sclerosis
- Previous surgery or injury to the spine or pelvis

- Previous radiation
- Deformity of the spine
- A slipped disc
- A brain tumour or abnormal cell growth that affects the nervous system
- Diabetes
- Numbness or pain in the hands or feet (called peripheral neuropathy)



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Fig. 1a: Pelvic floor muscles in women





Fig. 1b: Pelvic floor muscles in men



## Symptoms and complications

Symptoms and complications of neurogenic lower urinary tract dysfunction depend on where the problem is in the nervous system. Maybe you have noticed that normal storage and passing of urine is disrupted. Sometimes a problem doesn't cause any discomfort.

Symptoms include:

- Slow or incomplete emptying of the bladder
- No sensation of the bladder
- Feeling abdominal fullness
- Not knowing when or if you will urinate (bladder spasticity)
- A frequent and compelling urge to empty the bladder, day or night, that is difficult to defer
- Incontinence
- Pain in the bladder or genital region

The location of the neurological problem usually influences the type of symptoms the patient may experience, for example: storage symptoms, such urinary urgency or voiding symptoms, such as a weak urinary stream (**Figure 1**). Urological problems that occur after sudden changes like spinal injury tend to be more severe than those caused by chronic conditions.

Neurogenic lower urinary tract dysfunction can cause a variety of short- or long-term complications:



Fig. 2: Patterns of lower urinary tract dysfunction following neurological disease

- Damaged kidney function caused by high pressure in the bladder is the most significant complication.
- The bladder can deteriorate and lose the ability to empty if high pressure builds up during storage or urination.
- Incomplete emptying of the bladder or backflow of urine to the kidneys might cause recurrent urinary tract infections, which can lead to dangerous effects on organs or even the whole body.

Delay of treatment might lead to worsening of all lower urinary tract function. This results in the need for more drastic therapy. Generally, treatment and follow-up examinations are based on the type of neurourological disorder and the underlying cause.

## Diagnosis

## Diagnosis of neurourological disorders

Early diagnosis and treatment are essential in neurourological disorders. Early intervention can prevent irreversible changes of the lower and upper urinary tract.

When diagnosing neurourological symptoms, your doctor may:

- Take a thorough medical history
- Ask you to keep a bladder diary
- Ask you to complete a quality-of-life questionnaire
- Do a physical examination
- Test how your bladder fills and empties with pressure measurements (urodynamics)
- Check your kidney function

## **Medical history**

The medical history is the cornerstone of evaluation. The answers will help determine diagnosis and treatment options. Your doctor will ask you about past and present symptoms and illnesses. Your doctor also might want to know all medications you are taking regularly. The questions may address urinary and bowel symptoms as well as sexual function. Patients with neurourological symptoms may have related bowel and sexual problems.

## **Bladder diary**

Your doctor may ask you to keep a bladder diary. You will be asked to document the number of times you urinated, the volume of urine passed, pad weight if you are using pads, and incontinence and urgency episodes. This is typically done over 24 hours and for 3 consecutive days to help identify the problem.



## **Quality-of-life questionnaires**

Your doctor may ask you to fill out several questionnaires to assess your present and future quality of life. This aspect is important to monitor the effect of your therapy.

## **Physical examination**

Your doctor may also do a thorough physical examination. The examination tests all sensations and reflexes in the urogenital area as well as the anal sphincter and pelvic floor functions. This information is needed to understand later diagnostic tests.

Your doctor may also decide to analyse your urine and blood chemistry. Ultrasound or other imaging techniques may be recommended to evaluate the urinary tract.

## **Urodynamics**

Urodynamic tests help your doctor to assess the function of your bladder.

#### **Urodynamics in depth**

During urodynamics tests, your bladder is filled and then emptied while pressure readings are taken from your bladder and your abdomen. The examination involves sending fluid through a catheter into the bladder and evaluating the bladder's muscle and nerve function. Various aspects are measured, including pressure within the bladder, the sensation of urgency that you feel when your bladder is full, and muscle contractions by the bladder wall. Urodynamics may be combined with the use of x-rays or fluoroscopy, in which case the bladder is filled with a liquid contrast dye. Your doctor may also decide to perform special tests such as electromyography, to look at signals to the pelvic floor muscles, urethral sphincter, and/or anal sphincter, or sensory testing of the bladder and urethra.

#### Sudden high blood pressure

Some patients have a risk of sudden high blood pressure during urodynamic testing. This risk has to be managed. It is a sudden and exaggerated automatic response to various stimuli in patients with spinal cord injury or spinal dysfunction. The stimulus can be a distended bladder or bowel. It can also be secondary to sexual stimulation or pain, for example, an infected toe nail or pressure sore. Sudden high blood pressure can be lifethreatening if not properly managed.

## **Kidney function**

In many patients with neurourological disorders, kidney function is at risk. Patients with spinal cord injury or birth defects of the spinal cord have an especially high risk of developing kidney failure. Your doctor will watch carefully for any signs or symptoms of possible deterioration of kidney function.

## **Disease Management**

If you have a neurourological problem, the main goal is to protect your kidneys and ureters. These organs compose the upper urinary tract.

Kidney failure may result from many neurological conditions, for instance, spinal cord injuries. Your urologist may suggest a treatment to protect your kidney function even if you don't have bothersome symptoms.

Provided that your kidneys are safe, priorities in neurourology treatment are:

- Restoring the normal function of the bladder
- Achieving or maintaining continence to improve quality of life

# Non-invasive conservative treatment

## Assisted bladder emptying

Incomplete bladder emptying is a serious risk for urinary tract infection, high pressure inside the bladder (with kidney damage), and incontinence. Methods to improve urination are usually necessary. Methods can be performed outside the body (non-invasive), by putting a device inside the body (invasive), or using drug therapy (pharmacological). An approach should be chosen with your doctor after careful and complete urological assessment.

## Bladder expression (Credé manoeuvre) and urinating by abdominal straining

These manoeuvres can help empty the bladder but are rarely recommended. Pressure inside the bladder may rise over acceptable limits and impair kidney function over time (**Figure 3**). Only in very specific cases may your urologist suggest these techniques. The same applies to *triggered reflex voiding*, which is possible in some patients—for instance, by repeated light taps on a specific body location—but only following medical advice.



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Fig.3: Bladder expression and abdominal straining should be avoided unless proven necessary because high pressure inside the bladder and impairment of kidney function may result.

#### **External appliances**

These devices are designed to catch urine that leaks during incontinence. Pads and diapers are the most well-known external appliances. For men, a condom catheter with a urine collection device is a practical alternative. Penile clamps should only be used in selected patients and after full medical evaluation.

## Neurourological rehabilitation

A variety of techniques are available for rehabilitation of neurourological problems and can be performed in the doctor's office. Treatments that have shown some positive results for specific neurourological problems include:

- Electrical stimulation of specific nerves
- Pelvic floor muscle training
- Biofeedback

Ask your urologist which methods are available and recommended in your situation.

## **Drug treatment**

No one optimal medical therapy is available for neurourological symptoms. Medications are often used in combination (one drug or more) with other techniques, such as intermittent detrusor. Treatments are tailored to the patient.

#### Drugs for storage symptoms

Antimuscarinic drugs are used in neurourological patients:

- to treat overactive bladder (see also patient information on overactive bladder)
- to increase bladder capacity
- to reduce urinary incontinence caused by bladder overactivity

These medications have some side effects, such as dry mouth, than can be reduced by lowering the dose or by taking the drug a different way (for instance, through the skin).

Some antimuscarinic drugs are oxybutynin, trospium, tolterodine, propiverine, darifenacin, and solifenacin.

A new category of medications called beta-3 adrenergic receptor agonists was recently introduced. Their use in neurourological patients is currently being studied.

#### **Drugs for voiding symptoms**

Drugs called alpha blockers seem to improve urination and may reduce the risk of sudden high blood pressure (autonomic dysreflexia). Some alpha blockers are tamsulosin and naftopidil.

Drug therapy is not recommended if your bladder does not contract enough (underactive bladder) or if your sphincter is not strong enough (severe stress urinary incontinence).

## Minimally invasive treatment

### Catheterisation

If you cannot empty your bladder naturally, you or your healthcare provider can use a catheter as needed for emptying. This technique is called intermittent catheterisation. It can be done by the patient at home and is recommended for neurourological patients. Intermittent catheterisation prevents many complications associated with catheters that stay in place (indwelling), including a high risk of urinary tract infections.

Intermittent catheterisation must be performed correctly to prevent infection. This is most important in managing the urinary tract of patients with neurourological symptoms.



## Botulinum toxin injections in the bladder

This treatment is most effective for overactive bladder caused by multiple sclerosis or spinal cord injury.

The drug is given by injection inside the bladder. In this procedure, a device called a cystoscope is inserted in your bladder and the botulinum toxin is injected in the bladder wall using a special needle.

The drug causes the bladder muscle to stop contracting regularly for about 9 months. Repeated injections may be necessary, but the treatment continues to be effective after new injections.

After the injection, the bladder may not empty completely. Intermittent catheterisation may be necessary for a time. Urinary tract infections also may occur with this treatment.

### **Bladder neck and urethral procedures**

A neurourological condition might make urination difficult by causing a lot of resistance at the bladder neck or the sphincter. In this case, your doctor might suggest minimally invasive treatment to improve urination and to protect the upper urinary tract.

#### Sphincterotomy

The urinary sphincter can be cut to reduce the sphincter's resistance to the passage of urine. The urethra will still be able to close somewhat. Incontinence may occur afterwards and can be managed. In many patients, this procedure has to be repeated. It does not have severe complications. Some patients may be able to have a urethral stent implanted, but the costs, complications, and need for further surgery have limited their use.

#### **Bladder neck incision**

Injury and previous procedures can cause the tissue at the bladder neck to thicken or scar. If this has happened, this tissue can be cut to help passage of urine through the bladder neck.

## Surgical treatment

Sometimes conservative or minimally invasive treatment will not control the symptoms or the risk of kidney damage. In this case, your doctor will suggest more invasive surgical treatment. Depending on the problem, several procedures can be performed.

## **Bladder neck and urethral procedures**

Some procedures may be recommended to increase bladder neck or sphincter resistance for continence. This should be attempted only after careful study of the bladder and urethra. Several procedures are available and your doctor may recommend a particular technique based on your situation (**Table 1**).

Table 1: Procedures used to increase the resistance in thebladder neck and urethra		
Urethral slings (synthetic, autologous)	A piece of material is placed as a sling in women to compress the bladder neck and increase resistance to urine flow; material can be man-made (synthetic) or tissue taken from another part of the patient's body (autologous)	
Artificial urinary sphincter	This device is composed of a cuff that compresses the urethra, a balloon that prevents urine from leaking, and a pump that controls the release of urine; it is surgically implanted	
Bladder neck and urethral surgical recon- struction	Surgical reconstructions may be an alter- native only in selected cases and gen- erally after failure of more conservative techniques	

## Sacral anterior root stimulation, sacral rhizotomy and sacral neuromodulation

In patients with a complete spinal lesion, the nervous system cannot send signals below the level of the injury. A device can be implanted that is connected to parts of the spinal cord below the lesion to stimulate the bladder and cause urination if activated.

This is called sacral *anterior root stimulation*. It can also be used to induce defecation or erection. This approach has been used successfully in some patients. Severing of other nerves, called *sacral rhizotomy*, is used mostly in support of this procedure but also can reduce overactive bladder symptoms.

Sacral neuromodulation is a less invasive technique. Small electrodes are implanted next to the sacral nerves and modulate nerve activity. This technique is widely used in patients without neurological disease. It also might help neurourological patients, but its role has not been well established.



#### Bladder covering by striated muscle

Covering the bladder with muscle tissue from the belly or the back can strengthen the bladder. It can establish a new way to control urinary function (voluntarily or by electrical stimulation). This complex surgical procedure has been used successfully in some neurourological patients.

#### **Bladder augmentation**

Bladder capacity may be increased and overactivity reduced by surgical expansion of the bladder. This may be achieved by surgery using part of the bladder muscle (autoaugmentation) or intestine or other expandable tissue. The procedure is called *augmentation cystoplasty*. It has possible complications such as infections that come back, formation of stones in the urinary tract, and tissue perforation. Patients should be chosen carefully to undergo such major reconstructive surgery.

### **Urinary diversion**

Urinary diversion means creating an artificial way to pass urine from the kidneys without going through the bladder. When all other therapies have failed, this option can protect the kidneys and improve quality of life. Although a diversion can be undone, it may be technically difficult. **Discuss this treatment in detail with your doctor before choosing this option.** 

#### **Continent diversion**

A pouch can be constructed in the body for intermittent catheterisation. Frequent complications may occur such as leakage or narrowing of the tube that carries urine (stenosis).

#### **Incontinent diversion**

The surgeon will create a <u>stoma</u>, which is a small portal in the belly. The urine flows through the stoma to an attached collecting bag. This is technically easier to achieve than a continent diversion and usually has fewer complications. Incontinent diversion cannot be used if you are not able to catheterise or already have severe kidney damage.

## Urinary tract infection in neurourological patients

Urinary tract infection (UTI) is diagnosed by common signs and/or symptoms:

- Strong urge to urinate that doesn't go away
- Burning sensation or discomfort when urinating (dysuria)
- Passing frequent, small amounts of urine
- Cloudy urine with increased urine odour

- Pink, red, or brownish urine
- Pain above the pubic bone in women

Laboratory findings like a lot of bacteria or white blood cells in the urine confirm the diagnosis.

In neurourological patients, UTI can be caused by:

- Weakened defence mechanisms
- Inability to empty the bladder completely
- Catheterisation

Asymptomatic bacteriuria is the presence of bacteria in the urine without symptoms. It is much more common in patients with spinal cord injury than in the general population. The condition varies depending on bladder management—for example, clean intermittent catheterisation or an indwelling catheter. It should not be routinely screened for or treated in patients with neurourological disorder.

If you have a symptomatic UTI, you may have other signs and symptoms in addition to or instead of traditional signs and symptoms of a UTI:

- Fever
- Incontinence
- Unpredictable need to urinate
- Malaise
- Lethargy or sense of unease
- Discomfort or pain over the kidney or bladder
- Sudden occurrence of high blood pressure (autonomic dysreflexia)

If a symptomatic UTI is present, your doctor may do a urinalysis and take a urine culture to identify the bacteria involved.

#### **Disease management**

Treating asymptomatic bacteriuria does not have a urological effect but causes many more resistant bacterial strains to develop. For this reason, it should not be treated in patients with neurourological disorders.

#### **Recurrent UTI and prevention**

If UTIs keep coming back in patients with neurourological disorders, it may be a sign that the underlying problem—for instance, incomplete bladder emptying or bladder stones—is not being addressed completely.

Sometimes improving bladder function and or removing a stone will solve the problem. If not, your doctor may consider individualised approaches like dietary supplements.



If an antibiotic treatment is necessary for UTI, your doctor may prescribe a 5- to 7-day course of antibiotic treatment that can be extended up to 14 days, depending on the extent of the infection.

## Sexual (Dys)function and fertility

Neurourological disease affects patients' sexual lives physically, psychologically, and sensorily (**Figure 4**). A negative effect may be caused by direct impairment of the nerves that signal the pelvic and genital area. The psychosocial and emotional impact of neurourological disease can also be negative and must be addressed along with other causes.

Multidisciplinary teams should be available to address the different aspects of sexual dysfunction in neurourological patients.



Fig. 4: Different levels at which neurourological diseases affect sexual function

## Male sexuality

#### Erectile dysfunction (ED)

If you have difficulty getting and maintaining an erection sufficient for sex, you may have erectile dysfunction, or ED. Your doctor will usually start treatment after doing the usual diagnostic tests for ED.

#### Male fertility

Male neurological patients often have a combination of erectile dysfunction, ejaculation disorder, and impaired sperm quality. This combination causes decreased fertility. If you want to father a child and it is not possible naturally, sperm can be collected for later use in assisted reproduction. In men with spinal cord injury, especially of the thoracic spine (Th6 disc or above), sudden high blood pressure (autonomic dysreflexia) might occur during sexual activity and ejaculation. If you have a spinal cord injury, you should keep this in mind and tell the staff at your fertility clinic.

Some men have retrograde ejaculation, which causes sperm to go inside the bladder during ejaculation instead of out of the penis. It can be reversed using specific drugs or a balloon that prevents sperm going to the bladder.

Different techniques can be used to collect sperm from men with spinal cord injury.

Techniques like prostatic massage or stimulation with a vibrator may be used for sperm collection. Transrectal electroejaculation uses a light electrical current to cause ejaculation while the patient is asleep under anaesthesia, but it yields less viable sperm.

If these techniques do not work, sperm can be collected through microsurgery of the tube that carries sperm from the testicles (epididymis) or surgical removal of testicular pulp.

Intracytoplasmic sperm injection is an assisted reproductive technology. Since its introduction, spinal cord injury patients have a good chance of becoming biological fathers regardless of the technique used to collect sperm.

### **Female sexuality**

Most of the information available is from women with spinal cord injury and multiple sclerosis. Several areas of sexual life are frequently impaired in neurourological female patients, such as sexual desire, lubrication, and orgasm. Most women continue to be sexually active but show decreased satisfaction levels.

#### Female fertility

Women with spinal cord injury may have a short period without menstruation (about 6 months) immediately after the injury. However, many are able to become pregnant once menstruation returns.

Special care must be taken during labour and delivery because complications can occur such as bladder problems, spasticity, pressure sores, anaemia, and sudden high blood pressure (autonomic dysreflexia).



\* The underlined terms are listed in the glossary.

## Living with a neurourological disorder

Many characteristics, symptoms, and hazards of neurourological disorders depend on the underlying cause. It is possible that you are not bothered by symptoms but have a risk of developing complications. A timely and thorough diagnostic evaluation helps prevent worsening of the situation.

Many treatment options enable individualised therapy. Safety and quality of life are the main goals of therapy, with kidney function being the main aspect of safety.

## Protect your kidneys

Depending on the characteristics, a neurourological disorder can lead to kidney problems. This is serious and might lead to intensive, time-consuming treatment, reduced quality of life, and early death.

The primary aim of treating neurourological disorders is the conservation of kidney function. Therapeutic measures like catheterisation may substantially reduce your quality of life but prevent even more serious problems. If your doctor's treatment advice seems unreasonable to you, you should discuss your concerns and ask for alternatives.

Depending on the characteristic of your neurourological disorder, your doctor might want to check your kidney function regularly. Your family doctor should be informed and should look for signs of kidney problems.

### Manage symptoms

Neurourological disorders are often unstable. The symptoms may vary widely, even within a relatively short time period. Regular follow-up with your doctor is necessary. How often depends on the underlying cause.

Urinary incontinence may significantly affect your social life. Many treatment options exist. You shouldn't be embarrassed to discuss your situation with your doctor.

A lot of tools exist, like different catheters, pads, or condom catheters. Some can help in your daily life. Some might be better suited to your lifestyle than others. If you try to explain the details of your problem, your doctor can help you select the right tools.

## Get more information

Learn more about urinary incontinence, overactive bladder syndrome, erectile dysfunction and nocturia at patients.uroweb.org

#### Questions to ask your doctor

Because neurourological disorders can present in many different ways, a specific diagnosis and therapy is important. EAU Patient Information gives you an overview of the possibilities.

You will have questions specific to your individual situation. Your doctor is the person to answer these questions. It can be helpful to prepare a list of questions before you see your doctor.

Here are some questions you might want to ask:

- Why do I have this problem?
- What are the risks of my condition?
- What can I do to prevent complications and worsening of the situation?
- Which treatment option do you recommend for me?
- What can I expect from that treatment?
- What are the possible side effects or risks of this treatment?
- What treatment alternatives exist?
- What are the benefits and drawbacks of the treatment options?



## Glossary of terms

#### Bladder

Organ that stores urine

#### **Bladder diary**

Records the times of urination and voided volumes, incontinence episodes, pad usage, and other information such as fluid intake, the degree of urgency, and the degree of incontinence.

#### **Bladder expression**

Various manoeuvres aimed at increasing pressure to facilitate bladder emptying (abdominal straining, Valsalva manoeuvre, and Credé manoeuvre)

#### Catheterisation

Technique for bladder emptying using a catheter to drain the bladder or a urinary reservoir

#### Detrusor

Bladder muscle

#### **Erectile dysfunction**

Difficulty getting and maintaining an erection sufficient for sex

#### **Indwelling catheter**

The most common type of bladder catheter, that remains in the bladder, urinary reservoir, or urinary passage for a period of time longer than one emptying

#### Intermittent catheterisation

Drainage or aspiration of the bladder or a urinary reservoir with subsequent removal of the catheter

#### Lower urinary tract

Bladder, prostate, and urethra

#### Minimally invasive treatment

A surgical procedure that does not make an incision in the body

#### **Nervous system**

Connects the brain and spinal cord to all parts of the body through a network of nerves

#### Neurourological disorders

Urinary problems caused by the nervous system

#### Nocturia

Waking at night one or more times to urinate. Each urination is preceded and followed by sleep.

#### **Overactive bladder syndrome**

Urgency, with or without urge incontinence, usually with frequency and nocturia

#### **Peripheral nerves**

Connect the brain and the spinal cord with the rest of the body

#### Stoma

An artificial opening for passing urine

#### Transrectal electroejaculation

Use of a light electrical current to cause ejaculation while the patient is asleep under anaesthesia

#### Upper urinary tract

The kidneys and ureters

#### Urethra

Tube that transports urine from the bladder out of the body

#### **Urinary sphincter**

Muscle just beneath the bladder that helps store urine and prevent leakage

#### **Urinary tract**

The organ system that produces and transports urine through and out of the body

#### **Urinary tract infection**

An infection in any part of the urinary tract

#### Urodynamics

Tests of bladder function, including the pressure within the bladder, the sensation of urgency when the bladder is full, and muscle contractions by the bladder wall



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