

# Urinary incontinence in neurological disease: assessment and management

Clinical guideline

Published: 8 August 2012

Last updated: 2 October 2023

[www.nice.org.uk/guidance/cg148](https://www.nice.org.uk/guidance/cg148)

## Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the [Yellow Card Scheme](#).

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should [assess and reduce the environmental impact of implementing NICE recommendations](#) wherever possible.

# Contents

Overview .....	4
Who is it for? .....	4
Introduction .....	5
Recommendations.....	8
1.1 Assessment of lower urinary tract dysfunction in patients with neurological conditions.....	8
1.2 Information and support .....	12
1.3 Treatment to improve bladder storage .....	12
1.4 Treatment for stress incontinence.....	16
1.5 Treatment to improve bladder emptying.....	17
1.6 Management with catheter valves .....	18
1.7 Management with ileal conduit diversion.....	18
1.8 Treatment to prevent urinary tract infection.....	18
1.9 Monitoring and surveillance protocols .....	19
1.10 Potential complications: providing information and initial management .....	20
1.11 Access to and interaction with services .....	22
Terms used in this guideline.....	24
Recommendations for research .....	30
1 Safety and efficacy of antimuscarinics .....	30
2 Safety and efficacy of botulinum toxin .....	30
3 Management strategies to reduce the risk of symptomatic urinary tract infections.....	31
4 Bladder management strategies .....	32
Finding more information and committee details.....	34
Update information .....	35

# Overview

This guideline covers assessing and managing urinary incontinence in children, young people and adults with neurological disease. It aims to improve care by recommending specific treatments based on what symptoms and neurological conditions people have.

## Who is it for?

- Healthcare professionals
- Commissioners and providers
- People with urinary incontinence and neurological disease and their families and carers

## Introduction

The lower urinary tract consists of the urinary bladder and the urethra. Its function is to store and expel urine in a coordinated and controlled manner. The central and peripheral nervous systems regulate this activity. Urinary symptoms can arise due to neurological disease in the brain, the suprasacral spinal cord, the sacral spinal cord or the peripheral nervous system. Damage within each of these areas tends to produce characteristic patterns of bladder and sphincter dysfunction. The nature of the damage to the nervous system is also important. In children, the neurological damage is often the result of congenital defects such as spina bifida or sacral agenesis. Conditions may produce a relatively fixed or stable injury to the nervous system (for example, stroke, spinal cord injury and cauda equina compression) or progressive damage (for example, dementia, Parkinson's disease, multiple sclerosis and peripheral neuropathy). Table 1 groups neurological conditions based on the anatomical site of the resulting neurological lesion with the likelihood of disease progression.

Table 1 Examples of neurological conditions that can affect lower urinary tract function

–	Congenital and perinatal conditions	Acquired, stable conditions	Acquired, progressive or degenerative conditions
Brain conditions	Cerebral palsy	Stroke Head injury	Multiple sclerosis Parkinson's disease Dementia Multiple system atrophy
Suprasacral spinal cord conditions	<u>Spinal dysraphism</u> (such as myelomeningocele)	Spinal cord injury	Multiple sclerosis Cervical spondylosis with myelopathy
Sacral spinal cord or peripheral nerve conditions	Spinal dysraphism Sacral agenesis Anorectal anomalies	Cauda equina syndrome Spinal cord injury Peripheral nerve injury from radical pelvic surgery	Peripheral neuropathy

The proximity of the neurological centres controlling bowel and sexual functions to those involved in lower urinary tract function means that many people with neurological disease will have a combination of urinary, bowel and sexual dysfunction. The clinical team should not treat lower urinary tract problems in isolation but should address associated problems in other systems using a holistic approach.

Symptoms of neurogenic lower urinary tract dysfunction may relate to impaired urine storage and/or bladder emptying difficulties. Symptoms of impaired storage include increased frequency of urination and urinary incontinence. Urinary tract symptoms have a significant impact on quality of life, for example, they can cause embarrassment, lead to social isolation and impair activities of daily living. Incontinence is particularly problematic and can arise as a result of an overactive bladder, dysfunction of the urethral sphincters or a combination of the 2.

Secondary effects can also arise as a result of neurogenic lower urinary tract dysfunction. For example, there is a marked increase in the risk of urinary tract infection in people with neurogenic lower urinary tract dysfunction and kidney function can be lost as a result of abnormally high pressures within the bladder, from the effects of urinary tract infection and as a result of kidney stones.

Medical interventions often do not restore normal urinary function, and quality of life may be affected by the medical management of neurogenic lower urinary tract dysfunction. Many patients will have to cope with the side effects of medication, the social and psychological consequences of using intermittent self-catheterisation, the impact of indwelling catheterisation and the continuing use of pads or appliances. These may also have an impact on quality of life for family members and carers, and there may be issues related to the physical demands of caring for a person with neurological disease and urinary problems, as well as psychological, relationship and social pressures.

The economic cost of managing neurogenic lower urinary tract dysfunction is considerable. There are major costs associated with the use of pads, appliances, catheters, drug treatments and surgical interventions. A further financial burden arises from the person's requirements for carer, nursing and medical support. A person's ability to work can be affected by their neurogenic lower urinary tract dysfunction. Further significant expenditure is associated with the follow-up of patients, some of whom are placed on long-term urinary tract surveillance.

An overview of the clinical approach that is used when dealing with neurogenic lower

urinary tract dysfunction is provided in 3 algorithms that are included in the [full guideline](#).

The guideline will assume that prescribers will use a drug's summary of product characteristics to inform decisions made with individual patients.

This guideline recommends some drugs for indications for which they do not have a UK marketing authorisation at the date of publication, if there is good evidence to support that use. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the [General Medical Council's good practice in prescribing and managing medicines and devices](#) for further information. Where recommendations have been made for the use of drugs outside their licensed indications ('off-label use'), these drugs are marked with a footnote in the recommendations.

## Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [NICE's information on making decisions about your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

### 1.1 Assessment of lower urinary tract dysfunction in patients with neurological conditions

Assessment applies to new people, those with changing symptoms and those needing periodic reassessment of their urinary tract management. The interval between routine assessments will be guided by the person's particular circumstances (for example, their age, diagnosis and type of management) but should not exceed 3 years.

These recommendations on assessment apply to people who have a neurological condition. If the assessment shows the incontinence to be non-neurogenic, see the [NICE guidelines on lower urinary tract symptoms in men](#) and [urinary incontinence and pelvic organ prolapse in women](#) for guidance on management.

#### Clinical assessment

1.1.1 When assessing lower urinary tract dysfunction in a person with neurological disease, take a clinical history, including information about:

- urinary tract symptoms
- neurological symptoms and diagnosis (if known)
- clinical course of the neurological disease



- bowel symptoms
- sexual function
- comorbidities
- use of prescription and other medication and therapies.

1.1.2 Assess the impact of the underlying neurological disease on factors that will affect how lower urinary tract dysfunction can be managed, such as:

- mobility
- hand function
- cognitive function
- social support
- lifestyle.

1.1.3 Undertake a general physical examination that includes:

- measuring blood pressure
- an abdominal examination
- an external genitalia examination
- a vaginal or rectal examination if clinically indicated (for example, to look for evidence of pelvic floor prolapse, faecal loading or alterations in anal tone).

1.1.4 Carry out a focused neurological examination, which may need to include assessment of:

- cognitive function
- ambulation and mobility
- hand function
- lumbar and sacral spinal segment function.

- 1.1.5 Undertake a urine dipstick test using an appropriately collected sample to test for the presence of blood, glucose, protein, leukocytes and nitrites. Appropriate urine samples include clean-catch midstream samples, samples taken from a freshly inserted intermittent sterile catheter and samples taken from a catheter port. Do not take samples from leg bags.
- 1.1.6 If the dipstick test result and person's symptoms suggest an infection, arrange a urine bacterial culture and antibiotic sensitivity test before starting antibiotic treatment. Treatment need not be delayed but may be adapted when results are available.
- 1.1.7 Be aware that bacterial colonisation will be present in people using a catheter and so urine dipstick testing and bacterial culture may be unreliable for diagnosing active infection.
- 1.1.8 Ask people and their family members and carers to complete a 'fluid input/urine output chart' to record fluid intake, frequency of urination and volume of urine passed for a minimum of 3 days.
- 1.1.9 Consider measuring the urinary flow rate in people who are able to void voluntarily.
- 1.1.10 Measure the post-void residual urine volume by ultrasound, preferably using a portable scanner, and consider taking further measurements on different occasions to establish how bladder emptying varies at different times and in different circumstances.
- 1.1.11 Consider making a referral for a renal ultrasound scan in people who are at high risk of renal complications such as those with spina bifida or spinal cord injury.
- 1.1.12 Refer people for urgent investigation if they have any of the following 'red flag' signs and symptoms:
- haematuria
  - recurrent urinary tract infections (for example, 3 or more infections in the last 6 months)

- loin pain
  - recurrent catheter blockages (for example, catheters blocking within 6 weeks of being changed)
  - hydronephrosis or kidney stones on imaging
  - biochemical evidence of renal deterioration.
- 1.1.13 Be aware that unexplained changes in neurological symptoms (for example, confusion or worsening spasticity) can be caused by urinary tract disease, and consider further urinary tract investigation and treatment if this is suspected.
- 1.1.14 Refer people with changes in urinary function that may be due to new or progressing neurological disease needing specialist investigation (for example, syringomyelia, hydrocephalus, multiple system atrophy or cauda equina syndrome).
- 1.1.15 Assess the impact of lower urinary tract symptoms on the person's family members and carers and consider ways of reducing any adverse impact. If it is suspected that severe stress is leading to abuse, follow local safeguarding procedures.

## Urodynamic investigations

- 1.1.16 Do not offer urodynamic investigations (such as filling cystometry and pressure-flow studies) routinely to people who are known to have a low risk of renal complications (for example, most people with multiple sclerosis).
- 1.1.17 Offer video-urodynamic investigations to people who are known to have a high risk of renal complications (for example, people with spina bifida, spinal cord injury or anorectal abnormalities).
- 1.1.18 Offer urodynamic investigations before performing surgical treatments for neurogenic lower urinary tract dysfunction.

## 1.2 Information and support

- 1.2.1 Offer people with neurogenic urinary tract dysfunction, their family members and carers specific information and training. Ensure that people who are starting to use, or are using, a bladder management system that involves the use of catheters, appliances or pads:
- receive training, support and review from healthcare professionals who are trained to provide support in the relevant bladder management systems and are knowledgeable about the range of products available
  - have access to a range of products that meet their needs
  - have their products reviewed, at a maximum of 2 yearly intervals.
- 1.2.2 Tailor information and training to the person's physical condition and cognitive function to promote their active participation in care and self-management.
- 1.2.3 Inform people how to access further support and information from a healthcare professional about their urinary tract management.
- 1.2.4 NICE has produced guidance on the components of good patient experience in adult NHS services. All healthcare professionals should follow the recommendations in the [NICE guideline on patient experience in adult NHS services](#). Recommendations on shared decision making and information enabling people to actively participate in their care can be found in the [NICE guidelines on shared decision making and patient experience in adult NHS services](#).

## 1.3 Treatment to improve bladder storage

### Behavioural treatments

- 1.3.1 Consider a behavioural management programme (for example, [timed voiding](#), [bladder retraining](#) or [habit retraining](#)) for people with neurogenic lower urinary tract dysfunction:

- only after assessment by a healthcare professional trained in the assessment of people with neurogenic lower urinary tract dysfunction **and**
- in conjunction with education about lower urinary tract function for the person and/or their family members and carers.

1.3.2 When choosing a behavioural management programme, take into account that prompted voiding and habit retraining are particularly suitable for people with cognitive impairment.

## Antimuscarinics

In August 2012, not all antimuscarinics had a UK marketing authorisation for the indications in recommendations 1.3.3 to 1.3.5 or for use in both adults and children. See [NICE's information on prescribing medicines](#).

1.3.3 Offer antimuscarinic drugs to people with:

- spinal cord disease (for example, spinal cord injury or multiple sclerosis) **and**
- symptoms of an overactive bladder such as increased frequency, urgency and incontinence.

1.3.4 Consider antimuscarinic drug treatment in people with:

- conditions affecting the brain (for example, cerebral palsy, head injury or stroke) **and**
- symptoms of an overactive bladder.

1.3.5 Consider antimuscarinic drug treatment in people with urodynamic investigations showing impaired bladder storage.

1.3.6 Monitor residual urine volume in people who are not using intermittent or indwelling catheterisation after starting antimuscarinic treatment.

1.3.7 When prescribing antimuscarinics, take into account that:

- antimuscarinics known to cross the blood-brain barrier (for example, oxybutynin) have the potential to cause central nervous system-related side effects (such as confusion)
- antimuscarinic treatment can reduce bladder emptying, which may increase the risk of urinary tract infections
- antimuscarinic treatment may precipitate or exacerbate constipation.

## Botulinum toxin type A

In August 2012, botulinum toxin type A did not have a UK marketing authorisation for the indications in recommendations 1.3.8 to 1.3.11. See [NICE's information on prescribing medicines](#).

1.3.8 Offer bladder wall injection with botulinum toxin type A to adults:

- with spinal cord disease (for example, spinal cord injury or multiple sclerosis) **and**
- with symptoms of an overactive bladder **and**
- in whom antimuscarinic drugs have proved to be ineffective or poorly tolerated.

1.3.9 Consider bladder wall injection with botulinum toxin type A for children and young people:

- with spinal cord disease **and**
- with symptoms of an overactive bladder **and**
- in whom antimuscarinic drugs have proved to be ineffective or poorly tolerated.

1.3.10 Offer bladder wall injection with botulinum toxin type A to adults:

- with spinal cord disease **and**
  - with urodynamic investigations showing impaired bladder storage **and**
  - in whom antimuscarinic drugs have proved to be ineffective or poorly tolerated.
- 1.3.11 Consider bladder wall injection with botulinum toxin type A for children and young people:
- with spinal cord disease **and**
  - with urodynamic investigations showing impaired bladder storage **and**
  - in whom antimuscarinic drugs have proved to be ineffective or poorly tolerated.
- 1.3.12 Before offering bladder wall injection with botulinum toxin type A:
- explain to the person and/or their family members and carers that a catheterisation regimen is needed in most people with neurogenic lower urinary tract dysfunction after treatment, **and**
  - ensure that they are able and willing to manage such a regimen should urinary retention develop after the treatment.
- 1.3.13 Monitor residual urine volume in people who are not using a catheterisation regimen during treatment with botulinum toxin type A.
- 1.3.14 Monitor the upper urinary tract in people who are judged to be at risk of renal complications (for example, those with high intravesical pressures on filling cystometry) during treatment with botulinum toxin type A.
- 1.3.15 Ensure that people who have been offered continuing treatment with repeated botulinum toxin type A injections have prompt access to repeat injections when symptoms return.

## Augmentation cystoplasty

- 1.3.16 Consider augmentation cystoplasty using an intestinal segment for people:
- with non-progressive neurological disorders **and**
  - complications of impaired bladder storage (for example, hydronephrosis or incontinence) **and**
  - only after a thorough clinical and urodynamic assessment and discussion with the patient and/or their family members and carers about complications, risks and alternative treatments.
- 1.3.17 Offer patients life-long follow-up after augmentation cystoplasty because of the risk of long-term complications. Potential complications include metabolic effects, such as the development of vitamin B12 deficiency and the development of bladder cancer.

## 1.4 Treatment for stress incontinence

### Pelvic floor muscle training

- 1.4.1 Consider pelvic floor muscle training for people with:
- lower urinary tract dysfunction due to multiple sclerosis or stroke **or**
  - other neurological conditions where the potential to voluntarily contract the pelvic floor is preserved.
- Select patients for this training after specialist pelvic floor assessment and consider combining treatment with biofeedback and/or electrical stimulation of the pelvic floor.

### Urethral tape and sling surgery

- 1.4.2 Consider autologous fascial sling surgery for people with neurogenic stress



incontinence.

- 1.4.3 Do not routinely use synthetic tapes and slings in people with neurogenic stress incontinence because of the risk of urethral erosion.

## Artificial urinary sphincter

- 1.4.4 Consider surgery to insert an artificial urinary sphincter for people with neurogenic stress incontinence only if an alternative procedure, such as insertion of an autologous fascial sling, is less likely to control incontinence.
- 1.4.5 When considering inserting an artificial urinary sphincter:
- discuss with the person and/or their family members and carers the risks associated with the device, the possible need for repeat operations and alternative procedures
  - ensure that the bladder has adequate low-pressure storage capacity.
- 1.4.6 Monitor the upper urinary tract after artificial urinary sphincter surgery (for example, using annual ultrasound scans), as bladder storage function can deteriorate in some people after treatment of their neurogenic stress incontinence.

## 1.5 Treatment to improve bladder emptying

### Alpha-blockers

- 1.5.1 Do not offer alpha-blockers to people as a treatment for bladder emptying problems caused by neurological disease.

## 1.6 Management with catheter valves

- 1.6.1 In people for whom it is appropriate a catheter valve may be used as an alternative to a drainage bag.

[This recommendation is from the [NICE guideline on healthcare-associated infections: prevention and control in primary and community care](#)]

- 1.6.2 To ensure that a catheter valve is appropriate, take into consideration the person's preference, family member and carer support, manual dexterity, cognitive ability, and lower urinary tract function when offering a catheter valve as an alternative to continuous drainage into a bag.
- 1.6.3 Consider the need for continuing upper urinary tract surveillance in people who have impaired bladder storage (for example, due to reduced bladder compliance).

## 1.7 Management with ileal conduit diversion

- 1.7.1 For people with neurogenic lower urinary tract dysfunction who have intractable, major problems with urinary tract management, such as incontinence or renal deterioration:
- consider [ileal conduit diversion](#) (urostomy) **and**
  - discuss with the person the option of simultaneous [cystectomy](#) as prophylaxis against pyocystis.

## 1.8 Treatment to prevent urinary tract infection

- 1.8.1 Do not routinely use antibiotic prophylaxis for urinary tract infections in people with neurogenic lower urinary tract dysfunction.
- 1.8.2 Consider antibiotic prophylaxis for people who have a recent history of frequent or severe urinary tract infections.

- 1.8.3 Before prescribing antibiotic prophylaxis for urinary tract infection:
- investigate the urinary tract for an underlying treatable cause (such as urinary tract stones or incomplete bladder emptying)
  - take into account and discuss with the person the risks and benefits of prophylaxis
  - refer to local protocols approved by a microbiologist or discuss suitable regimens with a microbiologist.
- 1.8.4 Ensure that the need for ongoing prophylaxis in all people who are receiving antibiotic prophylaxis is regularly reviewed.
- 1.8.5 When changing catheters in patients with a long-term indwelling urinary catheter:
- do not offer antibiotic prophylaxis routinely
  - consider antibiotic prophylaxis for patients who:
    - have a history of symptomatic urinary tract infection after catheter change **or**
    - experience trauma during catheterisation (trauma defined as frank haematuria after catheterisation or 2 or more attempts of catheterisation).

In August 2012, no antibiotics had a UK marketing authorisation for this indication. See [NICE's information on prescribing medicines](#).

[This recommendation is from the [NICE guideline on healthcare-associated infections: prevention and control in primary and community care](#).]

## 1.9 Monitoring and surveillance protocols

- 1.9.1 Do not rely on serum creatinine and estimated glomerular filtration rate in isolation for monitoring renal function in people with neurogenic lower urinary

tract dysfunction. For more information on the measurement of kidney function, see the [NICE guideline on chronic kidney disease](#).

- 1.9.2 Consider using isotopic glomerular filtration rate when an accurate measurement of glomerular filtration rate is required (for example, if imaging of the kidneys suggests that renal function might be compromised). For more information on the measurement of kidney function, see the [NICE guideline on chronic kidney disease](#).
- 1.9.3 Offer lifelong ultrasound surveillance of the kidneys to people who are judged to be at high risk of renal complications (for example, consider surveillance ultrasound scanning at annual or 2 yearly intervals). Those at high risk include people with spinal cord injury or spina bifida and those with adverse features on urodynamic investigations such as impaired bladder compliance, detrusor-sphincter dyssynergia or vesico-ureteric reflux.
- 1.9.4 Do not use plain abdominal radiography for routine surveillance in people with neurogenic lower urinary tract dysfunction.
- 1.9.5 Consider urodynamic investigations as part of a surveillance regimen for people at high risk of urinary tract complications (for example, people with spina bifida, spinal cord injury or anorectal abnormalities).
- 1.9.6 Do not use cystoscopy for routine surveillance in people with neurogenic lower urinary tract dysfunction.
- 1.9.7 Do not use [renal scintigraphy](#) for routine surveillance in people with neurogenic lower urinary tract dysfunction.

## 1.10 Potential complications: providing information and initial management

### Renal impairment

- 1.10.1 Discuss with the person, and their family members and carers, the increased risk

of renal complications (such as kidney stones, hydronephrosis and scarring) in people with neurogenic urinary tract dysfunction (in particular those with spina bifida or spinal cord injury). Tell them the symptoms to look out for (such as loin pain, urinary tract infection and haematuria) and when to see a healthcare professional.

- 1.10.2 When discussing treatment options, tell the person that indwelling urethral catheters may be associated with higher risks of renal complications (such as kidney stones and scarring) than other forms of bladder management (such as intermittent self-catheterisation).
- 1.10.3 Use renal imaging to investigate symptoms that suggest upper urinary tract disease.

## Bladder stones

- 1.10.4 Discuss with the person, and their family members and carers, the increased risk of bladder stones in people with neurogenic lower urinary tract dysfunction. Tell them the symptoms to look out for that mean they should see a healthcare professional (for example, recurrent infection, recurrent catheter blockages or haematuria).
- 1.10.5 Discuss with the person, and their family members and carers, that indwelling catheters (urethral and suprapubic) are associated with a higher incidence of bladder stones compared with other forms of bladder management. Tell them the symptoms to look out for that mean they should see a healthcare professional (for example, recurrent infection, recurrent catheter blockages or haematuria).
- 1.10.6 Refer people with symptoms that suggest the presence of bladder stones (for example, recurrent catheter blockages, recurrent urinary tract infection or haematuria) for cystoscopy.

## Bladder cancer

- 1.10.7 Discuss with the person, and their family members and carers, that there may be

an increased risk of bladder cancer in people with neurogenic lower urinary tract dysfunction, in particular those with a long history of neurogenic lower urinary tract dysfunction and complicating factors, such as recurrent urinary tract infections. Tell them the symptoms to look out for (especially haematuria) that mean they should see a healthcare professional.

1.10.8 Refer for investigation with urinary tract imaging and cystoscopy using a suspected cancer pathway referral, people with:

- visible haematuria **or**
- increased frequency of urinary tract infections **or**
- other unexplained lower urinary tract symptoms.

## 1.11 Access to and interaction with services

### Access to and interaction with services

1.11.1 Provide contact details for the provision of specialist advice if a person has received care for neurogenic lower urinary tract dysfunction in a specialised setting (for example, in a spinal injury unit or a paediatric urology unit). The contact details should be given to the person, and their family members and carers, and to the non-specialist medical and nursing staff involved in their care.

1.11.2 Provide people with neurogenic lower urinary tract dysfunction, and their family members and carers, with written information that includes:

- a list of key healthcare professionals involved in their care, a description of their role and their contact details
- copies of all clinical correspondence
- a list of prescribed medications and equipment.

This information should also be sent to the person's GP.

1.11.3 NICE has produced guidance on the components of good patient experience in adult NHS services. All healthcare professionals should follow the recommendations in the [NICE guideline on patient experience in adult NHS services](#), particularly relating to:

- [tailoring healthcare services for each patient](#)
- [continuity of care and relationships](#).

## Transfer from child to adult services

1.11.4 When managing the transition of a person from paediatric services to adult services for ongoing care of neurogenic lower urinary tract dysfunction:

- formulate a clear structured care pathway at an early stage and involve the person and their parents and carers
- involve the young person's parents and carers when preparing transfer documentation with the young person's consent
- provide a full summary of the person's clinical history, investigation results and details of treatments for the person and receiving clinician
- integrate information from the multidisciplinary health team into the transfer documentation
- identify and plan the urological services that will need to be continued after the transition of care
- formally transfer care to a named individual(s).

1.11.5 When receiving a person from paediatric services to adult services for ongoing care of neurogenic lower urinary tract dysfunction:

- review the transfer documentation and liaise with the other adult services involved in ongoing care (for example, adult neuro-rehabilitation services)
- provide the person with details of the service to which care is being transferred, including contact details of key personnel, such as the urologist

and specialist nurses

- ensure that urological services are being provided after transition to adult services.

1.11.6 Consider establishing regular multidisciplinary team meetings for paediatric and adult specialists to discuss the management of neurogenic lower urinary tract dysfunction in children and young people during the years leading up to transition and after entering adult services.

## Terms used in this guideline

### Alpha-blocking agents

Drugs that inhibit the response to sympathetic impulses by blocking the alpha receptor sites of effector organs. Because they inhibit the contraction of non-vascular smooth muscle such as that found at the bladder neck and within the prostate, alpha-blockers are commonly used to treat bladder outflow obstruction in men with normally innervated urinary tracts. Also known as 'alpha adrenergic blocking agents' or 'alpha adrenergic antagonists'.

### Antimuscarinic drugs

An anticholinergic agent that specifically blocks the muscarinic form of the cholinergic receptor. Because they decrease the responsiveness of the bladder wall muscle to stimulating nerve impulses, antimuscarinic drugs are used in the management of the overactive bladder.

### Augmentation cystoplasty

Surgical reconstruction of the bladder using an isolated intestinal segment to augment bladder capacity.

### Autologous fascial sling surgery

A procedure to treat stress urinary incontinence, in which a harvested strip of rectus fascia



is used to provide support to the urethra. Also see [urethral tape and sling surgery](#).

## Behavioural management programmes

Behavioural therapies are usually used to treat urge urinary incontinence and mixed urinary incontinence. Such therapies include:

- Timed voiding where the person is asked to void at set time intervals, rather than in response to a sense of bladder filling.
- Bladder retraining where intervals between voids are progressively increased, or the patient is asked to delay voiding for a specific time when they experience the need to void.
- Habit retraining involves identifying an incontinent person's toileting pattern and developing an individualised toileting schedule in order to pre-empt episodes of incontinence.

## Biofeedback

The process of becoming aware of various physiological functions using instruments that provide information on the activity of those same systems, with a goal of being able to manipulate them at will.

## Bladder retraining

See [behavioural management programmes](#).

## Bladder stone

Stone found in the urinary bladder formed by crystallisation and concretion of salts from the urine and containing phosphate and oxalate salts of calcium or ammonium. Stones typically form in conjunction with bacterial colonisation of the urine, for example, when an indwelling catheter is present, or bladder emptying is incomplete.

## Cauda equina compression

A serious condition caused by compression of the nerve roots in the lower portion of the

spinal canal that supply the lower limbs and the bladder and urethral sphincter.

## **Cystectomy**

Surgical removal of all or part of the urinary bladder.

## **Filling cystometry**

Part of urodynamic testing in which the bladder is slowly filled with liquid while pressure and volume measurements are taken in order to assess bladder function.

## **Habit retraining**

See [behavioural management programmes](#).

## **Hydronephrosis**

Distension and dilation of the renal pelvis and calyces, usually caused by obstruction of the free flow of urine from the kidney. Untreated, it leads to progressive atrophy of the kidney as a result of back pressure.

## **Ileal conduit diversion**

Surgical technique for the diversion of urine after a patient has had their bladder removed. Urine is transported from the ureters (the tubes draining urine from the kidneys) to a stoma on the abdominal wall using an isolated segment of small intestine.

## **Neurogenic**

Originating in the nerves or nervous tissue.

## **Neuromuscular electrical stimulation**

Procedure used to strengthen healthy muscles or to maintain muscle mass during or following periods of enforced inactivity. This helps to maintain or gain range of motion, to facilitate voluntary motor control, and temporarily reduces spasticity when the nerve supply to the muscle is intact. This procedure involves sending small electrical impulses

through the skin to the underlying nerves and muscles to create an involuntary muscle contraction.

## **Overactive bladder**

Produces symptoms of urinary urgency, with or without urge incontinence, usually with an increased frequency of micturition. The strong, sudden need to urinate is usually caused by involuntary contractions of the bladder or 'bladder spasms'.

## **Pelvic floor muscle training**

Daily training programme to strengthen the muscles that support the uterus, bladder and other pelvic organs and help prevent accidental urine leakage. Also called Kegel exercises or pelvic muscle rehabilitation.

## **Pelvic floor prolapse**

Loss of muscle tone and/or ligamentous elasticity resulting in the descent of the uterus or other pelvic organs into the vagina. If severe, the prolapse can protrude out of the vaginal orifice.

## **Pressure-flow studies**

Simultaneous measurement of bladder pressure and flow rate during the voiding phase of the micturition cycle. The test is used to assess the process of bladder emptying. For example, bladder outflow obstruction can be diagnosed if there is a low urinary flow rate in conjunction with a raised bladder pressure during voiding.

## **Prompted voiding**

A behavioural management programme that is used to encourage people to initiate their own toileting. It usually involves positive reinforcement and education of both the person with incontinence and their carer(s).

## **Renal scintigraphy**

Photographic recording, using a gamma camera, of the distribution of a radioisotope

(radioactive substance) given by injection. The radioisotope accumulates in the kidneys, allowing pictures to be produced showing details of both kidney structure and function.

## **Sacral agenesis**

A condition that exists when either part or all of the sacrum is absent due to a failure of the sacral spine to develop normally. In many cases, some or all of the nerves that supply the pelvic organs will also have failed to develop normally.

## **Spina bifida**

A condition in which the bones of the spine do not close due to a failure of normal development in the fetus. In cases of myelomeningocele, the bony abnormality is accompanied by abnormal development of the spinal cord or nerves and their covering membranes, which leads to abnormalities in the nerve supply to the lower limbs and pelvic organs.

## **Spinal dysraphism**

A general term that encompasses a number of different developmental abnormalities of the spine and spinal cord, of which spina bifida is an example.

## **Stress incontinence**

Stress urinary incontinence describes a symptom, a sign and a diagnosis, although it is only following urodynamic investigation that a diagnosis of urodynamic stress incontinence can be made. This condition is defined as 'the involuntary leakage of urine during increased abdominal pressure in the absence of a detrusor contraction'.

## **Suspected cancer pathway referral**

Person to receive a diagnosis or ruling out of cancer within 28 days of being referred urgently by their GP for suspected cancer. For further details, see [NHS England's webpage on faster diagnosis of cancer](#).

## Timed voiding

See [behavioural management programmes](#).

## Urethral tape and sling surgery

A procedure that restores bladder control for people who lose urine when they cough or exercise. The urethral tape procedure involves positioning an artificial tape under the urethra, which is the tube that runs from the bladder through which you urinate. The tape will then rest like a hammock under the urethra, giving support and maintaining continence. A urethral tape consists of a thin mesh ribbon that is placed in order to provide support to the urethra. Urethral sling surgery involves placing a sling around the urethra to lift it back into a normal position and to exert pressure on the urethra to aid urine retention. The sling is attached to the abdominal wall. Also see [autologous fascial sling surgery](#).

## Urodynamic investigations

Investigation of the function of the lower urinary tract (the bladder and urethra) using physical measurements such as urine pressure and flow rate, as well as clinical assessment. Video-urodynamic investigations involve using a dye to fill the bladder enabling X-rays of the lower urinary tract to be taken during filling and emptying of the bladder.

# Recommendations for research

The guideline development group has made the following recommendations for research.

## 1 Safety and efficacy of antimuscarinics

What is the safety and efficacy of more recently developed antimuscarinics compared with (a) placebo/usual care and (b) other antimuscarinics in the treatment of neurogenic lower urinary tract dysfunction?

### Why this is important

No high-quality clinical trials looking at the use of the newer antimuscarinic drugs in people with neurogenic lower urinary tract dysfunction have been carried out. Both placebo-controlled and comparative studies are lacking. This is important because the more recently developed medications are of unknown efficacy, are more expensive and claim (in the non-neurogenic population) to have fewer adverse effects. The adverse effects of antimuscarinics are mostly due to their action at sites other than the bladder (for example, causing a dry mouth) but there is now increasing concern that antimuscarinic effects on the central nervous system may adversely affect cognitive function in both children with brain damage (caused by cerebral palsy or hydrocephalus) and adults with impaired cognition (caused by cerebral involvement in multiple sclerosis or neurodegenerative diseases).

## 2 Safety and efficacy of botulinum toxin

What is the safety and efficacy of botulinum toxin compared with (a) usual care, (b) antimuscarinics and (c) augmentation cystoplasty in people with neurogenic lower urinary tract dysfunction?

### Why this is important

Further research is needed to determine whether repeated intradetrusor injections of botulinum toxin type A have long-term efficacy. The efficacy in terms of continence and upper urinary tract preservation should be studied.

Botulinum toxin injection into the detrusor is an effective means of managing incontinence and improves urodynamic measures of bladder storage with the potential to protect the kidneys from the effects of high intravesical pressures. It is well tolerated in a spectrum of conditions and ages. However, the longer-term efficacy over many injections has not been established.

A clinical trial is needed to study the outcome in terms of continence and renal preservation over many cycles of repeated injection. Quality of life is an important outcome. A trial should enrol children and adults. The indications for botulinum toxin need not be modified for inclusion, but entrants into a trial must have anatomically normal kidneys (on imaging) and normal renal function.

What is the safety and efficacy of botulinum toxin compared with (a) usual care, (b) antimuscarinics and (c) augmentation cystoplasty in people with primary cerebral conditions with lower urinary tract dysfunction?

## Why this is important

The effects of intradetrusor botulinum toxin type A injection should be investigated in groups of people with underlying cerebral conditions that are associated with lower urinary tract dysfunction, as well as those with spinal cord injury, spina bifida and multiple sclerosis. Reports of its use in other conditions are limited to small numbers of patients within case series studies that include heterogeneous groups of patients. Potential benefits of successful treatment in cerebral disease may include the avoidance of cognitive impairment, which can be seen as a side effect of antimuscarinic medication.

A trial should include people with primary cerebral conditions including (but not restricted to) stroke, head injury and cerebral palsy, but excluding multiple sclerosis. Children and adults should be recruited. Tolerability and acceptability are important outcomes, as well as the primary outcomes of continence, preservation of the upper urinary tracts and quality of life. Measurement of carer burden and quality of life is also important.

## 3 Management strategies to reduce the risk of symptomatic urinary tract infections

In people with neurogenic lower urinary tract dysfunction, which management strategies (including the use of prophylactic antibiotics and various invasive and non-invasive

techniques to aid bladder drainage) reduce the risk of symptomatic urinary tract infections?

## Why this is important

Recurrent urinary tract infections in people with neurogenic bladder dysfunction are a cause of considerable morbidity. Urinary tract infections may exacerbate incontinence, cause symptoms of malaise and may progress to involve the upper urinary tract with possible loss of renal function. In the population with neurological diseases such as multiple sclerosis, Parkinson's disease and dementia, the rise in temperature with urinary tract infections can cause deterioration in neurological function and even a relapse of multiple sclerosis. There are therefore numerous reasons why people with neurogenic lower urinary tract dysfunction should avoid urinary tract infections.

The causes for the high prevalence of urinary tract infections in such people include loss of physiological bladder function and high intravesical pressures. Intermittent or permanent catheterisation inevitably exacerbate the problem, but incomplete bladder emptying is also a predisposing factor for urinary tract infections.

Research in this area is faced with methodological difficulties, not least because it may be difficult to distinguish between bladder colonisation (asymptomatic bacteriuria) and true infection.

In view of the considerable clinical burden of urinary tract infections and the global problem of antibiotic resistance, it is important to establish whether or not any infection prevention strategies, including patient training or the provision of information relating to prophylactic antibiotics are effective in reducing symptomatic urinary tract infections.

## 4 Bladder management strategies

What are the long-term risks and effects on quality of life of different bladder management strategies for lower urinary tract dysfunction in people with neurological disease?

## Why this is important

The range of bladder management strategies available to manage lower urinary tract dysfunction in neurological disease includes permanent urethral catheterisation and



suprapubic catheterisation, intermittent self-catheterisation, penile sheath collection systems and pads. However, there is very sparse evidence about which strategies are most acceptable to patients and their family members and carers. The current research base relates mainly to the spinal injury population but may be relevant to people with other neurological diseases.

Bladder management strategies are a long-term treatment with implications for maintaining health and quality of life. In order to make informed choices about the most appropriate method of bladder management, patients and their family members and carers require information about the risks and benefits of the available options. There is currently little evidence about which methods are most likely to produce long-term complications (renal impairment, urinary stones and infections, hydronephrosis, bladder malignancy). The effect on quality of life for patients and their family members and carers of different bladder management strategies is not known. There are methodological difficulties due to the heterogeneity of the population with neurological disease, the long-time course of treatments and the presence of cognitive impairment in some sub-populations.

Proposed studies could include prospective cohort studies of disease-specific populations examining the effect of each method on quality of life using both generic and disease-specific assessment methods. In addition, prospective screening for complications including renal impairment, stone formation and infection should be carried out and comparisons made for each bladder management method. Particular emphasis should be placed on quality-of-life outcomes for family members and carers, especially for those looking after people with cognitive impairment.

## Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the [NICE topic page on urinary incontinence](#).

For full details of the evidence and the guideline committee's discussions, see the [full guideline](#). You can also find information about [how the guideline was developed](#), including details of the committee.

NICE has produced [tools and resources to help you put this guideline into practice](#). For general help and advice on putting our guidelines into practice, see [resources to help you put NICE guidance into practice](#).

# Update information

**October 2023:** We updated recommendation 1.10.8 in line with [NHS England's standard on faster diagnosis of cancer](#).

## Minor changes since publication

**November 2021:** We added a link to NICE's shared decision making guideline in recommendation 1.2.4. We incorporated footnote text into the recommendations to meet accessibility requirements.

ISBN: 978-1-4731-5441-4