

Urinary incontinence in neurological disease: management of lower urinary tract dysfunction in neurological disease

NICE guideline

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If you wish to comment on this version of the guideline, please be aware that all the supporting information and evidence is contained in the full version.

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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	Spinal dysraphism (e.g. myelomeningocele)	Spinal cord injury	Multiple sclerosis Cervical spondylosis with myelopathy
Sacral spinal cord or peripheral nerve conditions	Spinal dysraphism Sacral agenesis Ano-rectal 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 neurological 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 two.

Secondary effects can also arise as a result of neurological lower urinary tract dysfunction. For example, there is a marked increase in the risk of urinary tract infection in people with neurological 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 neurological 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 neurological 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 neurological 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.

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. 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.

Patient-centred care

This guideline offers best practice advice on the care of adults and children with incontinence due to neurological disease.

Treatment and care should take into account patients' needs and preferences. People with incontinence due to neurological disease should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. If patients do not have the capacity to make decisions, healthcare professionals should follow the [Department of Health's advice on consent](#) and the [code of practice that accompanies the Mental Capacity Act](#). In Wales, healthcare professionals should follow [advice on consent from the Welsh Government](#).

If the patient is under 16, healthcare professionals should follow the guidelines in the Department of Health's '[Seeking consent: working with children](#)'.

Good communication between healthcare professionals and patients is essential. It should be supported by evidence-based written information tailored to the patient's needs. Treatment and care, and the information patients are given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English.

If the patient agrees, families and carers should have the opportunity to be involved in decisions about treatment and care.

Families and carers should also be given the information and support they need.

Care of young people in transition between paediatric and adult services should be planned and managed according to the best practice guidance described in the Department of Health's '[Transition: getting it right for young people](#)'.

Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with incontinence due to

neurological disease. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care.

Key priorities for implementation

The following recommendations have been identified as priorities for implementation.

Assessment of neurogenic lower urinary tract dysfunction

- 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. **[1.1.1]**

- 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. **[1.1.6]**

- 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. **[1.1.7]**

- Refer people for urgent investigation if they have any of the following 'red flag' signs and symptoms:
 - haematuria
 - recurrent urinary tract infections
 - loin pain
 - recurrent catheter blockages
 - hydronephrosis or kidney stones on imaging
 - biochemical evidence of renal deterioration. **[1.1.12]**

Treatment to improve bladder storage

- Offer bladder wall injection with botulinum toxin type A¹ to adults:
 - with spinal cord disease **and**
 - with symptoms of an overactive bladder **and**
 - who are either unresponsive to, or intolerant of, antimuscarinic drugs.

[1.3.8]

- Ensure that patients who have been offered continuing treatment with repeated botulinum toxin type A injections have prompt access to repeat injections when symptoms return. **[1.3.15]**

Treatment to prevent urinary tract infection

- Do not routinely use antibiotic prophylaxis for urinary tract infections in people with neurogenic lower urinary tract dysfunction. **[1.8.1]**

Monitoring and surveillance protocols

- Offer lifelong ultrasound surveillance of the kidneys to people who are judged to be at high risk of renal complications, including 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. **[1.9.3]**

Access to and interaction with services

- 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/or their parents and carers
 - involve the person's parents and carers when preparing transfer documentation

¹ At the time of publication (March 2012), botulinum toxin type A did not have UK marketing authorisation for this indication. Informed consent should be obtained and documented.

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- 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). **[1.11.4]**

1 Guidance

The following guidance is based on the best available evidence. The [full guideline](#) [hyperlink to be added for final publication] gives details of the methods and the evidence used to develop the guidance.

The following recommendations apply to both adults and children unless otherwise stated.

1.1 ***Assessment of neurogenic lower urinary tract dysfunction***

Initial 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, look for evidence of pelvic floor prolapse, constipation 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 (for example, take a midstream urine sample for people who can void or a urine sample from a freshly inserted, sterile catheter, and avoid taking samples from a leg bag) to test for the presence of blood, glucose, protein, leukocytes and nitrites.
- 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.
- 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/or 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 a 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
 - loin pain
 - recurrent catheter blockages

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- 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, 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, their family members and carers specific information and training when starting a new urinary tract management system such as intermittent catheterisation, penile sheath collection or indwelling catheterisation.

- 1.2.2 Tailor information and training to the individual's physical condition and cognitive function to promote their active participation in care and self-management.
- 1.2.3 Inform patients 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 '[Patient experience in adult NHS services](#)' (NICE clinical guideline 138). Recommendations on shared decision making and information enabling patients to actively participate in their care can be found in section 1.5.

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 a specialist continence assessment **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 for people with cognitive impairment, take into account that prompted voiding and habit retraining are particularly suitable for cognitively impaired people.

Antimuscarinics

- 1.3.3 Offer antimuscarinic² 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 antimuscarinic² drug treatment in people with:
- conditions affecting the brain **and**
 - symptoms of an overactive bladder.
- 1.3.5 Consider antimuscarinic² 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 catheterisation or an indwelling catheter after starting antimuscarinic treatment.
- 1.3.7 When prescribing antimuscarinics, take into account that:
- antimuscarinics known to cross the blood-brain barrier (for example, oxybutynin²) 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.

² At the time of publication (March 2012), oxybutynin was not licensed for children under 5 years old. Informed consent should be obtained and documented.

Botulinum toxin type A

1.3.8 Offer bladder wall injection with botulinum toxin type A³ to adults:

- with spinal cord disease **and**
- with symptoms of an overactive bladder **and**
- who are either unresponsive to, or intolerant of, antimuscarinic drugs.

1.3.9 Consider bladder wall injection with botulinum toxin type A³ for children and young people:

- with spinal cord disease **and**
- with symptoms of an overactive bladder **and**
- who are either unresponsive to, or intolerant of, antimuscarinic drugs.

1.3.10 Offer bladder wall injection with botulinum toxin type A³ to adults with:

- spinal cord disease **and**
- urodynamic investigations showing impaired bladder storage.

1.3.11 Consider bladder wall injection with botulinum toxin type A³ for children and young people with:

- spinal cord disease **and**
- urodynamic investigations showing impaired bladder storage.

³ At the time of publication (March 2012), botulinum toxin type A did not have UK marketing authorisation for this indication. Informed consent should be obtained and documented.

- 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 may be needed 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 patients 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 bladder augmentation 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.

1.4 Treatment for stress incontinence

Pelvic floor muscle training

1.4.1 Consider pelvic floor muscle training using biofeedback and/or electrical stimulation of the pelvic floor for people with:

- lower urinary tract dysfunction due to multiple sclerosis or stroke
- other neurological conditions where the potential to voluntarily contract the pelvic floor is preserved.

Select patients for this training after specialist pelvic floor assessment.

Urethral tape and sling surgery

1.4.2 Consider autologous fascial sling surgery for 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 urinary incontinence.

1.4.5 When considering inserting an artificial urinary sphincter:

- discuss alternative procedures, the risks associated with them, and the possible need for repeat procedures with the person and/or their family members and carers
- ensure that the bladder has adequate low-pressure storage capacity.

- 1.4.6 Monitor the upper urinary tract after artificial urinary sphincter surgery.
- 1.4.7 Do not use artificial urinary sphincter insertion for people in whom an alternative procedure, such as insertion of an autologous fascial sling, is as likely to control incontinence.

1.5 Treatment to improve bladder emptying

Alpha adrenergic antagonists

- 1.5.1 Do not offer alpha-blockers to patients with 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 'Infection prevention and control' (NICE clinical guideline in development). Publication expected March 2012.]

- 1.6.2 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.

1.7 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 history of recent, frequent or severe urinary tract infection.

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)
- consider and discuss with the person the risks and benefits of prophylaxis
- check local protocols approved by a microbiologist or discuss with a microbiologist.

1.8.4 Regularly review the need for ongoing prophylaxis in all people who are receiving antibiotic prophylaxis.

1.8.5 When changing catheters in people with a long-term indwelling urinary catheter:

- do not offer antibiotic prophylaxis routinely
- consider antibiotic prophylaxis for people who:
 - have a history of symptomatic urinary tract infection after catheter change **or**
 - experience trauma during catheterisation.

[This recommendation is from 'Infection prevention and control' (NICE clinical guideline in development). Publication expected March 2012.]

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.
- 1.9.2 Consider using isotopic glomerular filtration rate when an accurate measurement of glomerular filtration rate is required.
- 1.9.3 Offer lifelong ultrasound surveillance of the kidneys to people who are judged to be at high risk of renal complications, including 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 spinal 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 patients and/or 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) and tell them the symptoms to look out for that mean they should see a healthcare professional.

- 1.10.2 When discussing treatment options, inform patients that urethral catheters may be associated with higher risks of renal complications than other forms of bladder management.
- 1.10.3 Use renal imaging to investigate symptoms that suggest upper urinary tract disease.

Bladder stones

- 1.10.4 Discuss with patients and/or their family members and carers the increased risk of bladder stones in people with neurogenic lower urinary tract dysfunction and tell them the symptoms to look out for that mean they should see a healthcare professional.
- 1.10.5 Discuss with patients and/or 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 and tell them the symptoms to look out for that mean they should see a healthcare professional.
- 1.10.6 Refer people with symptoms that suggest the presence of lower urinary tract stones (for example, recurrent catheter blockages, recurrent urinary tract infection or haematuria) for cystoscopy.

Bladder cancer

- 1.10.7 Discuss with patients and/or 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 the condition and complicating factors, such as recurrent urinary tract infections, and tell them the symptoms to look out for that mean they should see a healthcare professional.
- 1.10.8 Arrange urgent (within 2 weeks) investigation with urinary tract imaging and cystoscopy for people with:

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

1.11 Access to and interaction with services

Access to and interaction with services

- 1.11.1 If a person has received care for neurological lower urinary tract dysfunction in a specialised setting (for example, in a spinal injury unit or a paediatric urology unit), provide contact details to the person and/or their family members and carers, and to the non-specialist medical and nursing staff involved in their care, for specialist advice and information.
- 1.11.2 Provide people with neurological lower urinary tract dysfunction, and/or 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.

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 '[Patient experience in adult NHS services](#)' (NICE clinical guideline 138). Recommendations on tailoring healthcare services for each patient can be found in section 1.3 and recommendations on continuity of care and relationships can be found in section 1.4.

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/or their parents and carers
- involve the person's parents and carers when preparing transfer documentation
- 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.

2 Notes on the scope of the guidance

NICE guidelines are developed in accordance with a [scope](#) that defines what the guideline will and will not cover.

How this guideline was developed

NICE commissioned the National Clinical Guideline Centre to develop this guideline. The Centre established a Guideline Development Group (see appendix A), which reviewed the evidence and developed the recommendations.

There is more information about [how NICE clinical guidelines are developed](#) on the NICE website. A booklet, 'How NICE clinical guidelines are developed: an overview for stakeholders, the public and the NHS' is [available](#).

3 Implementation

NICE has developed [tools to help organisations implement this guidance](#).

Note: these details will apply when the guideline is published.

4 Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to improve NICE guidance and patient care in the future. The Guideline Development Group's full set of research recommendations is detailed in the full guideline (see section 5).

4.1 *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 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 impact on 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).

4.2 *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 required 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 continence, 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.

4.3 *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 the face 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.

4.4 *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/or 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/or 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/or 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.

5 Other versions of this guideline

5.1 Full guideline

The full guideline, 'Urinary incontinence in neurological disease: management of lower urinary tract dysfunction in neurological disease' [\[add hyperlink for final publication\]](#) contains details of the methods and evidence used to develop

the guideline. It is published by the National Clinical Guideline Centre. **Note:** these details will apply to the published full guideline.

5.2 *NICE pathway*

The recommendations from this guideline have been incorporated into a [NICE pathway](#). **Note:** these details will apply when the guideline is published.

5.3 *'Understanding NICE guidance'*

A summary for patients and carers (['Understanding NICE guidance'](#)) is available.

For printed copies, phone NICE publications on 0845 003 7783 or email publications@nice.org.uk (quote reference number N[XXXX]). **Note:** these details will apply when the guideline is published.

We encourage NHS and voluntary sector organisations to use text from this booklet in their own information about [condition].

6 Related NICE guidance

Published

- [Patient experience in adult NHS services](#). NICE clinical guideline 138 (2012).
- [Nocturnal enuresis](#). NICE clinical guideline 111 (2010).
- [Constipation in children and young people](#). NICE clinical guideline 99 (2010).
- [Lower urinary tract symptoms](#). NICE clinical guideline 97 (2010).
- [Percutaneous posterior tibial nerve stimulation for overactive bladder syndrome](#). NICE interventional procedure guidance 362 (2010).
- [Laparoscopic augmentation cystoplasty \(including clam cystoplasty\)](#). NICE interventional procedure guidance 326 (2009).
- [Chronic kidney disease](#). NICE clinical guideline 73 (2008).
- [Single-incision sub-urethral short tape insertion for stress urinary incontinence in women](#). NICE interventional procedure guidance 262 (2008).

- [Suburethral synthetic sling insertion for stress urinary incontinence in men](#). NICE interventional procedure guidance 256 (2008).
- [Urinary tract infection in children](#). NICE clinical guideline 54 (2007).
- [Faecal incontinence](#). NICE clinical guideline 49 (2007).
- [Insertion of extraurethral \(non-circumferential\) retropubic adjustable compression devices for stress urinary incontinence in men](#). NICE interventional procedure guidance 224 (2007).
- [Dementia](#). NICE clinical guideline 42 (2006).
- [Parkinson's disease](#). NICE clinical guideline 35 (2006).
- [Urinary incontinence](#). NICE clinical guideline 40 (2006).
- [Insertion of biological slings for stress urinary incontinence](#). NICE interventional procedure guidance 174 (2006).
- [Intramural urethral bulking procedures for stress urinary incontinence](#). NICE interventional procedures guidance 138 (2005).
- [Insertion of extraurethral \(non-circumferential\) retropubic adjustable compression devices for stress urinary incontinence in women](#). NICE interventional procedure guidance 133 (2005).
- [Transobturator foramen procedures for stress urinary incontinence](#). NICE interventional procedure guidance 107 (2005).
- [Sacral nerve stimulation for urge incontinence and urgency-frequency](#). NICE interventional procedure guidance 64 (2004).
- [Multiple sclerosis](#). NICE clinical guideline 8 (2003).

Under development

NICE is developing the following guidance (details available from [the NICE website](#)):

- Infection: prevention and control of healthcare-associated infections in primary and community care. NICE clinical guideline. Publication expected March 2012.
- Spasticity in children. NICE clinical guideline. Publication expected June 2012.

7 Updating the guideline

NICE clinical guidelines are updated so that recommendations take into account important new information. New evidence is checked 3 years after publication, and healthcare professionals and patients are asked for their views; we use this information to decide whether all or part of a guideline needs updating. If important new evidence is published at other times, we may decide to do a more rapid update of some recommendations. Please see our website for information about updating the guideline.

Appendix A: The Guideline Development Group, National Collaborating Centre and NICE project team

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Appendix B: Glossary

Adrenergic blocking agent: an agent that inhibits response to sympathetic impulses by blocking the alpha or beta receptor sites of effector organs. Drugs blocking alpha receptors are also known as an alpha adrenergic antagonist or, simply, alpha blockers.

Anticholinergic: an anticholinergic agent is a substance that blocks the neurotransmitter acetylcholine in the central and the peripheral nervous system.

Antimuscarinic: an anticholinergic agent that specifically blocks the muscarinic form of the cholinergic receptor.

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.

Behaviour 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 by the clock, 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 behaviour management programmes.

Bladder stone: solid mass found in the urinary bladder.

Cauda equina compression: serious condition caused by compression of the nerves in the lower portion of the spinal canal.

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 behaviour 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.

Ileal conduit diversion: surgical technique for the diversion of urine after a patient has had their bladder removed.

Neurogenic: related to diseases of the central nervous system.

Neurogenic bladder: lower urinary tract dysfunction due to disease of the nervous system.

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.

Neuropathic: any pathology of the peripheral nerves.

Overactive bladder syndrome: consists of 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.

Pressure flow studies: simultaneous measurement of bladder pressure and flow rate during the voiding phase of the micturition cycle. The best method of quantitatively analysing voiding function.

Prolapse: condition where organs, such as the uterus, slip out of place.

Prompted voiding: a toileting programme that is a supplement to habit training. Prompted voiding attempts to teach people to assess their urinary incontinence status and to request toileting from care givers. This type of programme has been successful with people who have functional and mental impairments.

Sacral agenesis: a condition that exists when either part or all of the sacrum is absent. It is possible for two of the five sacral segments to be absent without causing problems with the nerve supply. However, if three or more of the sacral segments are absent, it is probable that there will be some abnormality of the nerves coming out of the sacrum.

Scintigraphy: photographic recording of the distribution of an internally administered radiopharmaceutical agent with the use of a gamma camera.

Spina bifida: a condition in which the bones of the spine do not close. 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.

Timed voiding: see behavioural management programmes.

Urethral tape and sling surgery: procedure that restores bladder control for people who lose urine when they cough or exercise. A urethral tape consists of a thin mesh ribbon that is placed in order to provide support to the urethra.

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.

Urodynamic 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'.