

Managing urinary incontinence in people with a neurological condition

Information for the public

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About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

This information explains the advice about the care and management of urinary incontinence in people with a neurological condition that is set out in NICE clinical guideline 148.

Does this information apply to me?

Yes, if you have urinary incontinence and a neurological condition, or are the family or carer of someone with urinary incontinence and a neurological condition.

The advice in the NICE guideline covers urinary incontinence related to a neurological condition in adults and children (from birth).

Your care

If you think that your care does not match what is described in this information, please talk to a member of your healthcare team in the first instance.

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution (www.dh.gov.uk/en/DH_132961). All NICE guidance is written to reflect these. You have the right to be involved in discussions and make informed decisions about your treatment and care with your healthcare team. Your choices are important and healthcare professionals should support these wherever possible. You should be treated with dignity and respect.

To help you make decisions, healthcare professionals should explain urinary incontinence related to neurological conditions and the possible treatments for it. They should cover possible benefits and risks related to your personal circumstances. You should be given relevant information that is suitable for you and reflects any religious, ethnic, or cultural needs you have. It should also take into account whether you have any physical or learning disability, sight or hearing problem or language difficulties. You should have access to an interpreter or advocate (someone who helps you put your views across) if needed.

Your family and carers should be given their own information and support. If you agree, they should also have the chance to be involved in decisions about your care.

You should be able to discuss or review your care as your treatment progresses, or your circumstances change. This may include changing your mind about your treatment or care. If you have made an 'advance decision' (known as a 'living will' in the past) in which you have already given instructions about any treatments that you do not wish to have, your healthcare professionals have a legal obligation to take this into account.

All treatment and care should be given with your informed consent. If, during the course of your illness, you are not able to make decisions about your care, your healthcare professionals have a duty to talk to your family or carers unless you have specifically asked them not to. Healthcare professionals should follow the Department of Health's advice on consent (www.dh.gov.uk/en/DH_103643) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.nhs.uk/CarersDirect/moneyandlegal/legal. In Wales healthcare professionals should follow advice on consent from the Welsh Government (www.wales.nhs.uk/consent).

If you are under 16, your parents or carers will need to agree to your treatment, unless it is clear that you fully understand the treatment and can give your own consent.

Urinary incontinence related to a neurological condition

Urinary incontinence (referred to as incontinence in the rest of this information) is the leakage of urine when you do not mean to urinate (pass urine). It is a common condition with many causes and is particularly common in people with neurological conditions.

Neurological conditions affect the body's nervous system, involving damage to the brain, spinal cord or other nerves. The nervous system plays an important role in regulating the storage of urine in the bladder and coordinating and controlling when you pass urine. Damage to the nervous system may cause problems that affect the lower urinary tract. The lower urinary tract is the lower part of the urinary system, which includes the bladder, the tube that takes urine from the bladder (the urethra) and the muscles that control the release of urine (the sphincters). People with neurological conditions may have problems with the bladder or the sphincters or both, including:

- Problems with bladder storage, for example, needing to urinate urgently and/or frequently, or incontinence. One type is urge incontinence, when you feel a sudden need to urinate and then can't stop some urine leaking out. This is often caused by the bladder muscle contracting before the bladder is full (called an overactive bladder or overactive bladder syndrome).
- Stress incontinence, which involves leakage of urine when you strain, for example, on coughing or sneezing, or with the effort of lifting a heavy object.
- Problems with bladder emptying, such as having a delay between trying and starting to urinate, a slow or weak urinary stream, the need to strain or problems with urine being held in the bladder.

Incontinence can have a major impact on people's lives. It can be distressing and can affect daily life and stop them taking part in activities.

The care described in this information may be provided by a range of professionals depending on your particular condition and circumstances. These could include your GP, specialists in urology or neurology and specialist or community nurses. Members of your healthcare team are referred to as healthcare professionals.

Questions you might like to ask your healthcare team

- Please tell me more about how my urinary problem is caused by my neurological condition.
- Are my urinary problems going to get worse over time?
- Are there any support organisations in my local area?
- Can you provide any information for my family/carers?
- What help is available?

For family members, friends or carers:

- What can I/we do to help and provide support?
- Is there any additional support that I/we as a carer(s) might benefit from or are entitled to?

Finding out what is wrong

If you have a neurological condition and have or develop urinary problems, a healthcare professional should do an initial assessment to find out the type of problem. An assessment should also be carried out if your symptoms change and periodically to ensure that you are receiving the best care.

Your healthcare professional should ask questions about your urinary symptoms, your neurological condition, any other health problems you have (such as bowel or sexual problems) and your use of any medications and therapies. You should have an examination that includes checking your blood pressure and examining your abdomen and genitals, and you may be offered a vaginal or rectal examination if your healthcare professional thinks it would be helpful. Your healthcare professional should also assess your neurological condition, which might involve testing your ability to walk or move around, the use of your hands, checking your spine and assessing your mental ability and memory.

A sample of your urine should be taken to perform a 'dipstick test'. This test can help to detect an infection or may suggest other possible problems that may contribute to your urinary problem. If the results suggest you may have an infection, your urine should be sent for further testing (a bacterial culture test and an antibiotic sensitivity test) to help decide what type of antibiotic treatment is most suitable for you.

You or a family member or carer should be asked to keep a 'bladder diary' to record how much fluid you drink, how often you urinate and how much urine you pass. You should keep the diary for at least 3 days.

If you are able to urinate, your healthcare professional may measure your 'urinary flow rate'. This involves you passing urine into a special urinal or toilet that measures the amount of urine released and how fast it comes out.

You should then be offered an ultrasound scan to measure how much urine is left in the bladder after you urinate. And you may be offered several further scans on different occasions to look at how your bladder empties at different times and in different circumstances.

People with some neurological conditions, such as spina bifida and spinal cord injury, are at particular risk of kidney problems. If you are considered at high risk of kidney problems you may also be offered an ultrasound scan of the kidneys. You should also be offered tests called video-urodynamic investigations (see box on urodynamic investigations, below).

If you are not at higher risk of kidney problems, you should not usually need urodynamic investigations. However, you should be offered them before undergoing any surgery for urinary problems.

Urodynamic investigations

Urodynamic investigations are tests that assess how well the bladder empties and stores urine. They may include a variety of tests, some of which involve passing a thin tube into and along your urethra and into your bladder, and then filling the bladder with warm water. Several different measurements are then taken to check the pressure in the bladder and the flow of urine in the bladder as it fills and empties.

Video-urodynamic investigations involve using a special dye to fill the bladder, enabling X-rays to be taken during filling and emptying of the bladder.

You should be referred to a specialist (called a urologist) for urgent investigation if you have any of the following:

- blood in your urine

- repeated urinary infections
- loin pain
- repeated catheter blockages
- an ultrasound scan showing kidney stones or enlargement of the kidney caused by urine blockage (hydronephrosis)
- blood test results suggesting a worsening kidney problem.

Urinary problems can sometimes cause unexplained changes to your neurological symptoms (such as worsening spasticity or confusion). Your healthcare professional may offer assessment and treatment for urinary disease if this is suspected.

You may also need to be referred to a neurology specialist if your healthcare professional suspects that your urinary problems are caused by new or worsening neurological disease needing specialist investigation.

Your healthcare professional should also assess the impact of your urinary problems on your family members and carers, and look into how this can be reduced.

Deciding on treatment for urinary problems

Once your healthcare professional has identified the type of urinary problem that you have, the most suitable care can be offered. Your healthcare professional will assess which types of treatment might best suit your situation and abilities, taking into account whether you have support, what treatments you are able to manage (for example, if you have problems with using your hands or moving around) and whether they are compatible with your lifestyle.

Questions about finding out what is wrong (diagnosis)

- Please give me more details about the tests/investigations I should have.
- What do these tests involve?
- Where will these be carried out? Will I need to have them in hospital?
- How long will I have to wait until I have these tests?

- How long will it take to get the results of these tests?
- Will my neurological condition affect the choice of treatment available to me?

Treatments for problems with bladder storage

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about specific treatments and options covered in this information, please talk to a member of your healthcare team.

Training programmes

If your urinary symptoms are caused by problems with storing urine in the bladder, you may be offered a training programme after a specialist assessment to check if your condition is suitable for this treatment. Training programmes include different methods aimed at changing the pattern of urinating, for example by urinating at set times rather than when your bladder feels full, gradually increasing the time between urinating or delaying urination, or identifying your pattern of urination and using it to predict and avoid incontinence (habit retraining). You and/or your family or carer should also be given information to help understand the training and how the bladder and urethra work.

Medications

You should be offered a type of drug called an 'antimuscarinic drug' (which work by relaxing the bladder muscle) if you have spinal cord disease (such as spinal cord injury or multiple sclerosis) and symptoms of an 'overactive bladder' such as needing to urinate more frequently, an urgent and sudden need to urinate, or incontinence. Your healthcare professional should take into account the possible side effects (such as a dry mouth, blurred vision, impaired thinking and constipation) and increased risk of urinary tract infection associated with these drugs.

You may also be offered an antimuscarinic drug if your neurological condition affects your brain (such as cerebral palsy, head injury or stroke) and you have symptoms of an overactive bladder, or if you have had urodynamic investigations that show you have problems with storing urine in your bladder.

If you are taking an antimuscarinic drug and are not using a catheter, the amount of urine left in your bladder after urination should be monitored because you may be at increased risk of infection or need a catheter to help with draining urine.

Bladder injections

Adults with spinal cord disease should be offered an injection into the bladder wall with a drug called 'botulinum toxin type A' (which works by relaxing the bladder muscle) if antimuscarinic drug treatment is not successful.

Bladder injections are also an option for children and young people with spinal cord disease in whom antimuscarinic drug treatment is not successful.

Before offering you bladder injections, your healthcare professional should explain to you and/or your family and carers that after the injections you may not be able to pass urine normally and you may need to start using a catheter to empty your bladder. They should discuss with you whether you are able and willing to use a catheter if needed.

If you are having treatment with bladder injections and do not use a catheter, the amount of urine left in your bladder after urination should be monitored. If your doctor thinks that you might be at risk of kidney problems your kidneys should be monitored.

If bladder injection is successful, and you have been offered continuing treatment, repeat injections should be available promptly when your urinary symptoms return.

Surgery

If you have a neurological condition that is not going to get worse (non-progressive) and problems with storing urine in your bladder that cause problems such as incontinence or hydronephrosis (enlargement of the kidney caused by urine build-up) and other treatments have failed, you may be offered surgery called 'bladder augmentation'. This involves removing a segment from your intestine and using it to enlarge the wall of your bladder. This procedure should only be offered after a thorough assessment and discussion with you and/or your family and carers about possible problems, risks and alternative treatments.

After bladder augmentation, you should be offered ongoing checks for any problems, some of which may develop gradually over time.

Treatments for stress incontinence

Pelvic floor training

If you have stress incontinence and can still contract the muscles of the pelvic floor (the muscles that support your bladder) you may be offered pelvic floor muscle training (with or without a device to measure or stimulate the electrical signals in the muscles). You should only be offered this treatment if it is recommended for you after a specialist assessment of your pelvic floor.

Surgery

If pelvic floor training is not suitable or does not work for you, your healthcare professional may suggest surgery for stress incontinence. One option for surgery includes inserting a strip of tissue taken from another part of your body to form a sling that supports the urethra. This helps to stop urine from leaking out.

A further option is to insert a device called an artificial urinary sphincter (valve) to control the flow of urine from the bladder into the urethra. Some of the side effects of this operation can be serious, so your healthcare professional should discuss alternative procedures, the risks associated with the procedure, and the possible need for repeat procedures with you and/or your family and carers. It should only be offered if an alternative procedure, such as sling insertion, is less likely to be effective. If you have an artificial sphincter inserted, you should be monitored after the operation to check how well your kidneys are working.

Treatment for problems with bladder emptying

There are not many treatments for problems with bladder emptying in people with neurological conditions, and you may need to use a catheter (see box below) to help empty your bladder.

You should not be offered drugs called alpha-blockers to treat problems with emptying the bladder.

Urinary catheters

Some people may be offered a catheter to help with their incontinence. A catheter is a hollow tube that drains urine from your bladder. Usually, the catheter is inserted through the

urethra. Sometimes a catheter is inserted into the bladder through a small hole in the lower part of the tummy (this type of catheter is called a 'suprapubic catheter').

An indwelling catheter is one that's in place all the time.

The urine may drain directly into a bag or you may have a catheter valve instead, which is opened at regular intervals to drain the urine from your bladder. You may choose to use a catheter valve if you prefer it and your healthcare professional thinks it is suitable for you.

An intermittent catheter is inserted at regular intervals or when you feel the need to urinate.

Treatment to prevent urinary infection

Most people should not usually need antibiotics for prevention of infections. However, if you have recently had frequent or severe urinary infections your healthcare professional may offer you antibiotics to help prevent further infections. Before prescribing antibiotics, your healthcare professional should check whether there is a problem causing the infections that could be treated (such as bladder stones or bladder emptying problems), discuss with you the risks and benefits, and investigate which antibiotics are most suitable. If you are taking antibiotics to prevent infection, your healthcare professional should regularly review whether they are needed.

If you have a long-term indwelling catheter you should not usually be given antibiotics to prevent infection when your catheter is being changed. However, you may be given antibiotics if you have had symptoms of urinary infection in the past after a catheter change or you experience trauma during insertion of the catheter.

Managing major urinary problems that do not respond to treatment

If you have a major urinary problem (such as incontinence or a related worsening kidney problem) that cannot be managed with other treatments, your healthcare professional may offer you an operation called 'ileal conduit diversion' (also known as urostomy). This operation creates a new route for urine to pass from the body, avoiding the bladder. The tubes from the kidneys to the bladder (the ureters) are linked directly to the outside of your body, so the urine can be collected in a pouch without flowing into the bladder.

Your healthcare professional should discuss with you the option of having your bladder removed at the same time to help prevent problems with waste matter building up in the bladder.

Questions about the treatment

- Why have you decided to offer me this particular type of treatment?
- What are the pros and cons of having this treatment?
- What will the treatment involve?
- How will the treatment help me? What effect will it have on my symptoms and everyday life? What sort of improvements might I expect?
- How long will it take to have an effect?
- What other treatment options are available?
- How long will I have to take the medication?
- How often will I have to have bladder injections?
- Are there any serious side effects or risks associated with this treatment?
- What should I do if I get any side effects?
- Are there any long-term effects of taking this treatment?

Possible complications related to your urinary problem

Your healthcare professionals should discuss with you and/or your family or carers that you may be at increased risk of the following problems. Your healthcare professional should tell you and your family or carers which symptoms to look out for and when to see a healthcare professional.

Kidney problems

Your healthcare professional should discuss with you the risk of kidney problems such as kidney stones, hydronephrosis and scarring, particularly if you have spina bifida or spinal cord injury. You should look out for symptoms such as loin pain, urinary infections or blood in your urine.

Your healthcare professional should discuss with you that people using urethral catheters may be at a higher risk of developing kidney problems than people whose bladder problems are managed in different ways.

If your healthcare professional suspects you have symptoms of a kidney problem, an imaging scan should be used to check your kidneys.

Bladder stones

Your healthcare professional should discuss with you the risk of bladder stones. You should look out for symptoms such as repeated urinary infections, repeated catheter blockages or blood in your urine.

Your healthcare professional should discuss with you that people using indwelling catheters have a higher occurrence of bladder stones compared with people whose bladder problems are managed in different ways.

If you have symptoms of bladder stones you should be referred for a procedure called cystoscopy, in which a thin telescope is passed along the urethra into the bladder. This allows the healthcare professional to view inside the bladder and check for the presence of stones.

Bladder cancer

Your healthcare professional should discuss with you the risk of bladder cancer, particularly in people who have had urinary problems for a long time or have other factors such as repeated urinary infections. You should look out for symptoms such as blood in your urine.

You should be referred for urgent urinary imaging scans and cystoscopy if you have blood visible in your urine or an increase in the number of urinary infections or other unexplained urinary symptoms that may need further investigation.

Monitoring

If you are considered to be at high risk of kidney problems (for example, if you have spina bifida or spinal cord injury) you should be offered ongoing regular ultrasound scans of the kidneys (every 1 or 2 years) to check for problems.

If you are at high risk of urinary complications (for example, if you have spina bifida or spinal cord injury) you may be offered regular urodynamic investigations (see [Finding out what is wrong](#)) to check for problems.

Information and support

You and your family or carers should be given information including details of the healthcare professionals involved in your care, their role and contact details; copies of correspondence about your care; and a list of medications and equipment for your urinary problem.

If you are having care for your urinary problem in a specialist unit you should be given contact details so that you can obtain specialist urinary advice and information.

You and your family or carers should be offered information, training and support if you are starting to use a urinary management system, such as a catheter (see [Treatment for problems with bladder emptying](#)). This should be specific to your particular needs and should encourage you to be involved in your own care.

If you are using products such as catheters, appliances or pads, suitable products for your needs should be available, you should receive training and support in how to use them and you should have your products reviewed every few years by a healthcare professional with knowledge of the products available.

You should be told how to get further support and information from a healthcare professional, if you need it.

Moving from child services to adult services

If you are being transferred from child to adult services for continuing care of your urinary problem, clear arrangements should be made to transfer your care, and you and your family and carers should be involved in the arrangements at an early stage. A plan should be made to ensure that the services that you need are continued into adult care, and this should be checked after your care has been transferred.

You and your healthcare professional in adult services should be given a complete summary of your previous and current care, and you should be given the names and contact details of the key healthcare professionals who will look after you in adult services (such as the urologist and specialist nurses).

In some cases, specialists from child and adult services may meet regularly to discuss the management of your urinary condition during the years leading up to transfer and after entering adult services.

More information

The organisations below can provide more information and support for people with urinary incontinence related to a neurological condition. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Bladder and Bowel Foundation, 0845 345 0165 www.bladderandbowelfoundation.org
- PromoCon, 0161 607 8219 www.promocon.co.uk
- The Neurological Alliance www.neural.org.uk/directory-of-organisations
- Urostomy Association, 01889 563191 www.urostomyassociation.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more.

Accreditation

