



integrated working

NHS

**West Suffolk
Clinical Commissioning Group**



SHARED DECISION MAKING

This booklet is designed to help you understand more about urinary incontinence and the choices available to you. Please keep it and take it with you to your appointments.

A collaborative process that allows patients and their providers to make health care treatment decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences.

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Urinary incontinence is the unintentional leakage of urine. It can happen when you cough, laugh or sneeze, or if you suddenly need to pass urine but cannot get there in time.

Urinary incontinence is a very common problem, and affects between three and six million people in the UK. Almost twice as many women as men have it, and it becomes more common as people get older.

The good news is that there are lots of things which you and your doctor, continence advisor, specialist nurse or physiotherapist can do to help you manage incontinence more effectively.

This booklet will give you lots of information about the options available so that you and your healthcare professional can decide which is the best solution for you. You may need to try several things before you find something which works for you, but will be given all the support you need throughout your treatment.

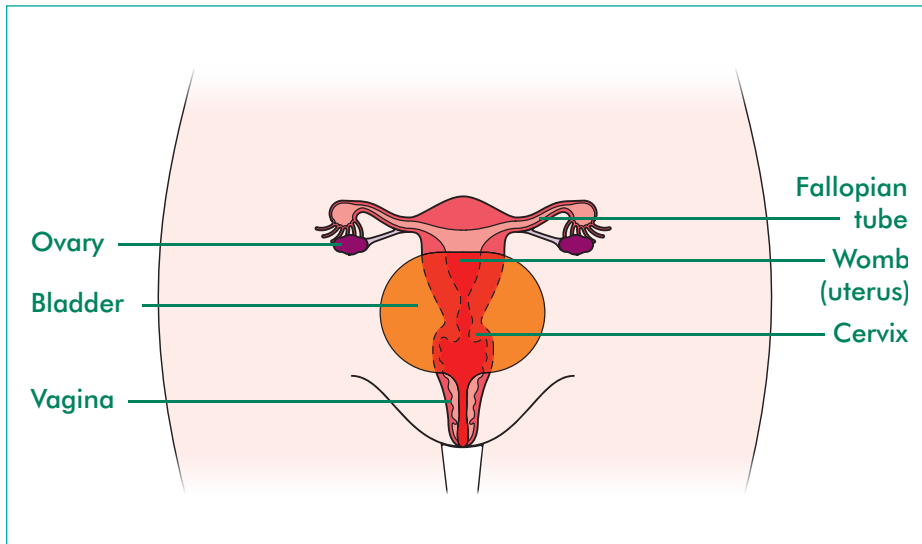
Please keep this booklet and take it with you to your appointments. Your healthcare professional will use it to record information with you which will help to show progress and inform future treatment decisions.

If you are experiencing any other symptoms, such as blood in your urine, recurrent urinary infection or pelvic pain, please make sure you tell your GP so that they can work with you to find the best treatment.

The bladder is part of your urinary system, which removes by-products and other waste from your body.

Most people produce three to four pints of urine each day, and use the toilet between four and eight times. As your bladder fills up, signals are sent to your brain to let you know you need to pass urine. Your bladder should then continue to store urine until your brain tells it that you are in an appropriate place to pass urine.

Problems can happen when the sensors which tell you your bladder is empty or full do not work properly or if your pelvic floor is weak or the nerves which communicate between your spinal cord and brain are damaged.



There are three main types of incontinence.

They are:

Stress urinary incontinence. This causes involuntary leakage when you laugh, cough, sneeze, exercise or do other activities which put your bladder under pressure. It happens because the pelvic floor muscles are too weak to prevent you from leaking. Stress incontinence can be caused by childbirth, weight gain or other damage that affects the pelvic floor.

Urge incontinence, also known as **overactive bladder (OAB).** This happens when you feel a sudden and intense need to pass urine. It often leads to accidental leaking soon after first feeling the urge. Urge incontinence is caused by a problem with the muscles in the walls of the bladder, and can be made worse by emotional stress, drinking too much coffee or alcohol. Health conditions which affect the brain, such as multiple sclerosis or Parkinson's disease, can also be a factor causing urge incontinence, but in other cases no triggering cause is found.

Mixed incontinence. This is a mixture of both types of incontinence. It may cause you to leak when you sneeze or laugh, while you may also experience very intense urges to pass urine. Mixed incontinence can happen when you have a pelvic floor weakness as well as an overactive bladder.

Do you leak urine suddenly when you cough, sneeze, laugh or exercise? Yes No

Have you ever had an accident when you have lifted something heavy? Yes No

Is the amount of urine you are leaking usually small? Yes No

Have you had children? Yes No

Would you like to lose weight to improve your health? Yes No

Do you ever feel a sudden and very intense need to pass urine? Yes No

Do you sometimes leak before you get to the toilet? Yes No

Do you need to get up several times during the night to urinate? Yes No

Does the sound of running water make you need to pass urine? Yes No

Have you been suffering from emotional stress? Yes No

Do you leak a lot of urine? Yes No

Your doctor or nurse will usually ask you to keep a bladder diary to help them to get as much information as possible about your condition. As well as helping them with diagnosis, this diary is also a really useful tool for monitoring the effect of different treatments. By comparing a diary recorded before you begin treatment with one taken afterwards, your doctor will be able to see if it is working and whether they need to make any tweaks or adjustments.

Keeping a bladder diary is easy.
All you need to do is note down:

- **How much you drink - you can do this by measuring the size of your cup or mug then recording how many drinks you have each day and the time**
- **What you drink - coffee, tea, alcohol and water, for example, can affect your system differently so it is important to let your doctor know what drink you are having and when**
- **The amount of urine you pass - you can do this by using a cheap jug from your local hardware shop kept next to the loo**
- **How many times you leak and when**
- **How many times you need the toilet urgently**

You will need to keep the diary for three days, but you can do this on days when you are at home to minimise any disruption to your normal routine. The template on the following page will show you what your diary may look like.

Before working with your doctor or specialist nurse to decide on the best treatment to suit you, it is important that you think about your own lifestyle, the impact your incontinence has on you and the pros and cons of each type of treatment. Your doctor will be able to give you advice, based on the best scientific evidence, about the treatment which may be most successful for you. Please do ask them lots of questions and make sure you have all of the information you need before making a decision.

Your healthcare provider will review your treatment regularly to make sure it is helping. If not, they may suggest trying something different to see if it has more impact on improving your condition.

One of the most effective things you can do to improve all types of incontinence is make some simple changes to your lifestyle. These can include:

- **gradually reducing the amount of caffeine you drink.** Caffeine can increase the speed at which the body produces urine, so you may find that slowly weaning yourself off coffee, tea and cola will help your condition. Products labelled “decaff” often still contain small amounts of caffeine, so stop these too.
- **drinking sensibly.** You should aim to drink 1.5-2 litres (six to eight glasses) of non-caffeinated drinks, spread throughout the day. Drinking too little or too much can cause symptoms which affect the bladder.
- **losing weight.** If you are overweight or obese, your bladder and pelvic floor will be put under extra pressure. Your family doctor will be able to tell you if you are a healthy weight for your height and can give you advice on eating a balanced diet and taking regular exercise. There are healthy weight classes offered by LiveWell Suffolk.
- **stopping smoking.** Giving up smoking is not easy, but could really help improve your condition. Smoking affects the collagen in your skin, muscles and connective tissues, while coughing can make your pelvic

floor weaker. Your family doctor would be happy to explain the effect which smoking has on the bladder if you would like to find out more. They can also support you if you would like to stop, and you can gain support through your pharmacist or LiveWell Suffolk.

Pros: Lifestyle changes can have a big impact, especially when used with other types of treatment. Many lifestyle changes also bring with them wider health benefits. For example, maintaining a healthy weight can reduce your risks of developing diabetes or a range of other conditions, and can also help boost your energy levels.

Cons: You will need to be motivated to develop new habits and might find some changes difficult, such as stopping smoking. But it's important to remember that support is available. Please do talk to your GP or nurse, or contact LiveWell Suffolk, on 01473 22 92 92, for free, confidential advice on making positive changes to your lifestyle.

Before making lifestyle changes, you may find it helpful to note down the answers to these questions so that you can discuss them with your doctor and use them to measure your progress:

What types of caffeinated drinks do you drink?

How many times a day do you drink them?

How much alcohol do you drink?

How much do you weigh?

How much do you smoke?

Around 40% of people with stress incontinence find that physiotherapy, along with lifestyle changes, will successfully treat their condition. Your GP can refer you to a specialist, based either in your local hospital or in the community, who will work with you and put together a tailored plan to meet your individual needs.

When you first visit your physiotherapist, they will need to carry out an internal examination so that they can see how strong your pelvic floor is and whether you are able to squeeze the muscles. If so, you will be given an exercise programme to strengthen your pelvic floor muscles so that they better support your bladder. You will need to do these exercises several times each day for at least three months. You might find it helpful to use a regular chore, such as brushing your teeth or washing up, as a prompt to remind yourself to do the exercises.

If you are unable to contract your pelvic floor muscles, your physiotherapist may talk to you about using an electrical stimulation device. This is inserted into the vagina and helps strengthen your pelvic floor muscles while you exercise them. Again, you will need to carry out these exercises several times each day and for a minimum of three months.

Physiotherapy can also be used to help with urge incontinence, along with other measures such as bladder retraining.

Pros: Physiotherapy, coupled with lifestyle changes, can be a very effective treatment for incontinence, and carries with it very little risk.

Cons: For the exercises to work, you will need to remember to complete the exercises several times each day, as described by your physiotherapist.

If you have urge incontinence, bladder retraining is the most significant single thing you can do to help. Research shows it can have a significant impact on improving quality of life by reducing the need to rush to the toilet and prevent leaks. Medication can also be used to support bladder retraining.

Retraining your bladder helps you to swap bad habits for good ones and puts you in control of your bladder, rather than the other way round. Your doctor will be able to talk through methods for retraining your bladder, and will teach you techniques to “ride the wave”, which will increase the length of time between feeling the need to urinate and having to go to the toilet. This can include things like tightening your pelvic floor muscles, putting firm pressure on the crotch area by crossing your legs or distracting your mind by counting to 100.

Keeping a diary (see page 7) can be a really useful tool when retraining your bladder as it will show you how often you go to the toilet, in turn helping you to gradually increase the time between visits.

Pros: Bladder retraining can make a significant difference to urge incontinence, reducing both frequency and urgency. Most people notice improvements within just two weeks.

Cons: You will need motivation and to continue with the techniques you have learned for the rest of your life. You may also need to use other methods, such as lifestyle changes and pelvic floor exercises, in addition to bladder training.



Medication is usually prescribed as part of an overall package of care to help with the symptoms of urge incontinence. To be effective, it needs to be used alongside other methods, such as lifestyle changes or bladder retraining. Because of this, your GP will often recommend you try other things first. They will also review your medication regularly - if it is not having a positive impact, they will suggest trying something else.

The main medication used for urge incontinence is called an anticholinergic. This is a drug which relaxes the bladder muscle, allowing it to hold more urine. If you cannot take this type of medication you may be given a different type of drug called a B3 agonist.

Pros: This medication can buy you time, making it easier to get to the loo without having an accident.

Cons: To be effective, medication must be used alongside lifestyle changes and bladder retraining, which need commitment. The side effects of the anticholinergics can sometimes cause constipation, dry mouth and dry eyes.

After three months, you and your healthcare professional might find it helpful to review the changes you have made to see what effects they have had. Your doctor or specialist nurse will be able to advise whether a different combination of approaches may be more effective.

Alternatively, they may refer you to see a urologist or urogynaecologist at your local hospital, who will be able to carry out further tests and consider if surgery is necessary.

These checklists will help you and your doctor or nurse work out what to do next. Please be as honest as you can when you fill them in so that your healthcare worker can give you the best possible advice to suit you.



Your symptoms:

Have your symptoms improved since you began treatments?

Yes No

If so, which treatment do you feel had the biggest impact?

Do you still leak urine suddenly when you cough, sneeze, laugh or exercise?

Yes No

Since starting treatment, have you had any accidents when you have lifted something heavy?

Yes No

Do you still feel a sudden and very intense need to pass urine?

Yes No

Do you sometimes leak before you get to the toilet?

Yes No

Do you need to get up several times during the night to urinate?

Yes No

Things you have already tried:

Keeping a bladder diary

Yes No

Reducing the amount of caffeine you drink:

- What types of caffeinated drinks do you drink now?

- How many times a day do you drink them?

Drinking sensibly:

- Do you drink 1.5-2 litres, spread throughout the day?

Yes No

- How much alcohol do you drink now?

Losing weight:

- How much do you weigh now? Your GP will be able to work out your BMI (body mass index) and advise you on ways to bring it down to the healthy range if necessary.

Smoking:

- How much do you smoke now?

Physiotherapy:

- Have you stuck to your programme of regular pelvic floor exercises for at least three months?

Yes No

Bladder retraining:

- Have you worked with your doctor and tried using the techniques they have taught you for at least six weeks?

Yes No

Medication:

- What drugs have you tried?

- What was the dose?

If the different treatments you have been trying have not been successful, your GP may refer you to hospital to see a urologist or urogynaecologist.

Please bring your bladder diary, this booklet and a record of any medication you have been taking to your appointment, as they will help your specialist to identify any patterns and see which treatments you have already tried. Together, you will review the things you have been doing and talk about whether it would be appropriate to try different combinations of treatments, or alternative medications. One size does not fit all when it comes to urinary incontinence, so it may be helpful to review and revisit some of the options for a second time.

You may also be referred for additional investigations, to give your specialist more information about the way your bladder is functioning. These can include:

- **Cystometry:** This is known as an urodynamic test and is used to evaluate your bladder function. It measures the pressure in your bladder at different degrees of fullness through a catheter inserted into your urethra. You may feel uncomfortable during this procedure but there is nothing to be embarrassed about - your specialist is here to help and will make the experience as pleasant as they possibly can.

If your specialist recommends cystometry, it is important to stop taking any incontinence medication around 10 days beforehand so that it does not have an impact on your test results.

- **Cystoscopy:** This uses a flexible viewing tube, called an endoscope, to look inside your body so that your specialist can assess the lining of your bladder and urethra. It is used to rule out other causes of incontinence.

The surgical options which you and your specialist may consider will vary depending on which type of incontinence you have and your own personal circumstances. Your healthcare professional will be able to advise you and answer any questions you may have.

It's important to remember that no operation is perfect, and will need to take place alongside the lifestyle changes detailed on page 12. Losing weight before surgery is essential as it can have a big impact on how effective your operation may be - a BMI of more than 30 not only increases risk from the anaesthetic, but also reduces the success rate from 70-80% to 40-50%. Your specialist will be able to talk to you about losing weight and may refer you back to your GP for help with healthy eating and exercise.

All procedures have potential side effects, while surgery for stress incontinence comes with a risk of causing more urgency in the future. Because of this, it is really important to make sure you have all of the information you need and have thought about your lifestyle and the factors which matter to you before making a decision.

There are three main types of surgery for urge incontinence. Your specialist will be able to discuss them with you and give you advice on which they recommend for your individual circumstances. They are:

1. Botox injections: where botox A (a toxin) is injected into the bladder wall through a cystoscope, paralysing the muscle and reducing the urgency and frequency of urination.

Pros: the procedure is fast, effective and takes place under local anaesthetic. Recovery is quick, which means you can soon return to your normal activities.

Cons: injections need to be repeated every nine to 18 months to remain effective, which means repeat trips to hospital. Some people are unable to empty their bladder properly after the operation and may need to learn a technique to empty their bladder, which involves using a catheter intermittently.

2. Sacral nerve stimulation: this sees a small electrical device, similar to a pacemaker, surgically inserted into your lower back. The device stimulates the nerves, in turn helping to control urgency.

Pros: the procedure is usually very effective, with no risk of self-catheterisation.

Cons: sacral nerve stimulation carries a risk of possible complications, such as technical issues, infection and adverse changes to your bowel function. You may need further surgery, or the device replacing after 10 years. As this procedure is very expensive, it is not easily available.

3. Clam cystoplasty: this major operation will see your surgeon move part of your bowel onto your bladder to increase its size and control the urgency with which you need the toilet.

Pros: this treatment is effective, and may not need any further surgery or top ups.

Cons: as this is a major procedure, it will take you a long time to recover. There is also a high risk that you will not be able to empty your bladder properly afterwards, and will need to insert a catheter at least twice a day to make sure it is fully empty. The operation also carries with it a high risk of contracting urinary tract infections, as well as developing complications in the bowel. Afterwards, you will need regular cystoscopies as the surgery slightly increases your risk of developing cancer in your bladder in the future.

There are also three main types of surgery for stress incontinence. Your specialist will be able to discuss them with you and give you advice on which they recommend for your individual circumstances. They are:

1. Bulking agents: where bulking agent is injected into the urethra wall through a cystoscope to build up its thickness so that it can hold back urine more effectively.

Pros: the procedure is fast and is carried out as a day case, which means you are able to return to normal activities quickly. The injection of bulking agents carries with it a low risk of complications.

Cons: bulking agents are not as effective as other options, and may need topping up every few years.

2. Bladder suspension: this is used to treat weakness in the bladder neck by raising the bladder and securing it back into its normal position.

Pros: this procedure usually has good long term outcomes.

Cons: A major operation, it has a long recovery period. This type of surgery carries with it the usual risks, which include damage to nearby organs, infection and bleeding. There is a risk of new onset urgency and urge incontinence and a mildly increased risk of developing a vaginal prolapse in the future. There is also a chance it may not fix your incontinence.

3. Low tension sub urethral tapes: this uses synthetic tapes to support the urethra so that it does not accidentally open when you cough or move suddenly.

Pros: this operation can be completed as a day case, allowing you to return to your normal activities quickly.

Cons: this type of surgery carries with it the usual risks, which include damage to nearby organs, infection and bleeding. There is a risk of new onset urgency and urge incontinence. In addition, it is using a synthetic material in the vagina with a small risk it can move in the future. There is also a chance it may not fix your incontinence.

If your specialist has recommended surgery, you may find it helpful to work through the following questions with them to decide on which option may best suit your needs. You can then use the answers to help your discussions before coming to a joint decision with your clinician.

If you do not feel you have enough information to make a decision, make sure you tell your doctor who will be able to answer any further questions you may have. It is important that you are completely comfortable with the treatment you will receive, as it will have a positive impact on your outcome.

What matters to you:

I need to return to my normal activities quickly

I would prefer a short operation

I don't mind how long my operation is

I don't mind how long it takes to recover

I do not mind about visible scars

I do not mind using synthetic material

I would prefer a procedure which is carried out using local anaesthetic

I don't mind if I have to self-catheterise after surgery

I do not want to keep returning to hospital for tops ups or further surgery



... is helping patients become involved in their own healthcare decisions.*

Normally there will be choices to make about your healthcare. For example, you may be asked:

- to decide whether or not you want to have treatment
- to choose between different types of treatment
- if you want to continue with the same treatment

What you choose to do should depend on what is important to you.

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.

Ask 3 Questions

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

1. What are my options?
2. What are the pros and cons of each option for me?
3. How do I get support to help me make a decision that is right for me?



*Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85

If you would like this information in another language or another format, including audio tape, braille or large print, please call 01473 770 014.

Jeżeli potrzebujesz pomocy w zrozumieniu tych informacji w swoim języku zadzwoń na podany poniżej numer.

Polish

Se precisar de ajuda para ler estas informações em outra língua, por favor telefone para o número abaixo.

Portuguese

Jeigu jums reikia suprasī šia, informacija, kita kalba prašom skambinti šiuo numeriu apačioje

Lithuanian

Kung kailangan mo ng tulong para maunawaan and inpormasiy on sa pamamagitan ng ibang salita, maaaring tumawag sa

Tagalog

Ci vous avez besoin d'aide pour comprendre cet information an une diferente langue, s'il vous plait contacter le numero ci dessous. Merci.

French

এই লেখাটি যদি অন্য ভাষায় বুঝতে চান তাহলে নিচের নম্বরে ফোন করুন

Bengali

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