

**PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US**

# LOOKING AFTER YOUR BLADDER AND BOWELS WHEN YOU HAVE PARKINSON'S

Information and support

**This booklet contains information about bladder and bowel problems that may affect people with Parkinson's, the treatments available and who to contact for professional advice.**

It also gives practical tips on what you can do to make living with bladder and bowel problems easier.

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# WHO CAN BE AFFECTED BY BLADDER AND BOWEL PROBLEMS?

If you have Parkinson's, you may be more likely to have problems with your bladder or bowels than people of a similar age without the condition. But not everyone with Parkinson's will experience these difficulties.

Some of these problems are common in men and women of all ages, whether they have Parkinson's or not. So any problems you might have are not necessarily a result of your condition. There may be other causes.

Whatever the reason for your bladder and bowel problems, you can usually do something to help. It may be that the problem can be cured completely. But if that isn't possible, there are many different ways of managing the symptoms so they don't rule your life.



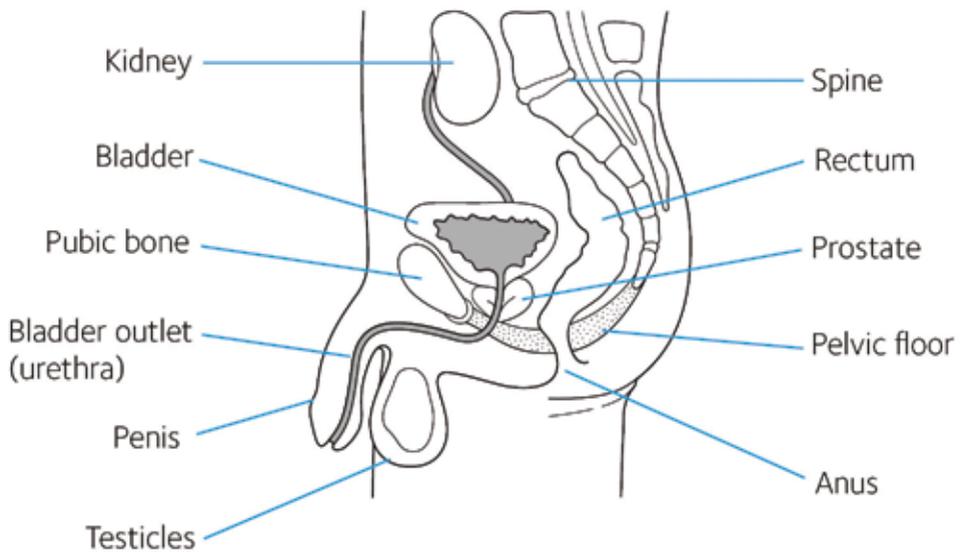
# HOW DOES THE BLADDER WORK?

The role of the bladder is to store urine and then empty it. When the bladder is full, you will need to use the toilet. You normally become aware of the bladder filling when it's about half full, and can wait to find the best time and place to urinate. This acts as an 'early warning system'. Someone with an 'average' bladder needs to use the toilet four to seven times a day and usually once or not at all at night.

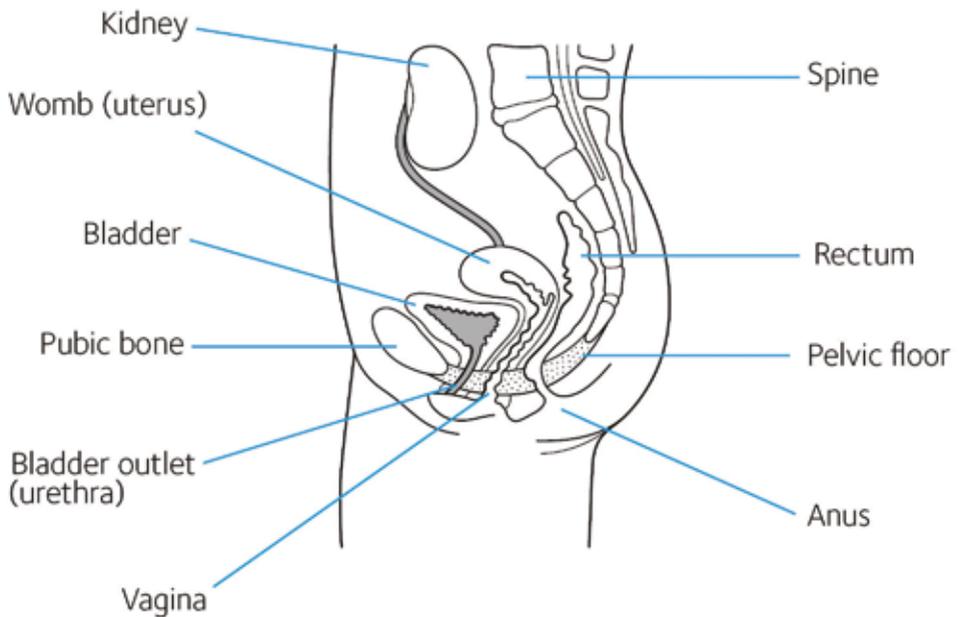
The muscles around the bladder outlet (the urethra) and the supportive muscles of the pelvic floor help to maintain a watertight seal, even when the bladder is put under a lot of pressure, for example, when coughing or jumping. This helps you to 'hold on' if you need to go.

Your brain gives your bladder instructions, sending messages telling it when to hold on and when to empty. When you go to the toilet the muscles and bladder outlet relax, and the bladder contracts and pushes the urine out.

## The male urinary system



## The female urinary system





# WHAT TYPE OF BLADDER PROBLEMS CAN I GET IF I HAVE PARKINSON'S?

This section looks at the bladder difficulties people with Parkinson's are more likely to have. Remember that not everyone with the condition will experience these problems and they may be caused by other things, so always talk to your GP if you are having problems.

Urge incontinence and nocturia are the most common bladder problems in Parkinson's. These may happen because the messages from the brain giving the bladder instructions aren't getting through properly.

## Urge incontinence

If you have an overactive bladder, you may feel the need to urinate immediately, without warning. This means that you can't 'hold on' as you might do normally if you don't reach a toilet in time. This is called incontinence.

## Nocturia

Nocturia is the need to urinate many times during the night because of an overactive bladder. As you get older, it is normal to need to get up once or twice in the night to urinate during the night. This may wake you up, or your bladder may empty while you are asleep.

Speak to your GP, specialist or Parkinson's nurse (if you have one) if you are experiencing these problems.

# WHAT OTHER BLADDER PROBLEMS ARE THERE?

Some bladder problems are common among the general population and can affect people with and without Parkinson's. These can include:

## For women

Childbirth can stretch the pelvic floor muscles and can damage the urethral sphincter (used to control the exit of urine in the urinary bladder through the urethra), which can cause incontinence. The pelvic floor muscles are the internal muscles around your bladder outlet.

## For men

The prostate is a small gland which only men have. It is about the size of a walnut and surrounds the first part of the urethra (the tube that carries urine from the bladder to the penis).

As men get older, the prostate can gradually get bigger. Although this is normal, for some it causes problems by blocking the flow

of urine. This makes it difficult to empty the bladder. You may experience the need to urinate more often, a difficulty in starting to urinate, a need to strain or an urgent need to go to the toilet.

Occasionally, the prostate can block the bladder completely and you might not be able to pass any urine at all. This is known as retention. If this happens to you for more than a few hours, or you are in great discomfort or pain, you should seek urgent medical help.

It can be difficult to tell the difference between an enlarged prostate gland and the problems emptying the bladder that Parkinson's can cause. You can get tests done on the bladder, but even then, it might not be clear what the problem is. The most important thing is to seek treatment, so make sure you share any concerns with your GP, specialist or Parkinson's nurse.

## Stress incontinence

This is when you let out urine because of physical stress, such as coughing, laughing, sneezing or exercise. This can happen to both men and women, but tends to be more common in women.

A smoker's or heavy cough and being overweight can put an extra strain on the bladder outlet, causing stress incontinence.



# WHAT TREATMENTS ARE AVAILABLE FOR BLADDER PROBLEMS?

If you have a bladder problem, remember that it might not necessarily be caused by Parkinson's. For example, you may have an infection which can be treated with antibiotics. So speak to your GP, specialist or Parkinson's nurse.

## Diet and lifestyle

If you have bladder problems, it is important not to cut down too much on the amount of fluid you drink as this won't help and may leave you dehydrated. But you may find it helpful to drink less fluid late in the evening to limit the number of times you need to urinate during the night. You might find it helpful to cut out caffeine too as this can make incontinence worse. It's worth experimenting to see what works for you.

Try to maintain a healthy weight by eating a balanced diet to help you to avoid stress incontinence. A dietitian will be able to advise you about this. Doing plenty of regular exercise, where possible, and stopping smoking will also help.

## Medication

Depending on what difficulties you are experiencing, medication may be an option for some bladder problems. Talk to your GP, specialist or Parkinson's nurse about medication that may be suitable for you.

## Bladder training

This can help control an overactive bladder. It involves keeping a record for several days of how often you urinate, and then attempting to delay when you feel the urge. This helps you practise 'holding on'. This can take a lot of willpower, and may not be possible for some people, so it is important to get professional support and advice. See page 36 for more information.

## Pelvic floor muscle exercises

Because stress incontinence is most often caused by weak pelvic floor muscles, exercising these muscles can help to strengthen them. These exercises can be tricky, but a physiotherapist, nurse or GP will be able to explain how to do them properly.

## Surgery

If stress incontinence is a real problem, and pelvic floor exercises or drug treatments have not helped, then surgery may be an option. There are several surgical procedures for the long-term treatment of incontinence. Talk to your healthcare professional for more details.

Remember that all surgical procedures may carry some risks so make sure you discuss the advantages and disadvantages of surgery with your healthcare professional.

“I give myself plenty of time and make sure that the bathroom is warm. Try to tell your family and friends about your ‘little problem’ – it is only embarrassing if you make it so!” ”

**Mary, who ran an entertainment group for ten years and now enjoys gardening and learning to sew**

## Using a catheter

Some people who are experiencing incontinence insert a small plastic tube, known as a catheter, into their own bladder several times each day. This is known as intermittent catheterisation and will drain out the urine that’s left. This may sound difficult, but with the correct instructions many people manage it very easily.

## Treating prostate problems

There are several different ways to treat an enlarged prostate gland. Medication and making changes to your lifestyle may help.

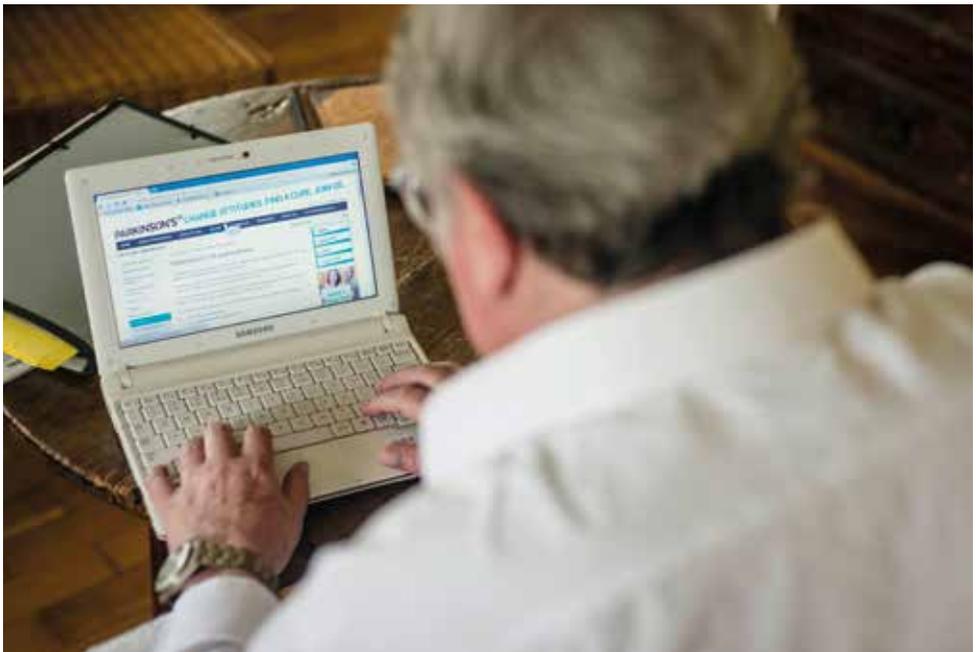
If your symptoms are severe, and medication hasn't helped, then your doctor may suggest surgery. A procedure called a transurethral resection of the prostate (or TURP) removes part or all of the prostate. This is usually done using a small telescopic instrument inserted into the urethra, so it won't cause scarring.

Some hospitals have introduced a procedure to shrink the prostate

using lasers. As laser surgery is a relatively new technique, there isn't research yet about how effective it is in the long term.

Before you start thinking about surgery, ask your GP, specialist or Parkinson's nurse about a referral to a urologist. They will examine you and carry out any necessary tests.

Like all types of surgery, there may be some small risks. Make sure you discuss any potential problems with your specialist, so you can make an informed decision.



# WHAT CAN I DO IF I STILL HAVE PROBLEMS WITH INCONTINENCE?

There are many different products specially designed to keep you comfortable and prevent anyone else from knowing you have bladder or bowel problems. Talk to your healthcare professional about what option is best for you.

## Hand-held urinals

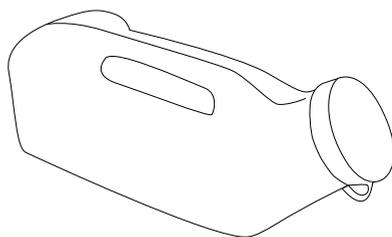
There are a variety of hand-held urinals available for men and women. These may be useful for someone who needs to urinate urgently, but who can't get out of a bed or a chair in a hurry or when there is nobody available to help. If you have a tremor, you may find it's slightly difficult to use these, so it's worth trying different types.

For men, a bottle with a handle, a flat bottom and a non-spill adaptor might help avoid accidents or anxieties about getting to the toilet on time.

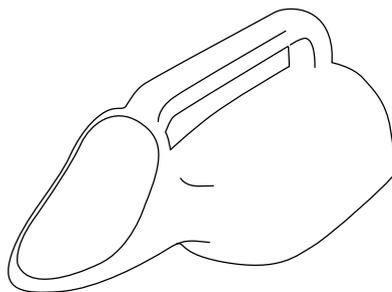
Some men find that when they use a bottle while sitting down the fly on their trousers is too short. Adapting trousers so that the opening is extended down to the

crotch seam, as well as closing it with Velcro tabs rather than buttons or a zip, can make using a bottle much easier.

## Example of a male hand-held urinal



## Example of a female hand-held urinal



## Pads and underwear

We don't recommend ordinary sanitary towels as protection against leakage caused by bladder problems. There are many pads available that are specially designed for this purpose, ranging from small ones to cope with mild leakage, to much larger pads for those who need them.

Most pads are disposable and held in place inside your underwear. You can also get washable underwear with a built-in absorbent gusset. This is particularly useful if you feel safer with a pad in place 'just in case' because of an unpredictable bladder. You may also be able to get larger disposable pads for free on the NHS or health service. Speak to your GP or district nurse about this. But in many areas, people with milder incontinence problems may have to buy their own pads or underwear.

## Bed protection

You can buy various mattress covers, absorbent sheets, bedpads, and duvet and pillow covers if you need them. Washable absorbent sheets tend to be the most comfortable, but they can be heavy and difficult to handle when wet.

## Appliances for men

Some men with urine incontinence may prefer to use a sheath or appliance rather than a pad. These fit over the penis and collect urine in a leg bag. They can be a bit difficult to put on, especially if you have a tremor, so you may need some help.

Appliances are available with a GP's prescription. In England, the usual prescription charges will apply.

## Odour control

This can be a common worry, but even if you have incontinence problems it is unlikely that anyone will notice a smell. Fresh urine should not smell unpleasant. It only starts to smell if it is left out in the air. So, as long as you get changed as soon as you can and keep wet pads, clothing or bedding in an airtight container (such as a bucket with a lid) until it is washed, there shouldn't be a problem.

Selecting a good pad or appliance is the best insurance against leakage of urine on to a mattress, chair or carpet, as these can often be difficult to clean effectively. Fresh air and use of an air freshener may also help if there is a slight smell.

If fresh urine does smell strongly, it could be due to a urine infection. If this is the case you should speak to your GP.

## Skin care

If you are incontinent, you shouldn't normally get sore skin, as long as you change frequently and take care to wash and dry your skin thoroughly. Try to have a bath or shower daily if you can. It's usually best to wash with ordinary unscented soap. Also, try to avoid using talcum powder or deodorants directly on your skin, as these can irritate. If you find that your skin

often gets sore, speak to your GP, specialist or Parkinson's nurse. This is important because if the skin becomes broken this may cause an infection. Your pharmacist may also be able to advise you on products for skin that gets sore.



## Permanent catheters

A catheter is a thin flexible tube, which is inserted into the bladder. This can be done along the tube where you pass urine (known as urethral catheterisation) or through a hole in the abdomen (suprapubic catheterisation).

If you have severe difficulties emptying your bladder, you may not want to insert a catheter into your bladder several times a day (intermittent catheterisation). In this case, you may prefer to use a catheter that stays in all the time.

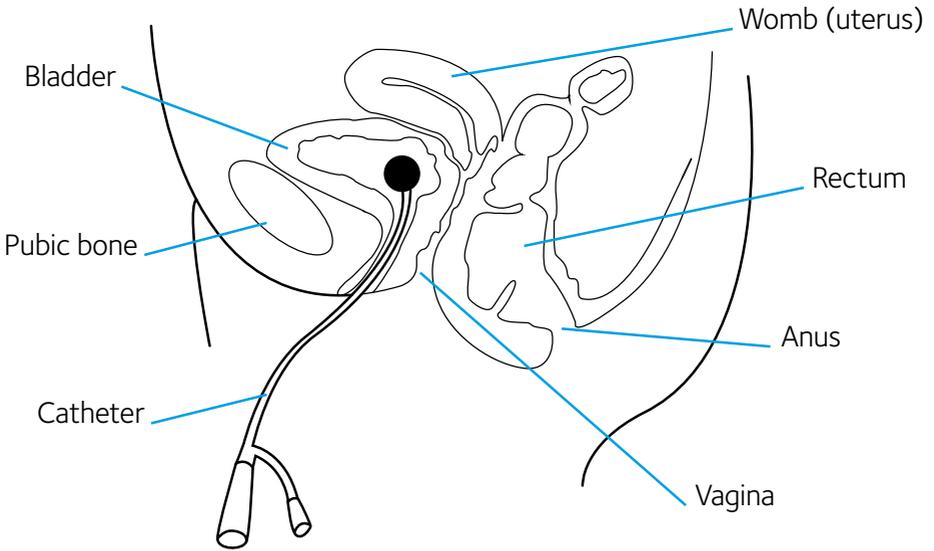
It can also help if you are incontinent and have not found any other way of managing the problem successfully, or if you've found it very difficult or impossible to get to the toilet.

For people with severe bladder problems, a catheter can be a positive choice and make life much easier.

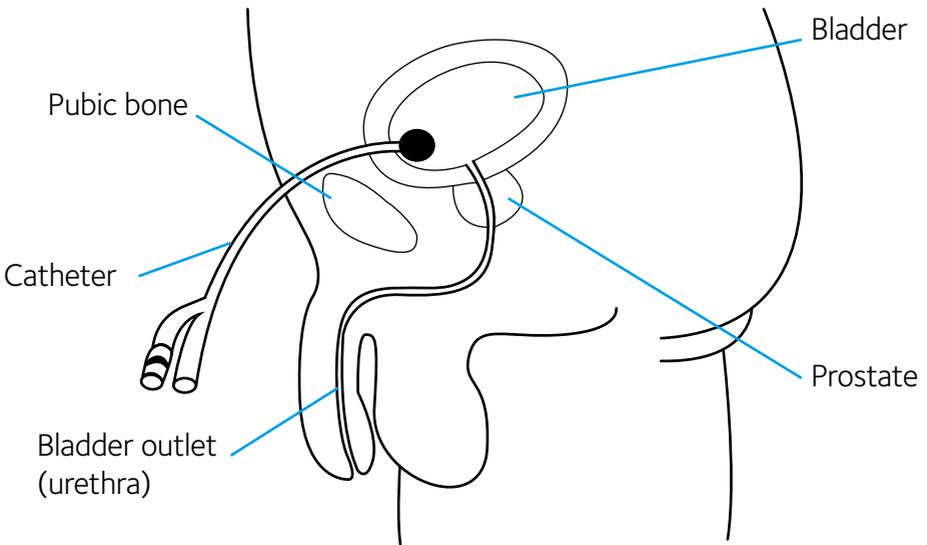
If you decide to use a long-term catheter, you may prefer a suprapubic one. This is because they tend to be more comfortable and easier to manage, although they may not be suitable for everyone.

To help you make an informed decision about your treatment, make sure you discuss all options with your healthcare professional. You can then weigh up the advantages and disadvantages of which catheter may be suitable for you.

## Urethral catheter



## Suprapubic catheter



Both types of catheters are available for men and women.

# HOW DOES THE BOWEL WORK?

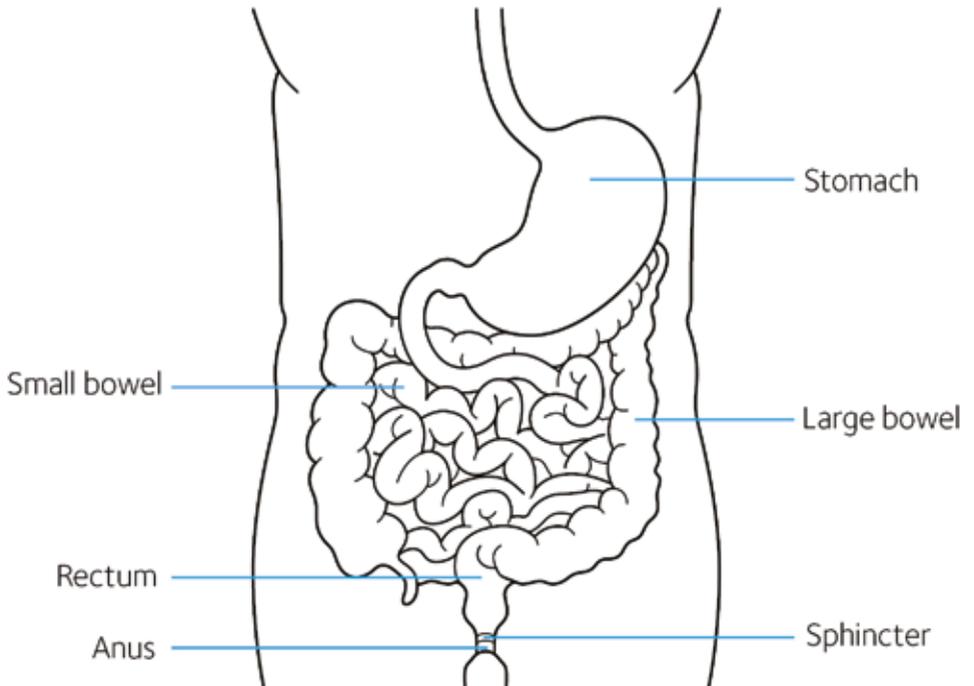
The bowel processes the food that we eat and extracts the nutrients that the body needs.

Food passes from the stomach into the small bowel. Eating, drinking or physical movement will help the movement of food through the large bowel to the rectum. The large bowel receives liquid waste from the small bowel and takes out some of the water to leave soft bowel motions (called faeces or stools). A person will pass these when they feel the need to go to the toilet. If the time and place are not convenient, a person should be able to wait.

When a person is ready to empty their bowel, the rectum contracts to push out the faeces. Then, the anal sphincter muscle relaxes and opens, and the stool is passed. This may be done with a little extra help from abdominal muscles bearing and pushing down and possibly a little straining.

Like the bladder, storing then emptying the bowel seems like a simple process, but the bowel is controlled by complex nerves and muscles.

## The bowel



# WHAT TYPE OF BOWEL PROBLEMS CAN I GET IF I HAVE PARKINSON'S?

## Constipation

Constipation is when your stools are hard and difficult to pass, or when you have bowel movements much less frequently than you've had before. Some people have a daily bowel movement, but many people go only once every two or three days and are not constipated. As long as the stool is soft and easy to pass without too much straining, there is nothing to worry about.

Constipation can be a common bowel problem for people with Parkinson's. This can be because of the following:

- Parkinson's symptoms, such as slowness of movement and rigid muscles, affect the muscles in the bowel wall. This can make it harder to push stools out of the body.
- If you find it difficult to move around or exercise much, this can also mean your bowel isn't stimulated to work properly.
- You may find it difficult to chew and swallow food. This means it's harder to have a diet with plenty of fibre, which helps to keep stools soft and easy to pass.
- If you don't drink enough fluid, this can cause stools to be harder and more difficult to pass. This can get worse during hot weather.
- Medication can make constipation worse. It may be your Parkinson's drugs or other types of medication, such as antidepressants.
- It may become difficult to contract your abdominal muscles and the anal sphincter may not relax at the right time to allow you to pass the stool easily. Sometimes, the sphincter may tighten when it should relax, which can make emptying the bowels difficult.

“Constipation can make me feel miserable and very down. I feel that I take enough medicines and really do not want to take anything else. Because of this I find that patience is the only solution. I also find that a raised comfortable loo seat helps, and that a frame is essential.”

**AJ, who lives in the West Midlands and has a keen interest in buses and trains**

If your constipation is very bad, it may make you feel unwell, tired and nauseous. It can also cause abdominal pain. If you need to strain a lot, you may get haemorrhoids (more commonly known as piles).

Sometimes if you get constipated, the bowel can become loaded with hard stools and you might find it difficult to pass anything. This is called ‘impaction’. In this case your bowel may overflow, and there can be accidental leakage. This may either be lumps of stool or a brownish mucus that looks like

diarrhoea. If this happens, you will need urgent medical attention and should contact your health professional, minor injuries clinic or go to A&E.

Constipation can mean your body isn’t able to absorb your Parkinson’s medication properly, which can lead to your symptoms getting worse. But things can be done to try to treat the problem, so speak to your GP, specialist or Parkinson’s nurse if you are having difficulties. There are also some things you can do yourself (see page 25).

## Diarrhoea

People with Parkinson's can get diarrhoea for the same reasons as people who don't have the condition. For example, because of an infection or food poisoning.

If you have Parkinson's, you might find it difficult to get to the toilet in time. You may also find it hard to squeeze the sphincter muscles in your bottom. This can cause leakage before you can reach the toilet.

## Weak sphincter

Childbirth and minor operations in the area (such as for piles) can cause your sphincter to become weak. This can cause difficulties in holding on to stools if you feel a need to empty your bowels. If you can't get to a toilet quickly, this can result in incontinence.

## Problems caused by poor mobility

Some people with Parkinson's might soil their underwear because mobility problems can make it difficult to wipe effectively after using the toilet. If this is the case, it might help to use moist toilet tissue, a bidet, or a specially adapted bottom wiper.

An occupational therapist or the Disabled Living Foundation will be able to offer further advice (see the More information and support section on page 34).

Bowel problems are very common in the general public. Any change in bowel habit, particularly if you see blood in your bowel motions, should be reported urgently to your GP.

# WHAT CAN I DO TO PREVENT BOWEL PROBLEMS?

Bowel problems are very common in the general public. But any change in bowel habit, particularly if you see blood in your bowel motions, should be reported to your GP.

Some problems are difficult to avoid, but there are some things you can do to make them less likely to happen.

## Exercising

As with Parkinson's in general, it helps to maintain a healthy lifestyle and stay as active as you can.

Exercise will stimulate your bowels, which can help prevent constipation and contribute to stronger pelvic floor muscles.

Exercise can also lift your mood and help you to keep a positive outlook. A physiotherapist can provide more advice on exercising when you have Parkinson's. Ask your GP, specialist or Parkinson's nurse about a referral.

## Increasing your fibre intake

Eating more fibre-rich foods and drinking more fluids can help if you have constipation.

Ways to get more fibre in your diet:

- Choose a breakfast cereal containing wheat, wheat bran or oats, such as Weetabix, porridge or bran flakes.
- Eat more vegetables, especially peas, beans and lentils.
- Eat more fruit – fresh, stewed, tinned or dried. Good ones include prunes or oranges.
- If you find it difficult chewing high-fibre food, you can get some types which dissolve in water. You can also get drinks which are high in fibre.
- Drink plenty of fluids throughout the day to avoid dehydration. Any fluid is suitable, including water, fruit juice, milk, tea, coffee and squashes.

Try to increase how much fibre you get gradually, to avoid bloating or flatulence (wind). A dietitian can give you more information and advice. You can usually get a referral through your GP, specialist or Parkinson's nurse.

**Find out more:** see our *booklet Diet and Parkinson's*.

## Addressing practical aspects of eating and drinking

Some people with Parkinson's may have problems chewing and swallowing. This can make it difficult to eat a diet with plenty of fibre. A speech and language therapist can give advice about this.

**Find out more:** see our information sheets *Eating, swallowing and saliva control in Parkinson's* and *Speech and language therapy and Parkinson's*.



If it takes you a long time to eat and your meal goes cold, eat smaller portions and go back for seconds that have been kept warm. You can get special plates that will help keep your meals warm – the Disabled Living Foundation has more information (see the More information and support section on page 34). An occupational therapist will also be able to give you some practical advice.

### Having a routine

Keeping to a routine can help, especially if you're away from home and your usual environment, so try to empty your bowels at the same time of day if you can. You might want to consider the best time of day for you to empty your bowels. This may be after breakfast, after a hot drink or when your medication is working best.

Many of us try to rush these things, but it is important to allow yourself enough time and to try to relax. Try to push from your waist, and try not to hold your breath and strain. Respond as soon as you can when you feel the urge to open your bowels – putting it off can lead to hard stools and more difficulty.

### Using laxatives

You may find that you need to use a laxative regularly to avoid constipation. You may need to use a laxative for long periods of time.

The medication available for constipation may not suit everyone, so it is important that you discuss possible treatments with your GP, specialist or Parkinson's nurse.

Remember, it is not crucial to empty your bowels on a daily basis, so don't worry if you're unable to do this. However, it is important to keep an eye on things and not let your bowel become impacted (when the bowel becomes loaded with hard stools).

# WHO CAN I TALK TO ABOUT BLADDER AND BOWEL PROBLEMS?

While self-help is very useful, it is important not to struggle alone with bladder and bowel problems. Plenty of professional help is available. A lot of people find it embarrassing to talk about these subjects, but don't let this stop you from getting help if you need it. The professional you see will have heard about similar problems before and will be able to help you find a solution.

Your GP will usually be your first port of call. You may find it useful to keep a short diary of your bladder and bowel habits before your GP appointment. This may help you explain the difficulties you are experiencing. Your GP can carry out some treatments, or they may refer you to one of the following specialists:

**A urologist**, who specialises in the urinary system.

**A gynaecologist**, who treats conditions and diseases in women.

**A gastroenterologist**, who specialises in the intestines and bowels.

**A coloproctologist**, who specialises in disorders of the lower bowel.

**A neurologist**, who specialises in diseases of the brain and nervous system.

**A geriatrician**, who specialises in conditions and diseases of older people.

You might also be referred to one of the following healthcare professionals:

**A district nurse** may visit you at home and help you with general advice, bladder training or pelvic floor muscle exercises. They may also be able to arrange a free supply of continence pads if you need them.

**A continence adviser** is a specialist nurse who assesses and manages

incontinence and who may visit you at home or see you in a clinic.

A **physiotherapist** can help you improve your general mobility and teach you pelvic floor muscle exercises.

**Find out more:** see our information sheet *Physiotherapy and Parkinson's*.

An **occupational therapist** can advise on physical aids, clothing adaptations and equipment to help with everyday activities such as going to the toilet and bathing. You can often see your occupational therapist without being referred by a GP – ask your local social services or social work department.

**Find out more:** see our information sheet *Occupational therapy and Parkinson's*.

A **dietitian** can give advice on increasing your fibre intake, and on food that is easier to chew and swallow. Your GP can advise you on finding a dietitian.

You can also speak in confidence about any bladder and bowel problem to a Parkinson's nurse. See the More information and support section on page 34 for details.





# WHAT MEDICAL EXAMINATIONS MAY I NEED TO HAVE?

Your GP or specialist will probably ask a series of questions to find out what the problem is. These may include:

- When did the trouble start?
- How often does it happen?
- Can you feel when your bladder or bowel is full?
- Are you having difficulty emptying your bladder or bowel?
- How often are you using the toilet?

Parkinson's symptoms, such as slowness of movement and rigid muscles, affect the muscles in the bowel wall. This can make it harder to push stools out of the body. You may be asked to keep a chart for several days of how often you use the toilet and how much you drink.

You may also be asked for a urine sample to test for infection and they will normally carry out a physical examination.

Bladder or bowel problems can be complex in Parkinson's, so sometimes specialist tests or X-rays may be needed. All of these can usually be done in an outpatient department or clinic.

# HOW CAN I MAKE IT EASIER TO GO TO THE TOILET?

Sometimes practical issues can make bladder and bowel problems worse. For example, if you have trouble moving, you may find it difficult to get to the toilet in time. Some people also find it hard to move themselves into the right position to use the toilet, or may have difficulty undoing clothes or fastenings, such as zips or buttons.

These problems can be frustrating, but there are things you can do to make using the toilet as easy as possible for you.

## Toilet adaptations

If the toilet is too low it can be very difficult to get down on to it and get up again afterwards, especially if you have stiff hips. A raised toilet seat can help, but it's important to get a seat that has adjustable clips to fix it securely to the toilet bowl.

If your feet do not reach the floor when you're sitting on the toilet, a footstool may help you to get in a better position to empty your bowels.

An occupational therapist will be able to give you advice on specialised equipment to make sure you are comfortable.

## Rails

There are a wide variety of grab rails and toilet frames available that can help you use the toilet independently.

## Clothing

If you have difficulty with movement and co-ordination, some items of clothing (such as those with buttons) may take a while to undo. This may put you under unnecessary pressure.

Sometimes, a very simple adaptation, such as adding a tab to a zip, may help. If you have poor grip, adding thumb loops to pants and choosing styles that are not too tight (such as boxer shorts for men) can make it quicker and easier to pull them up and down.

You can also get special braces to help lower your trousers without the risk of them falling down.

Trousers with an elasticated waist, such as tracksuit bottoms, may also help.

For women, skirts can be tucked into the waistband, so that both hands are free to use grab rails. This prevents clothes dangling into the toilet bowl and getting wet.

An occupational therapist will be able to offer more advice on clothing adaptations.

## A new toilet or an alternative

If you have real difficulties getting to the toilet, it may be possible to get a grant to build a new one, perhaps downstairs. An occupational therapist can advise you on this.

Not all homes are suitable for building new toilets, so a commode might be needed. A commode is a moveable toilet that doesn't use running water. It looks like a chair, with a container underneath that can be removed and cleaned after someone has used it. They can be very discreet.

## National Key Scheme

The National Key Scheme offers disabled people independent access to thousands of locked public toilets around the country. Toilets can be found in shopping centres,

pubs, cafés, bus and train stations and many other locations in most parts of the country.

For a small donation Disability Rights UK can give you details of where toilets are located and can supply a radar key. You can find their details in the More information and support section.

“When I go out I always make sure I have my radar key with me so I have access to disabled loos 24/7. I find that honesty is the best policy when out and about. Shops are usually very understanding and let me use their toilet if I explain that I have a medical condition.”

**AJ, who lives in the West Midlands and has a keen interest in buses and trains**

# MORE INFORMATION AND SUPPORT

## Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at [parkinsons.org.uk/nurses](https://parkinsons.org.uk/nurses)

## Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

Our helpline can also put you in touch with one of our local advisers, who provide one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

Our website has information about your local support team and how to contact them at [parkinsons.org.uk/localtoyou](https://parkinsons.org.uk/localtoyou)

You can find details of our local groups and your nearest meeting at [parkinsons.org.uk/localgroups](https://parkinsons.org.uk/localgroups)

You can also visit **[parkinsons.org.uk/forum](https://parkinsons.org.uk/forum)** to chat to other people with similar experiences on our online discussion forum.

### **Disabled Living Foundation**

A charity giving impartial advice and information on daily living aids, including mobility equipment. It has a helpline, factsheets and an equipment demonstration centre where you can try items for free.

Helpline **0845 130 9177**

(Monday to Friday, 10am–4pm)

**[info@dlf.org.uk](mailto:info@dlf.org.uk)**

**[www.dlf.org.uk](https://www.dlf.org.uk)**

### **Disability Rights UK**

A charity that offers a radar key, allowing you access to thousands of accessible toilets in the UK.

Helpline **020 7250 8181**

(Monday to Friday, 10.00–12.30pm and 1.30–4.00pm)

**[enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)**

**[www.disabilityrightsuk.org](https://www.disabilityrightsuk.org)**

### **PromoCon**

This organisation provides a service in England, working as part of Disabled Living, Manchester, to improve life for all people with bladder or bowel problems.

Helpline **0161 607 8219**

(Monday to Friday, 10am–4pm)

**[promocon@disabledliving.co.uk](mailto:promocon@disabledliving.co.uk)**

**[www.promocon.co.uk](https://www.promocon.co.uk)**

# GLOSSARY

## Anus

The outlet from the bowel (the 'back passage').

## Bladder

A balloon-shaped organ that stores the urine made in the kidneys and expels it through the urethra.

## Bowels

Comprises the small bowel (which takes nourishment from food after it moves beyond the stomach), the large bowel (which forms the remaining waste into faeces) and the rectum (see 'rectum').

## Catheter

A tube inserted into the bladder to drain urine. Catheters are usually inserted through the urethra (see 'urethra'). They may be left in place, draining the urine into a leg bag, or may be inserted as needed (see 'Using a catheter' on page 13). Alternatively, they can be inserted through the skin by a minor operation.

## Coloproctologist

Specialist in disorders of the lower bowel.

## Constipation

Difficulty in passing a bowel motion, resulting in hard, infrequent stools.

## Faeces

The waste product from the bowel, which is stored in the rectum and passed out through the anus.

## Gastroenterologist

A specialist in the intestines and bowels.

## Geriatrician

A specialist in the conditions and diseases of older people.

## Gynaecologist

A specialist in the conditions and diseases of women.

## Impaction

When the bowel becomes very loaded with hard stools and it becomes impossible to pass faeces.

## Incontinence

Any inability to control the passing of urine or faeces.

## Intermittent catheterisation

Inserting a small plastic tube or catheter into the bladder several times each day.

## Neurologist

A specialist in diseases of the brain and nerves.

## Pelvic floor

The muscles that support the outlets from the bladder and bowel.

## Prostate gland

A gland around the outlet from the bladder in men. It produces semen, which is added to sperm in ejaculation. As men get older, this gland enlarges and may cause obstruction to the normal flow of urine. This can make the urinary symptoms worse in older men with Parkinson's.

## Rectum

Hollow organ that stores and then expels faeces through the anus.

## Sphincter

The muscles that tighten around the outlet from the bladder or the rectum.

## Stress incontinence

Leakage of urine if someone is under physical stress, or during exertion such as coughing, laughing or exercise.

## Urethra

The passage out from the bladder.

## Urgency

The condition of needing to pass urine or faeces urgently.

## Urologist

A specialist in the urinary system.

## Vagina

The birth canal, which runs alongside the urethra in women.







# Looking after your bladder and bowels (B060/2016)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to [Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ](#), or email [publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk). Thank you!

## 1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in
  - I care for someone with Parkinson's
  - I have a friend or family member with Parkinson's
  - I'm a professional working with people with Parkinson's
  - Other (please specify)
- 
- 

## 2. Where did you get this information from?

- GP
  - Specialist
  - Parkinson's nurse
  - Parkinson's UK local group
  - Parkinson's UK local adviser
  - Ordered directly from us
  - Call to the helpline
  - Other (please specify)
- 
- 

## 3. Has it answered all your questions?

- Yes, completely
- Not sure
- Yes, mostly
- Not at all
- Partly

## 4. How easy was it to understand?

- Very easy
- Quite difficult
- Easy
- Very difficult
- Not sure

Continued over the page



## 5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- |   |   |
|---|---|
| <input type="checkbox"/> It helped a lot    | <input type="checkbox"/> It didn't help       |
| <input type="checkbox"/> It helped a little | <input type="checkbox"/> It made things worse |
| <input type="checkbox"/> No change          |   |

## 6. What is your ethnic background?\*

- |   |  |
|---|--|
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Mixed         |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> White British |
| <input type="checkbox"/> Chinese                | <input type="checkbox"/> White other   |
| <input type="checkbox"/> Other (please specify) |  |
- 

\*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

## Want to hear more from us?

- I would like a response to my feedback
- I would like to be a member of Parkinson's UK
- I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

## If you've answered yes to any of these options, please complete your details below.

Name

---

Address

---

Email

---

Telephone

---

## How would you prefer us to contact you?

- Email    Post    Phone

We will not pass on your details to any other organisation or third party. To find out more, read our privacy policy at [parkinsons.org.uk/termsandconditions](https://parkinsons.org.uk/termsandconditions)



Thank you to everyone who contributed to or reviewed this booklet:

**Duncan R Forsyth MA FRCP Consultant Geriatrician, Addenbrooke's Hospital Cambridge**

**Susan Ashley, Nurse Coordinator, Advisory Services Parkinson's UK**

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

All of the photographs in this booklet feature people affected by Parkinson's, health and social care professionals involved in caring for people with Parkinson's and Parkinson's UK staff. Thank you to everyone involved for letting us use their photograph.

### **Our information**

All of our most up-to-date information is available at **[parkinsons.org.uk/information-support](https://parkinsons.org.uk/information-support)**

If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **[parkinsons.org.uk/ordering-resources](https://parkinsons.org.uk/ordering-resources)** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **[publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk)**

### **Can you help?**

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **[parkinsons.org.uk/donate](https://parkinsons.org.uk/donate)**. Thank you.

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day  
when no one fears Parkinson's.**

Parkinson's UK  
215 Vauxhall Bridge Road  
London SW1V 1EJ

Free confidential helpline **0808 800 0303**  
(Monday to Friday 9am–7pm, Saturday 10am–2pm).

Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **[www.ngts.org.uk](http://www.ngts.org.uk)**

**[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**  
**[parkinsons.org.uk](http://parkinsons.org.uk)**

Order code: PKB060

Last updated July 2016. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

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