

PARKINSON'S^{UK} 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 affect some people with Parkinson's.

It also has information on what treatments are available, who to contact for professional advice, and practical tips on managing bladder and bowel problems.

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BLADDER AND BOWELS: THE BASICS

Bladder and bowel problems are common in men and women of all ages, but people with Parkinson's are more likely to have these problems than people who don't have the condition.

What's healthy for the bladder?

Someone with healthy bladder function will use the toilet four to seven times a day, and sometimes once at night.

The muscles around the bladder outlet (urethra) and the supportive muscles (pelvic floor) help us to 'hold on' before we go to the toilet.

The bladder should be able to 'hold on' even when it's put under a lot of pressure (such as when coughing).

What's healthy for the bowel?

People should have a bowel movement between three times a day and three times a week. If someone needs to go, but the time

and place are not convenient, it should be possible to wait.

A healthy stool is typically soft and easy to pass. When the bowel is ready to empty, the rectum contracts to push out the stool. 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.

Does Parkinson's cause bladder and bowel problems?

Sometimes, but not always. This booklet will explain which types of problems are Parkinson's-related and which are not.

Dealing with bladder and bowel problems can be difficult, and sometimes the changes they bring can be upsetting. But whatever the cause, there is support available and ways to manage the symptoms so they don't rule your life.

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

Urge incontinence and nocturia are the most common bladder problems in Parkinson's. These problems may happen because the messages the brain sends to the bladder are not going through properly.

Urge incontinence

Urge incontinence is when you feel the need to urinate immediately, at times without warning. This means that you can't 'hold on' as you might do normally when you feel the urge to go. As a result, you might not reach a toilet in time.

Nocturia

As you get older, it's normal to get up once or twice in the night to urinate. But nocturia is when there's a need to go more than once or twice at night, which may be because of an overactive bladder or an increase in urine production.

This may wake you up, or your bladder may empty while you're asleep. If Parkinson's drugs have worn off during the night, it may be harder to get to the toilet in time if you have nocturia.



What other bladder problems are there?

Many people experience bladder problems, whether they have Parkinson's or not. If you have Parkinson's, it can be difficult to know if your bladder problems are caused by the condition or by something else.

It's not uncommon for women to have problems with their pelvic floor muscles, or for men to develop prostate problems. And stress incontinence is a common bladder problem in both men and women.

Problems with pelvic floor muscles

This affects some women. The pelvic floor muscles support the internal muscles around your bladder outlet (urethra). Childbirth can stretch the pelvic floor muscles and damage the urethral sphincter, which can cause incontinence.

Prostate problems

The prostate is a small gland that only men have. It surrounds the bladder outlet (urethra). As men get older it can get bigger and sometimes affects the flow of urine. Some men experience the

need to urinate more often, find it hard to start, feel the need to strain or an urgent need to go.

Occasionally, the prostate blocks the bladder completely, so urine can't be passed at all (this is known as 'retention'). If this happens, or you're in discomfort or pain, seek urgent medical help by going to your nearest A&E.

It can be difficult to tell the difference between an enlarged prostate gland and the problems emptying the bladder that can be caused by Parkinson's. Bladder tests may help to find out what's causing the problem, so 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 heavy cough or 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 be caused by Parkinson's. Bladder problems can be caused by other health conditions.

For example, you might have a urinary tract infection (UTI). This can be treated with antibiotics. So speak to your GP, specialist or Parkinson's nurse.

Diet and lifestyle

If you have bladder problems, it's important not to cut down on the fluids you drink.

Cutting down on your fluid intake won't help with bladder problems and might leave you dehydrated. However, you might find it helpful to cut out caffeine, as this can make bladder symptoms worse.

Try to maintain a healthy weight by eating a balanced diet. This can help you avoid stress incontinence. A dietitian will be able to advise you on this.

Doing plenty of regular exercise, where possible, and stopping smoking can also help.

Bladder training

Bladder training can help control an overactive bladder, helping you to practise 'holding on'.

It involves keeping a record for several days of how often you urinate, and then attempting to delay when you feel the urge.

Bladder training is not suitable for some people, so it's important to get professional support and advice.

Exercises for your pelvic floor muscles

Because stress incontinence is most often caused by weak pelvic floor muscles, exercising these muscles can help to strengthen them.

A physiotherapist or nurse will be able to explain how to do pelvic floor muscle exercises properly.

Medications

Depending on what difficulties you're experiencing, medication may be an option for some bladder problems, but not all.

Talk to your GP, specialist or Parkinson's nurse about medications that may be suitable for you.

The NHS has information on drug treatments for urinary incontinence on their website. Visit www.nhs.uk/conditions/urinary-incontinence/treatment

Using a catheter

Some people who have problems urinating naturally insert a small plastic tube, known as a catheter, into their own bladder once or several times each day.

This is known as 'intermittent catheterisation' and will drain out any urine that is left in the bladder.

This may sound difficult, but with the correct guidance many people manage it easily.

Surgery

If the options mentioned above are not successful then surgery may be an option for you.



There are several surgical procedures for the long-term treatment of continence problems. Talk to your healthcare professional for more details.

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

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

There are many different products specially designed to keep you comfortable and help you manage bladder problems discreetly.

Hand-held urinals

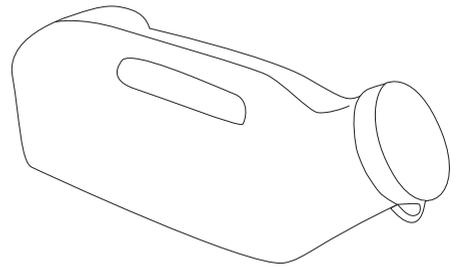
There are a variety of hand-held urinals available. They may be useful if you need to go urgently, but can't get out of a bed or chair quick enough, or when there's nobody available to help.

If you have a tremor, you may find it tricky to use these, so it's worth trying out different types.

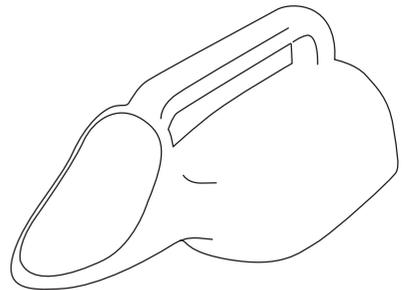
For men, a bottle with a handle, a flat bottom and a non-spill adaptor can be useful.

Some men find that the fly on their trousers is too short when they use a bottle sitting down. 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 ones which hold more urine.

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 useful if you feel safer with a pad in place 'just in case' because of an unpredictable bladder.

A continence team can assess your needs and suggest the most appropriate pad.

Many products are available on the NHS or health service, although people with milder problems may have to buy their own. Speak to your GP or district nurse to find out more.

Some pads can be tricky to put on, especially if you have a tremor, so you may need some help.

Appliances for men

Some men with urine incontinence prefer to use a sheath or appliance rather than a pad.

They fit over the penis and collect urine in a leg bag, and they're available with a GP's prescription.

Bed protection

There are many bed protection products available. You can buy mattress covers, absorbent sheets, bed pads, and waterproof 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.

Odour control

This is a common concern, but even if you have incontinence problems, it's unlikely that anyone will notice an odour. Fresh urine should not smell unpleasant. It only starts to smell if it's left out in the air.

As long as you try to 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's washed, there shouldn't be a problem.

Selecting a good pad or appliance is the best way to prevent leakage on to furniture.

If fresh urine does smell strongly, it could be a sign of a urine infection and you should speak to your GP.

Skin care

If you have continence problems, 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 best to wash with ordinary unscented soap, and to avoid using talcum powder or deodorants directly on your skin, as these can cause irritation.

If you find that your skin often gets sore, speak to your GP, specialist or Parkinson's nurse. This is important because if skin becomes broken it can become infected.

Your pharmacist may also be able to advise you on products for skin that gets sore.

Long-term catheter

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 a 'urethral catheter') or inserted via in the abdomen (known as a 'suprapubic catheter'). Both of these types of catheter are suitable for men and women.

If you have difficulties emptying your bladder, you might not want

to insert a catheter into your bladder several times a day (known as 'intermittent catheterisation'). In this case, you may prefer to use a long-term catheter that stays in all the time.

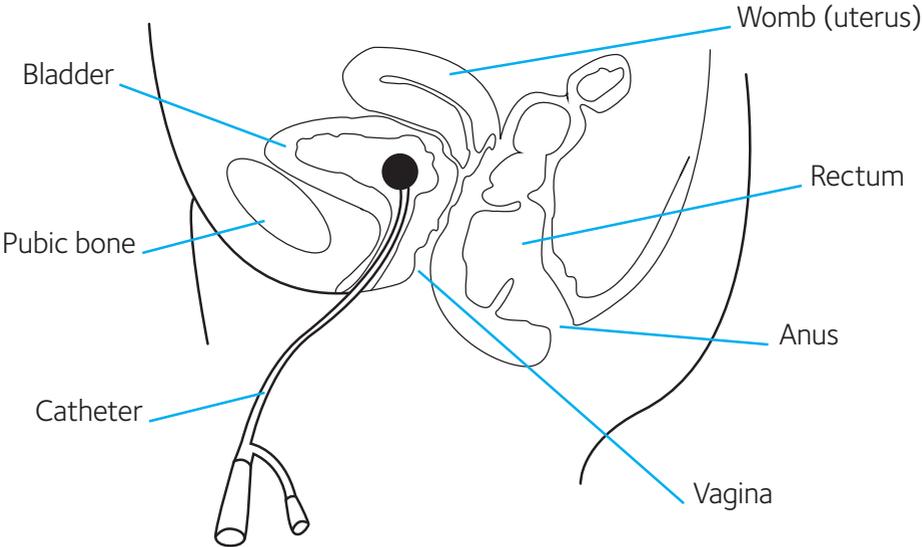
A long-term catheter can help if you're incontinent and haven't found any other way of managing the problem successfully, or if you've found it very difficult or impossible to get to the toilet in time.

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

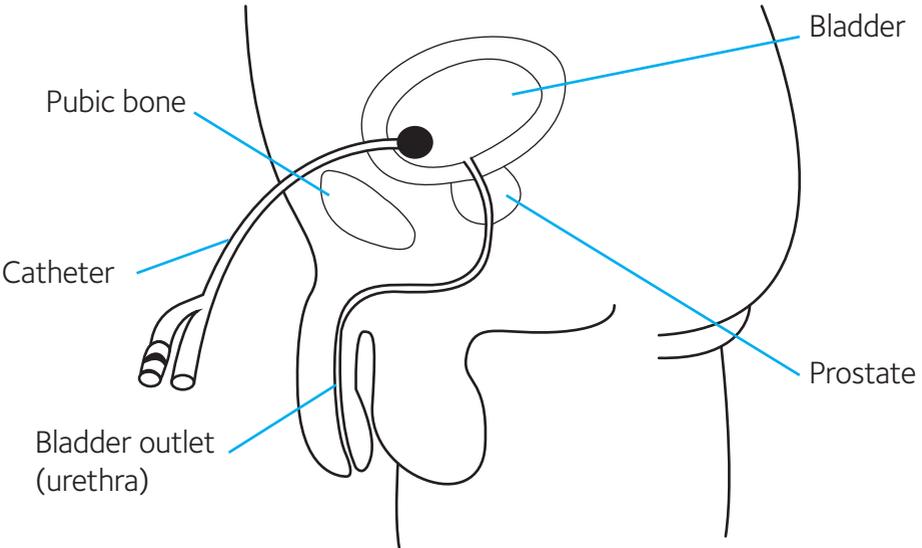
To help you make an informed decision about your treatment, make sure you discuss all options with your healthcare professional.

You can then weigh up the advantages and disadvantages of which catheter may be suitable for you.

Urethral catheter



Suprapubic catheter



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

Constipation

Constipation is when your stools become hard and difficult to pass, or when you have bowel movements 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 is common in people with Parkinson's. Some people don't recognise it as a problem because it has become 'normal' for them. Constipation can be caused by the following:

- **Parkinson's symptoms**
Slowness of movement and rigidity affect the muscles in the bowel wall, so food is not moved along in the bowel.
- **Not going to the toilet in time**
Not going to the toilet when you need to. The longer the stool remains in the body, the more fluid is reabsorbed through the bowel wall, making it dry. This can make it harder to push out stools.
- **A lack of physical activity**
If you find it difficult to move around or exercise, this can also mean your bowel isn't stimulated to work properly.
- **Eating problems**
If you find it difficult to chew and swallow food, it's harder to have a diet with plenty of fibre, which helps to keep stools soft and easy to pass.
- **Not drinking enough fluids**
This can cause stools to be harder and more difficult to pass. This can get worse during hot weather.
- **Medication**
Some medication makes constipation worse. It might be your Parkinson's drugs



or other types of medication, such as antidepressants or prescription painkillers. Speak to your GP, specialist or Parkinson's for advice on this.

- **Muscle problems**

Parkinson's can affect the muscles in different parts of the body. It might become more difficult for you 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 tightens when it should relax, which can make emptying the bowels difficult.

If you have severe constipation, you may feel unwell, tired and nauseous, and you might experience abdominal pain, acid reflux and bloating. You may also experience weight loss or weight gain.

You may feel you have to strain to pass a stool, or that your bowel is not empty even after you've passed one. If you strain a lot, you are at greater risk of getting haemorrhoids (piles).

Constipation often means your body isn't able to absorb your Parkinson's medication properly, which can lead to your symptoms getting worse.

Some people who have constipation find that when they do pass a stool, they fill the toilet. This is a sign of long-term constipation.

Constipation may also make you feel as though you need help to remove the stool. If this happens you, must tell your GP or Parkinson's nurse.

If you're constipated, the bowel can become loaded with hard stools and you might find it difficult to pass anything. This is called 'impaction'. If you experience impaction, your bowel may overflow, and there can be accidental leakage of lumps of stool or a brownish mucus that looks like diarrhoea. If this happens, you'll need urgent medical attention and should contact your health professional or call 111.

Things can be done to treat constipation, 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 the section 'What can I do to prevent bowel problems?'

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 limited mobility

Some people with Parkinson's might soil their underwear. This is because mobility problems can make it difficult to wipe after using the toilet.

If this is the case, it might help to use wet wipes, a bidet, or an adapted bottom wiper.

An occupational therapist or the Disabled Living Foundation can offer further advice (see the 'More information and support' section).

WHAT CAN I DO TO PREVENT BOWEL PROBLEMS?

Bowel problems are common. But you should tell your GP if there are any changes in your bowel habits, particularly if you see blood in your stool. Some problems are difficult to avoid, but there are things you can do to make them less likely to happen.

Exercising

Exercise will stimulate your bowels, which can help prevent constipation and contribute to stronger pelvic floor muscles. 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 the right amount of fibre and drinking enough fluids can help if you have constipation.

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. High fibre fruits include prunes or oranges.
- drink plenty of fluids throughout the day to avoid dehydration. Lots of fluids are suitable, including water, fruit juice, milk, tea and squashes. Cut out caffeine to avoid overstimulation of your bladder.

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.

Try to increase how much fibre you get gradually to avoid bloating or flatulence (wind).

A dietitian can give you further advice. Ask your GP, specialist or Parkinson's nurse for a referral.

Find out more: see our [information on diet and Parkinson's](#).

Addressing practical aspects of eating and drinking

Some people with Parkinson's 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. Ask your GP, specialist or Parkinson's nurse for a referral.

Find out more: see our information on eating, swallowing and saliva control, and speech and language therapy.

If it takes 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 also get special plates that keep your meals hot – the Disabled Living Foundation has more information (see the 'More information and support' section).

An occupational therapist will also be able to give you some tips and practical advice.

Find out more: see our information on occupational therapy.



Having a routine

Keeping to a routine can help, 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 to do this. This may be after breakfast, after a hot drink or when your medication is working best.

When you feel the urge to empty your bowels, go to the toilet as you soon as you can. Putting it off can lead to hard stools which are difficult to pass.

Allowing time and relaxing

When you go to the toilet, it's important to allow yourself enough time and try to relax. Try to push from your waist. Don't hold your breath and strain.

If you feel unsteady on the toilet, get advice from an occupational therapist. They can advise you on adaptations.

Using laxatives

Many people use a laxative regularly to avoid constipation and some people need to use a laxative for a long period of time.

It's important that you discuss using laxatives with your GP, specialist or Parkinson's nurse. It can also be useful to keep a diary

of bowel movements and laxative use, to discuss at appointments.

Some types of laxatives are not effective when used long-term. But softening laxatives are safe and effective for long-term use in lower doses.

Your GP or Parkinson's nurse can talk to you about the different types of laxatives available.

The NHS has information about different laxatives on their website. Visit www.nhs.uk/conditions/laxatives

When you first start taking softening laxatives, it's common that they soften the stool high up in the bowel, which then becomes liquified, and could be mistaken for diarrhoea. In this situation, you should stay on the laxatives, but they should be gradually reduced.

WHO CAN I TALK TO ABOUT BLADDER AND BOWEL PROBLEMS?

Many people manage bladder and bowel problems on their own, but it's important to get support if you need it. Some people find it embarrassing, but these problems are common, and the professionals you see will have treated these problems before.

If you're experiencing bladder and bowel problems, it's best to speak to your GP, who can then refer you to a specialist if necessary.

Your GP or specialist will probably ask a series of questions to find out what the problem is, such as:

- 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?

You might be asked to keep a chart for several days of how often you use the toilet and how much you drink. You will usually have a physical examination, and they may ask for a urine sample to test for infection.

Sometimes specialist tests or X-rays are needed. Usually, these can be done in an outpatient department or clinic.

The GP 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.

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

A district nurse may visit you at home and provide advice, bladder training or pelvic floor exercises. They can also arrange a free supply of continence pads if needed.

A continence adviser is a specialist nurse who assesses and manages incontinence. They may visit you at home or see you in a clinic.

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

An occupational therapist can advise on physical aids, clothing adaptations and equipment to help with everyday activities, such as going to the toilet. You can be referred by a GP or your local social services department.

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' for details.



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 might find it difficult to get to the toilet in time.

You might also find it hard to move yourself into the right position to use the toilet, or have difficulty undoing clothes or fastenings, such as zips or buttons.

These problems can be frustrating, but there are things that you can do to make using the toilet easier.

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 don't 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 can give you advice and recommend specialised equipment to make sure that you're 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 your movement and coordination, some items of clothing (such as those with buttons) may take a while to undo.

Sometimes simple changes can help, such as adding a tab to a zip.

If you have poor grip, adding thumb loops to pants and choosing styles that are not too tight (such as boxer shorts) can make it quicker and easier to pull them up and down.

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

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

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.

If you have difficulties getting to the toilet, it might be possible

to get a grant to build a new one, perhaps downstairs. An occupational therapist can advise you on this.

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.

To unlock them you need a Radar Key (sometimes called an NKS Key). It looks like a big, blue skeleton key, and it opens more than 10,000 locked, disabled toilets in the UK.

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.

MORE INFORMATION AND SUPPORT

Bladder and Bowel UK

This charity is part of the Disabled Living Foundation, and gives information and advice for people with bladder and bowel problems. They have a team of continence specialist nurses and continence product information staff, who can be contacted on their helpline.

0161 607 8219

bbuk@disabledliving.co.uk

www.bbuk.org.uk/adults

Disability Rights UK

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

0203 687 0790

shop@disabilityrightsuk.org

www.disabilityrightsuk.org

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**

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**

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**

You can find details of our local groups and your nearest meeting at **parkinsons.org.uk/localgroups**

You can also visit **parkinsons.org.uk/forum** to chat to other people with similar experiences on our online discussion forum.

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. 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.

Gynaecologist

A specialist in the conditions and diseases of women, especially those affecting the reproductive system

Impaction

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

Incontinence

An 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.

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.

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.

Looking after your bladder and bowels (B060/2020)

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. 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



Thank you to everyone who contributed to or reviewed this booklet, including experts and people affected by Parkinson's.

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

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** 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**

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**. 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**

hello@parkinsons.org.uk
parkinsons.org.uk

Order code: PKB060

Last updated March 2020. 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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