

Looking after your bladder and bowels in Parkinsonism

Advice for people with Parkinsonism and their carers

by Christine Norton



About the Parkinson's Disease Society

The Parkinson's Disease Society of the United Kingdom (PDS) works with people who have Parkinson's, their families and carers, and health and social care professionals. The work of the PDS includes:

- Research into the cause, cure and prevention of Parkinson's, and improvements in further treatments.
- Information and advice on Parkinson's and issues such as financial assistance, insurance and employment.
- A wide range of publications, audio cassettes and videos aimed at people with Parkinson's, families, carers and professionals.
- A comprehensive education and training programme for professionals.
- A national network of Field Staff and Branches, offering information, support, advice and social activities.

The Continence Foundation provides the public with information and advice, notably through its Helpline and literature. The Foundation provides health professionals with directories of products and services, publications and other resources, study days and conferences. It makes the case to Parliament and Government and the NHS for higher priority and improved policies for continence services. The Foundation acts as an umbrella body for more specialised organizations in the UK and maintains links with similar bodies overseas.

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The Royal College of Nursing Continence Care Forum is a national resource and network for nurses with an interest in continence care.

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Parkinsonism

The main symptoms of Parkinson's disease – shaking, stiffness and slowness of movement – are also the main symptoms of a wider condition known as parkinsonism.

The term parkinsonism refers to a collective group of conditions which feature the symptoms described above. It occurs when nerve cells do not work properly in a particular area of the brain, the substantia nigra. These nerve cells produce and store dopamine, the chemical messenger that controls the body's movements.

Parkinson's disease is the most common form of parkinsonism. It is sometimes referred to as idiopathic parkinsonism, which means simply that its cause is unknown.

Other, less common forms of parkinsonism include multiple system atrophy (MSA) and progressive supranuclear palsy (PSP) and drug-induced parkinsonism.

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Glossary

ACETYLCHOLINE – a chemical messenger (known as neurotransmitter) which works in balance with dopamine to produce smooth, co-ordinated movement.

ANTICHOLINERGIC – drugs which block the action of acetylcholine (e.g. Artane, Cogentin, Disipal) in order to try and restore the balance between dopamine and acetylcholine. They are not recommended for use in elderly people because they cause confusion.

ANUS – the outlet from the bowel (the ‘back passage’).

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

BOWELS – comprising 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 – tube inserted into the bladder to drain urine. Catheters are usually inserted through the urethra: in this case they may be left in place, draining the urine into the leg bag, or may be inserted periodically at need (see ‘intermittent catheterisation’). Alternatively, they can be inserted through the skin by a minor operation (‘supra-pubic catheterisation’).

COLOPROCTOLOGIST – a specialist in disorders of the lower bowel.

CONSTIPATION – difficulty in passing a bowel motion, resulting in hard, infrequent stools. This is a particular problem in parkinsonism.

DOPAMINE – a chemical messenger (known as a transmitter) which helps send messages between nerve cells or between nerve cells and the muscles, especially those concerned with movements.

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

FREQUENCY – the condition of needing to pass urine frequently.

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 anything.

INCONTINENCE – any inability to control the passing of urine or faeces.

INTERMITTENT CATHETERISATION – the periodic insertion of a catheter, performed either by oneself or a carer, through the urethra to drain the urine in the bladder into a toilet or other receptacle.

NEUROLOGIST – a specialist in nerve diseases.

PARKINSONISM – a collective group of conditions which feature the symptoms of shaking, stiffness and slowness of movement. It occurs when nerve cells do not work properly in a particular area of the brain, the substantia nigra. These nerve cells produce and store dopamine, the chemical messenger that controls the body's movements.

Parkinson's disease is the most common form of parkinsonism. It is sometimes referred to as idiopathic parkinsonism, which means simply that its cause is unknown. Other less common forms of parkinsonism include multiple system atrophy (MSA) and progressive supranuclear palsy (PSP), and drug-induced parkinsonism.

PELVIC FLOOR – the muscles that support the outlets from the bladder and bowel.

PROSTATE GLAND – a gland round the outlet from the bladder in men; it manufactures a fluid added to the sperm in ejaculation.

RECTUM – hollow organ which stores and then expels faeces through the anus.

SPHINCTER – the muscles that tighten round the outlet from the bladder or the rectum.

STRESS INCONTINENCE – leakage of urine upon physical stress or 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.

URINE – liquid produced by the kidneys to get rid of some of the body's waste chemicals and water.

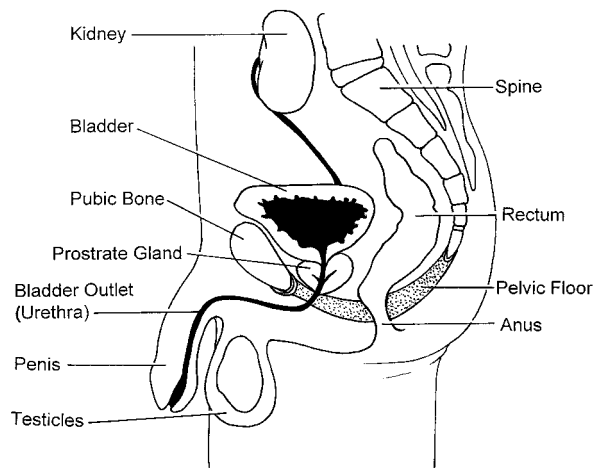
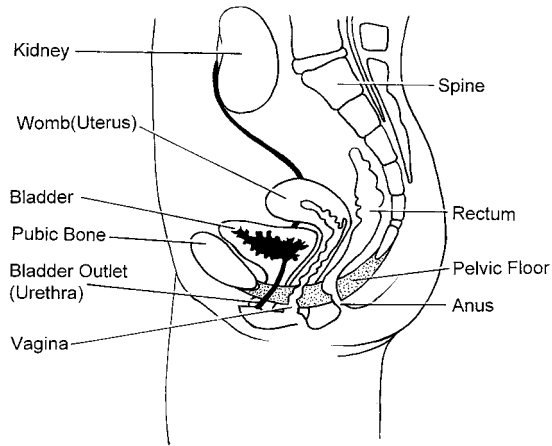
URODYNAMICS – the study of bladder function, especially of bladder pressure and the volume of urine.

UROLOGIST – a specialist in the urinary system.

VAGINA – the birth canal, which runs alongside the urethra in women.

[Figure 1]

**The bladder –
top: female
bottom: male**



An Introduction

Few of us like to talk about our bladders and bowels. In our society these matters are generally considered private, and it can be embarrassing and difficult to bring up the subject. Unfortunately, this means that many people just put up with problems and never get proper help. A few even try to hide problems from those closest to them and cut themselves off rather than risk someone else knowing.

This is a pity, because nobody should just accept bladder or bowel problems: something can always be done to help. However, each case needs individual assessment. Sometimes problems can be cured completely and even if a cure is not possible, there are many different ways of managing the symptoms so that they do not rule your life. So, *think positive!*

It is by no means inevitable that people with parkinsonism will experience bladder or bowel problems. Many people don't, and those that do often find that they have had parkinsonism for many years before the bladder or bowel becomes troublesome. It is true, however, that in some forms of parkinsonism bladder problems feature early and can be a real nuisance.

It is important to realise that bladder and bowel problems are common in people of all ages, both sexes, with and without parkinsonism, and that people with parkinsonism are not much more likely to have problems than people of a similar age without it. So do not just assume that any problem is a result of your parkinsonism. There are many other causes as well.

If you do not have bladder or bowel problems, you may still find the information in this document helps to give you some ideas on preventing problems from arising. Do not let it depress you. Most people with parkinsonism do not develop these symptoms.

How should the bladder work?

The bladder has two functions: to store and hold urine after it has been made in the kidneys – see *Figure 1* - and then to empty out completely. Most people feel that the bladder is filling when it is about half full (when there is about half a pint in it), but can delay going to the toilet until the time and place is convenient. There is therefore an efficient 'early warning system' which warns us to look out for a toilet, but most people have quite a long time (even an hour or more) between when they first feel the need to empty the bladder and when it becomes urgent.

An average bladder will hold up to about a pint and need emptying four to six times a day and usually not at all at night, although some people always have to get up once. The sphincter 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 severe pressure, such as during coughing or jumping.

This may sound simple, but in fact this control of filling (when the bladder must relax and fill) and emptying (when the bladder must contract to squeeze out the urine and the urethra must

relax to allow it out) is very complex. It involves co-ordination of nerves and muscles, and very long nerve pathways between the bladder and brain.

What can go wrong with the bladder in Parkinsonism?

There are two main problems that can occur with the bladder in parkinsonism – an overactive or 'unstable' bladder, and difficulty in emptying. It is important to stress that not everyone with parkinsonism will have these problems, and those that do may have them only mildly or intermittently. However, it is possible to have one or both problems. In addition, your parkinsonism may affect other functions such as mobility, so that coping with the bladder becomes more difficult.

The unstable bladder This is caused when messages from the brain telling the bladder to hang on and relax are not getting through properly. Instead of being able to delay finding a toilet, you experience urgency – when you've got to go, you've got to go! If you cannot reach the toilet in time, incontinence may result. This is called 'urge incontinence' or urgency. The bladder also need emptying more often than before (frequency), and may wake you up at night, or even empty while you are asleep.

Difficulty emptying Parkinsonism can cause difficulty with starting to empty the bladder, either because the bladder does not start to contract when you want it to, or the sphincter does not relax to allow urine out, or a combination of these. Or there may be difficulty in keeping a bladder contraction going until the bladder is completely empty. Either way, a residual amount of urine is often left in the bladder all the time. This can cause a feeling of needing to empty the bladder very often and, if the residue becomes large enough, it may 'overflow' as a dribbling incontinence that you cannot control.

A tendency to incomplete emptying can be made worse if you are taking anticholinergic drugs (such as benzhexol or orphenadrine, whose proprietary names are respectively Artane and Disipal) to help with your parkinsonism. People whose bladder does not empty completely are also likely to get urine infections as the residue of urine acts as a sort of stagnant pond which is ideal for growing bacteria.

Practical problems Often the problems which people with parkinsonism have in coping with the bladder are caused by difficulties in getting to or using the toilet rather than by incontinence. The physical difficulties with mobility and the slowness of movement which often occur in parkinsonism can make getting to, or onto, the toilet a slow process. If at the same time you have urgency, it may simply take you too long and your bladder may start to empty. At night, people with parkinsonism often experience reduced dopamine levels, which can make it even more difficult to get out of bed, get to the toilet, or finally start to pass urine. It can be very frustrating to struggle to the toilet and then not be able to start once there. Sleep may be interrupted by several fruitless trips to the toilet.

There can also be difficulty in using the toilet – for instance, it may be too high or too low, or it may not have grab rails when needed. Sometimes, undoing clothes or fastenings such as zips or buttons can also be a problem. An occupational therapist can advise on ways of making these problems easier to deal with and can suggest adaptations to equipment or clothing which may help. See Making it easier to go to the toilet, page 14, for more information.

If you depend on the assistance of a carer to use the toilet, much will turn on your ability to communicate effectively and on the availability and understanding of your carer. It may be that a carer who does not know you well will find it more difficult to understand how best to help.

What else can go wrong with the bladder?

There are several other bladder problems common in all people, not just those with parkinsonism. If you have problems, it may be more to do with having had children, or having an enlarged prostate gland, than with parkinsonism.

Stress incontinence Many people experience leakage of urine upon physical (not emotional) stress or exertion such as coughing, laughing or exercise. This is

called stress incontinence and is most common in women, who have a much shorter and weaker bladder outlet than men.

Childbirth can cause considerable stretching of the pelvic floor muscles and damage to the urethral sphincter. After the menopause ('change of life'), falling hormone levels may also mean that there is a less effective watertight seal. Repeated heavy lifting, a smoker's cough or being overweight can all put an extra strain on the bladder outlet.

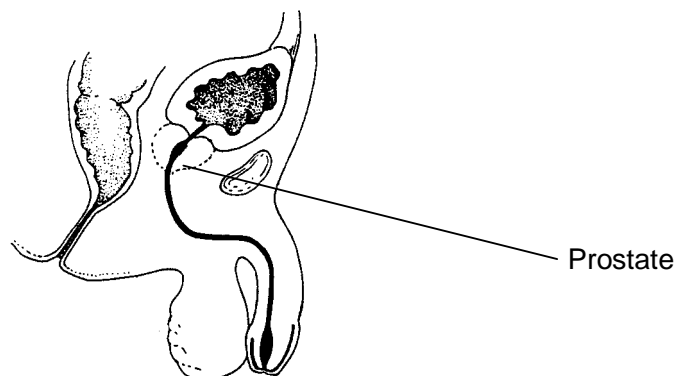
Prostate problems As men get older, a small gland around the neck of the bladder gradually gets bigger (see *Figure 2*). This is normal in all men over 50 years, but for some men, it causes problems by blocking the outflow of urine and making it difficult or slow to empty the bladder. Occasionally, the blockage is complete and no urine can be passed at all ('retention'). If this persists for more than a few hours, urgent medical attention is needed. For many older men the prostate gets bigger gradually, causing the bladder not to empty completely each time. This results in frequency (passing urine often, and at night), hesitancy (difficulty starting the stream), needing to strain and sometimes urgency (having to rush to the toilet).

It may be very difficult to distinguish between an enlarged prostate gland and the emptying difficulties that can be caused by parkinsonism without urodynamic tests on the bladder.

It may seem as though, with all these possible problems, it is amazing that anyone has good bladder control. In fact, bladder problems are very common. For example, as many as one woman in four will experience incontinence at some time in her life. One man in ten will have a prostate gland that needs treatment. But don't despair – a lot can be done to help.

Figure 2

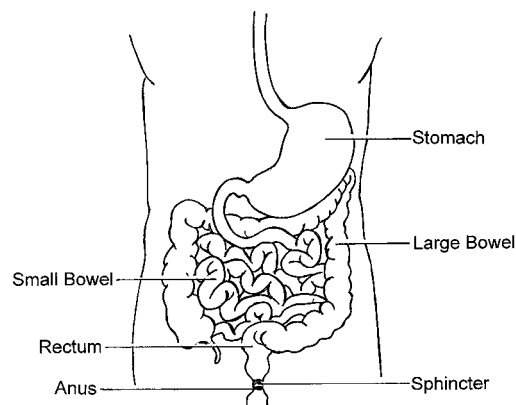
*The male
Urinary system*



How should the bowel work?

The job of the bowel is to process the food that we eat, extract the nutrients that the body needs (in the small bowel), and then hold and expel waste products (the work of the large bowel, rectum and anus) (see *Figure 3*). 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 stool). Movement of faeces along the large bowel is often stimulated by eating, drinking or physical movement. This is why many people find that their bowel needs emptying after breakfast – getting up and eating causes a ‘mass movement’ of faeces along the bowel into the rectum.

Figure 3
The bowel



When faeces enter the rectum you should get a feeling that you need to find a toilet. However, if the time and place are not right, this can be put off, you can ‘hold on’. Then, when you are at the toilet the rectum contracts to squeeze out the faeces, the anus relaxes and opens and the stool is passed, maybe with a little extra help from your abdominal muscles bearing and pushing down and possibly a little straining.

Many people consider that the bowels must be opened every day. In fact, there is a wide range of ‘normal’ patterns of behaviour, with some people going only once every two or three days, others two or three times every day. As long as the stool is formed but soft and easy to pass without undue straining this is nothing to worry about.

As with the bladder, this seemingly simple storing then emptying is in fact controlled by complex nerves and muscles, and this control is easily disturbed.

What can go wrong with the bowel in parkinsonism

Constipation The most common bowel problem in parkinsonism is constipation. It is important to define what this means. It is not crucial to have a daily bowel motion for good health, and 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 undue straining there is nothing to worry about. Constipation is when the stools are hard and difficult to pass.

Constipation is common in all sections of the population, not just people with parkinsonism. In parkinsonism it has several different causes. As with other muscles in the body, the muscles of the bowel wall can be affected by parkinsonism, with slowing and poverty of movement and rigidity. In addition, the relative lack of movement and exercise generally experienced by people with parkinsonism means that the bowel does not get these stimuli to function properly. Some people with parkinsonism have difficulty in chewing and swallowing food, and so it is difficult to eat a diet with plenty of fibre.

There can be problems in actually emptying the bowel. It may be difficult to brace the abdominal muscles to assist bowel emptying and the anal sphincter may not relax at the right time to allow the stool to be passed easily. Some people actually get a paradoxical contraction of the sphincter when trying to empty the bowel – the anus tightens up when they think they are relaxing it. This tendency to constipation can be made worse if anti-cholinergic drugs (such as benzhexol or orphenadrine – Artane or Disipal) are taken to treat the parkinsonism.

Constipation can be a nuisance, but seldom leads to serious complications. If severe, it may make you feel unwell, lethargic and even nauseated. A few older people may become restless and confused at night if constipated. It can also disturb the bladder, either by increasing bladder urgency, or by making bladder emptying more difficult.

The longer a stool remains in the rectum, the harder it becomes as more and more water is absorbed from it. If the bowel becomes very loaded with hard stools this is called 'impaction' and it can become impossible to pass anything. In the end the bowel may overflow and there is accidental leakage, either of lumps of stool, or of brownish mucus which looks like diarrhoea but is not. Very rarely, impaction can cause a complete obstruction to the bowel and urgent medical attention is needed.

Diarrhoea If you have parkinsonism, you can still get diarrhoea for the same reasons as anyone else, such as food reaction, 'holiday tummy' or infection. This may be difficult to cope with if you have parkinsonism – it is not easy to hurry to the toilet, and you may find that you cannot squeeze the sphincter muscles in your bottom very well to stop you leaking on the way to the toilet. This means that if you have diarrhoea, you may be more likely than other people to have an accidental leakage.

Weak sphincter The anal sphincter muscle is easily damaged, especially by childbirth or minor operations in the area (e.g. for piles). This will usually cause a difficulty in holding onto stool once the urge to empty the bowel is felt. Urgency, and even urge incontinence of stool may result if the toilet is not reached quickly.

Other bowel problems are very common throughout the population. Any change in bowel habit and particularly if you see blood in your bowel motions, should be reported urgently to your doctor. A few people with parkinsonism experience soiling of their pants because they are unable to wipe effectively after opening the bowels. Moist toilet tissue, use of a bidet, or a specially adapted bottom wiper may help. An occupational therapist or the Disabled Living Foundation will be able to offer further advice. (See *Useful Addresses*, page 21).

How can I prevent problems or help myself?

Many of the problems outlined above are difficult to avoid, but you can help to make them less likely to lead to incontinence. As with parkinsonism generally, the more healthy your lifestyle, and the more active and mobile you can keep yourself, the better. Exercise will stimulate your bowel to help prevent constipation and contribute to stronger pelvic floor muscles. Moreover, a positive outlook and attitude helps a lot.

For bladder problems it is important not to cut down too much on the amount of fluid you drink as this will not help and may lead to bladder infections. You may, however, find that it helps to cut out caffeine and some types of alcohol. This is very individual, so it is worth experimenting to see what helps *you*. If you have stress incontinence, losing some weight, stopping smoking and doing pelvic floor exercises may each help. (The Continence Foundation has a leaflet on these exercises (see *Useful Addresses*, page 21) or you can ask your GP, district nurse, physiotherapist or continence advisor about them.)

In bowel problems, it is also important to make sure that you drink enough and eat a diet with plenty of fibre, such as fruit, vegetables and wholemeal bread and cereals. If you have difficulty chewing high fibre food, there are soluble varieties available and even some high fibre drinks. If it takes you a long time to eat, so that your meal goes cold and you go off it, try smaller portions and go back for seconds that have been kept warm. Special plates are available that will help keep your meals warm: ask your occupational therapist or the Disabled Living Foundation. (See *Useful Addresses*, page 21)

Try to keep your bowels in a routine, especially if you are away from home and your usual environment. Many people find that 20 minutes after breakfast or a hot drink is a good time to empty the bowel. It is important to allow yourself enough time and to try and relax. Many of us try to rush these things. If your feet do not reach the floor, a footstool may help you to get in a better position to empty your bowel.

As stated earlier, a daily bowel motion is not crucial, so try not to become obsessed by your bowels. However, it is important to keep an eye on things and not to let yourself become impacted. You may find that you need to use a laxative regularly to stop yourself from getting constipated. It is not a good idea to use a laxative for long periods unless your doctor advises this, as some types can eventually damage the bowel. Liquid paraffin in particular should be avoided as it can interfere with the absorption of some drugs used to treat parkinsonism.

Who should I talk to if I have problems?

While self-help is very useful, it is important not to struggle on alone for too long with bladder and bowel problems. Plenty of professional help is available. A lot of people find it embarrassing to talk about these subjects. Don't let this stop you from getting help if you need it. If you would find it useful to talk anonymously before you go to your doctor or nurse, or if you are not sure whether your problems are serious enough to bother your doctor, try the Continence Foundation's Helpline (020 7831 9831). (See also *Useful Addresses*, page 21.)

Your General Practitioner (GP) – as with most problems, your family doctor (or GP) will usually be your first port of call. Your doctor will talk to you about your difficulties and may examine you and test a urine sample. Some treatments can be carried out by your doctor; others need referral to a specialist.

Hospital specialists – several different specialist doctors may be of help. Among those who may have a special interest in bladder or bowel problems are the urologist (who specialises in the urinary system), the gynaecologist (who treats conditions and diseases of women), gastro-enterologist (who specialises in the intestines and bowels), coloproctologist (who specialises in disorders of the lower bowel), neurologist (who specialises in nerve diseases) and geriatrician (who specialises in conditions and disease of older people). Your GP will know which can help you and which has access to equipment for any special tests you may need in your hospital.

Your GP or hospital consultant can refer you to other specialists, such as the following:

The district nurse – who may visit you at home and help you with general advice, bladder training or pelvic floor exercises when these are needed. The district nurse may be able to arrange a free supply of continence pads if you need them.

A continence advisor – a specialist nurse who assesses and manages incontinence and who may visit you at home or see you in a clinic. Many continence advisors will see members of the public without referral from a GP or other professional. You can obtain details about your local continence advisors from the Continence Foundation Helpline (See *Useful Addresses*, on page 21).

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

An occupational therapist can advise on 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/social work department.

A dietician – can give advice on increasing your fibre intake, and on food which is easier to chew and swallow.

A subsidised or free laundry service is available in a few areas. Contact your local social services/social work department for details.

What examinations may be necessary?

The professional involved will first need to get a full history and picture of the problem. You are likely to be asked:

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

These, and other questions relevant to you (such as reference to childbirth or any injuries or operations you have had in the past) should help to build up a picture of the likely cause of your problem.

You may be asked to keep a chart for several days of how often you use the toilet and how much you drink. A urine specimen will usually be tested for infection and a physical examination will usually be needed.

As the bladder or bowel problem can be complex in parkinsonism, sometimes specialist tests, such as urodynamic tests to measure how the bladder works, similar tests on the bowel, or X-rays, may be needed. All of these can usually be done in an outpatient department.

What treatments are available?

Drug treatment For an unstable bladder which works too often and too urgently, the best treatment is a drug which calms the unwanted bladder contractions and allows the bladder to relax more during filling. There are several different drugs which can do this, such as oxybutynin, tolteradine, imipramine or propantheline

and new ones are under development. Some of these may take several weeks to produce a full effect, so it is worth persevering.

For people troubled by being woken at night to pass urine, there is a drug called desmopressin, which cuts down urine production for eight to ten hours after it is taken.

Bladder training This also is used for frequency and urgency, often in combination with the drugs mentioned above. People with urgency and the experience of leaking tend to panic when they feel the bladder filling. This is understandable, as it is very embarrassing to have an accident. Bladder training involves keeping a record for several days of how often you pass urine, and then attempting to delay when you feel the urge – to practise holding on. This demands a lot of willpower, and may be impossible for some people, so it is important to get professional support and advice (for instance, from your continence advisor).

Intermittent catheterisation People who cannot empty the bladder completely and experience overflow incontinence may be able to learn to insert a small plastic tube or catheter into their own bladder several times each day to drain out the residual urine. This procedure is known as intermittent catheterisation. This may sound difficult, but many people manage it very easily. Those who cannot may have a carer or a nurse who can insert the catheter for them.

Pelvic floor exercises As stress incontinence is most often caused by weak pelvic floor muscles, the first line of treatment is usually pelvic floor exercises. These exercises are designed to strengthen the internal muscles around your bladder outlet. They are quite tricky to do correctly, and it is usually advisable to get a physiotherapist, nurse or doctor to explain them properly. The Continence Foundation also has a free exercise instruction sheet (*See Further Reading page 22*).

Women with stress incontinence after the change of life may find that hormone replacement therapy will help. If stress incontinence is a real problem, then sometimes an operation will be suggested. This will need very careful consideration for someone with parkinsonism, and should only be undertaken after full urodynamic investigation. The aim of an operation is to tighten the bladder outlet, and anyone who already has some difficulty in emptying the bladder completely may find it even more difficult after such an operation. Your surgeon will, of course, be happy to discuss the advantages and disadvantages of surgery.

Some women find that wearing a pessary or a tampon in the vagina will help to control stress incontinence. This should be discussed with your doctor or nurse.

Prostate enlargement There are several different approaches to treating an enlarged prostate gland. Some drugs are available which slow down prostate growth, or even reduce its size. The most common treatment is an operation to

remove the prostate. This is usually done through a small telescopic instrument inserted into the urethra, and so doesn't involve any scars on your stomach. More recently, some hospitals have introduced a procedure to shrink the prostate by using lasers.

As with operations for stress incontinence, it is very important that a man with parkinsonism is fully examined before prostate surgery. Since some forms of parkinsonism can start with symptoms very similar to those caused by an enlarged prostate gland, it is important that your neurologist confirms that you have Parkinson's disease and that your urologist confirms that you have an obstruction to the outflow of urine caused by the prostate and not by your neurological problems before any operation is contemplated. As the aim of this operation is to make it easier to pass urine, there is a risk of making it slightly too easy if you have an overactive bladder as well, and causing incontinence.

Bowel Treatments Constipation is covered earlier (*See How can I prevent problems or help myself? page 10*). If laxatives fail to establish a regular habit, sometimes suppositories or an enema may be needed. For other bowel problems, a variety of drug and surgical treatments are possible, but should be used with care in parkinsonism. Seek advice from your doctor.

Making it easier to go to the toilet

Physical disabilities such as the slowness of movement that can be a feature of parkinsonism can make using a toilet difficult. There may be practical problems to overcome. Consider how accessible the toilet is – you may, for instance, find it difficult to get to an upstairs toilet when you are downstairs or the distance you have to cover may be too great. The height of the toilet may be a problem, or you may need grab rails to make it safer and easier to use. It is worth thinking carefully about how to make independent use of the toilet as easy as possible. Some solutions are listed below. Further advice and assessment can be obtained from your occupational therapist, who should also know about any grants that may be available for equipment or adaptations.

Height If the toilet is too low it can be very difficult to get down on to it, and even more difficult to get up again afterwards, especially if you have stiff hips. A raised toilet seat can make the toilet up to 15cm (6 inches) higher. It is important to get a seat which has adjustable clips to fix it securely directly to the toilet bowl. A raised seat perched on top of the ordinary seat will be very unstable and dangerous. Your occupational therapist may be able to advise on other, more specialised equipment.

Rails There is a wide variety of grab rails and toilet frames designed to assist independent use of the toilet. It is important that the right design is chosen to help with each individual's difficulties. Rails can be fixed to the walls or floor. Horizontal rails help with pushing up, while vertical rails can help you to pull yourself up.

Clothing Clothing is easier to remove in a hurry if it is not too tight-fitting and has as few fastenings and layers as possible. Button fly openings or fiddly zips can take ages to open for someone with a tremor. Sometimes a very simple adaptation such as adding a tab to the zip (see *Figure 4*) may help. If you have poor grip, adding thumb loops on to pants and choosing styles which are not too tight (such as boxer shorts for men) can make it quicker and easier to pull them up and down. A wraparound skirt can be tucked into the waistband so that both hands are free for use with grab rails without fear that the skirt will dangle into the toilet bowl and get wet (see *Figure 5*). Special braces can enable trousers to be lowered without losing them completely. Tracksuit trousers are found useful by many men. Your occupational therapist can advise on many more clothing adaptations.

Figure 4
Tab on zip

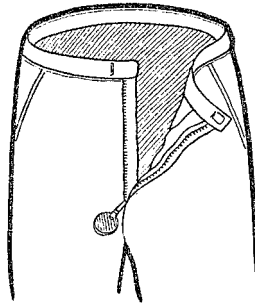
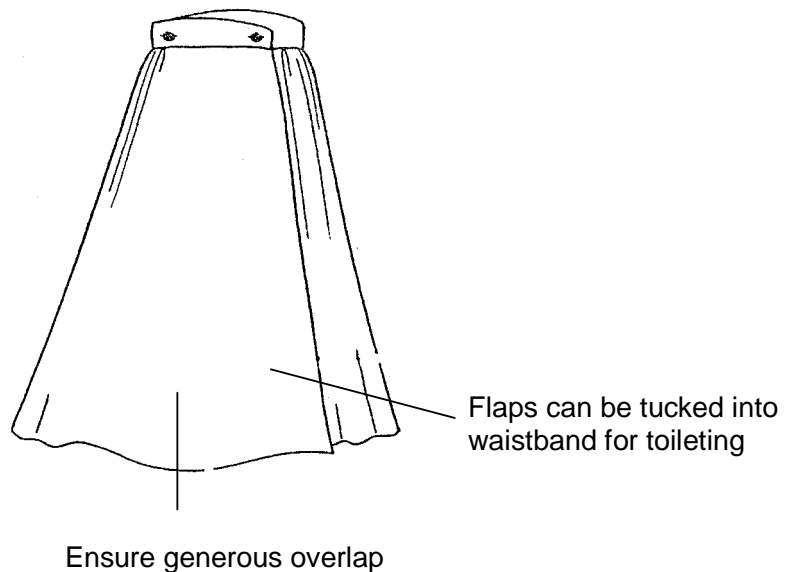


Figure 5
Wrap-around Skirt

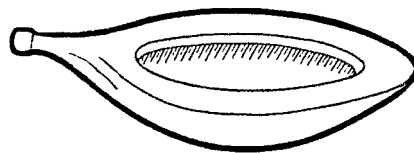
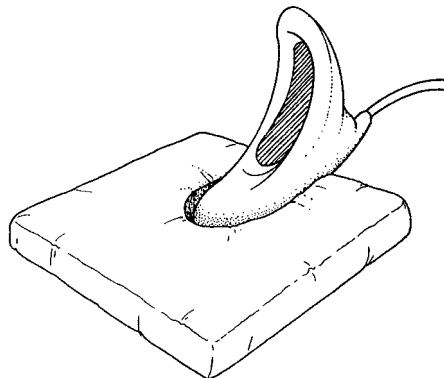


A new toilet or an alternative? If you have severe difficulties in getting to the toilet it may be possible to get a grant to build a new one, perhaps downstairs. Your occupational therapist can advise on this. However, not all houses are suitable for this. Sometimes the answer is a commode, maybe discreetly curtained off or by the bed. Some designs look like normal furniture when not in use.

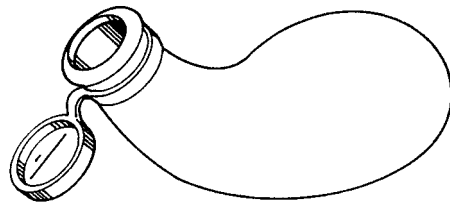
There is also a variety of hand-held urinals for men and women (see *Figure 6*). These may be useful for someone with urgency who cannot get out of a bed or chair in a hurry, or when there is nobody available to help. However, use may be made difficult by a tremor. It is worth experimenting with different types. For men, a bottle with a handle, a flat bottom and a non-spill adaptor may avoid some problems (see *Figure 7*). Men using a bottle when seated often find that the fly opening on modern trousers is too short. Extending the opening down to the crotch seam, and maybe closing it with Velcro tabs rather than buttons or a zip, can make using a bottle much easier (see *Figure 8*).

Figure 6
Hand-held urinals for men and women

Bridge urinal
with U-shaped
cushion
(female)



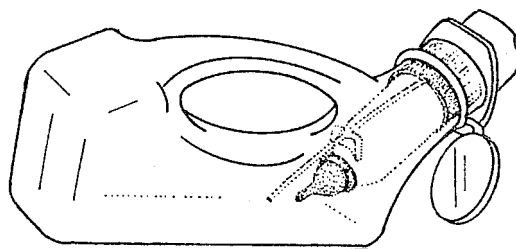
Hand-held urinal (female)



Bottle with snap-on lid (male)

Figure 7

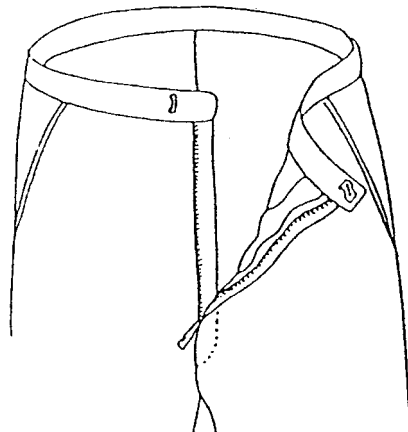
Male urinal with handle



Flat-bottomed bottle with non-return valve

Figure 8

Trousers with extending opening



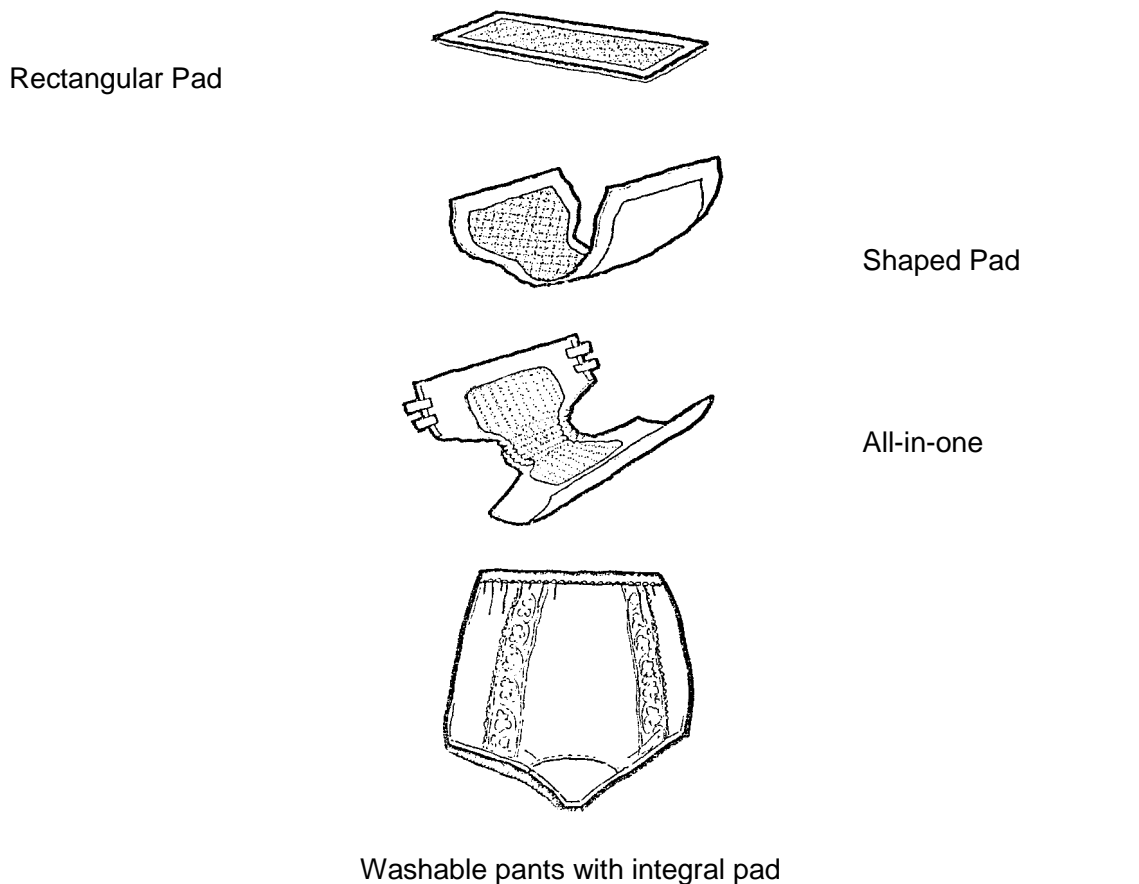
What if I still have some problems with incontinence?

Don't despair if you still have problems. Many people live with a bladder or bowel which doesn't work perfectly, and still manage to lead a full and varied life. There are many different products specially designed to keep you comfortable and prevent anyone else from needing to know.

Pads and pants There is a huge variety of different pads to suit all needs. From ordinary sanitary towels to cope with mild leakage, to much larger pads for those who need them, there should be something to suit everyone (see *Figure 9*). Most pads are disposable and held in place inside stretch pants. There are also washable pants with a built-in absorbent gusset, which are particularly useful for people with an unpredictable bladder who feel safer with a pad in place 'just in case'. Larger disposable pads are usually available free of charge on the National Health Service (via the district nurse) for those who need them, but in many areas people with milder problems have to buy their own.

Bed protection Various mattress covers, absorbent sheets and bedpads, duvet and pillow covers are available if needed. Some can be supplied free of charge by the district nurse. Washable absorbent sheets tend to be the most comfortable and absorbent, but they can be heavy and difficult to handle when wet.

Figure 9
Pads and pants



Appliances for men Some men with incontinence of urine 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 fiddly to put on, especially if you have a tremor, and assistance may be needed. People who can help are district nurses and continence advisors. Appliances are available with a GP's prescription and the usual prescription charges apply.

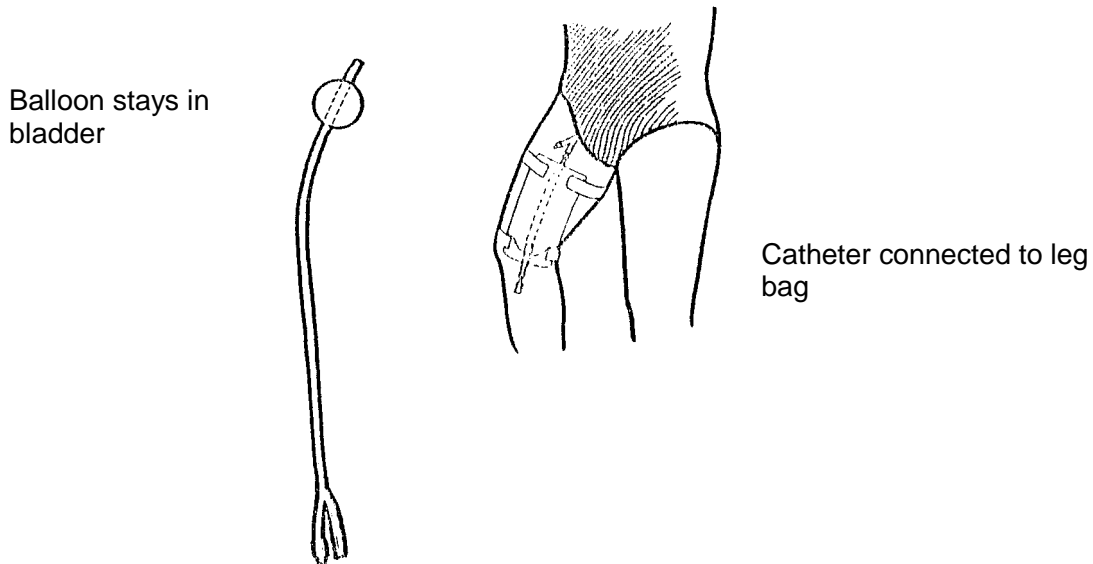
Odour control Even if you are incontinent, it is unlikely that anyone else will notice a smell, although this is a common worry. Fresh urine should not smell unpleasant (if it does you may have a urine infection). Urine only starts to smell if it is left out in the air so as long as you change soon and keep wet pads, clothing or bedding in an airtight container (such as a bucket with a lid) there should not be a problem.

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

Skin care Most people who are incontinent do not get sore skin, as long as they change frequently and take care to wash and dry their skin thoroughly. Take a bath or shower daily if you can. Washing with ordinary unscented soap is usually best. Avoid using highly perfumed soaps, disinfectant, talcum powder or deodorants directly on your skin as these can irritate. If the skin becomes sore, a simple barrier cream may help; your pharmacist can advise you. If the skin becomes broken always seek help from a doctor or nurse.

Will I need a permanent catheter? A catheter is a hollow tube which drains urine from your bladder into a drainage bag on your leg (see *Figure 10*). For a few people with severe emptying difficulties who cannot manage intermittent catheterisation, a catheter which stays in all the time may be the answer. It can also help people who are incontinent and have not found any other way of coping successfully and those for whom actually getting to the toilet has become impossible.

Figure 10
Catheter and leg-drainage bag



Modern catheters can give freedom from the need to worry about the bladder. However, using a catheter does need careful consideration as there can be problems such as infection. If a catheter is ever suggested, your doctor or nurse should discuss all other alternatives with you to enable you to weight up the advantages and disadvantages. For people with severe bladder problems, a catheter can be a positive choice and make life much easier.

Conclusion

Bladder and bowel problems are common in all sections of the population, with and without parkinsonism. With a positive outlook and determination to overcome these problems, they should not become a major limitation on your life.

Useful Addresses

The Continence Foundation

307 Hatton Square, 16 Baldwins Gardens, London EC1N 7RJ (This is the administrative office only. No personal callers please.)

Tel: 020 7404 6875 Fax: 020 7404 6876 Helpline: 020 7831 9831 (Monday-Friday 9.30am-4.30pm) Email: continence.foundation@dial.pipex.com.

www.continence-foundation.org.uk

The Continence Foundation is open weekdays from 9.00am to 6.00pm. Callers speak to nurses with a specialist knowledge of the subject, who can offer advice and assistance. The Foundation has a database of continence services throughout the UK and of products that may be of use to people with continence problems.

The Continence Foundation has a range of literature for both people who experience continence problems and the professionals who help them. It runs study days for professionals, promotes awareness of the problems of incontinence and argues in political forums the need for higher priority for continence services. It acts as an umbrella body for a number of more specialised organisations in the field.

Continence Resource Centre & Helpline for Scotland

Southern General Hospital, 1345 Govan Road, Glasgow G51 4TF

Tel: 0141 201 1861

The Disabled Living Foundation

380-384 Harrow Road, London W9 2HU

Tel: 020 7289 6111 Helpline: 0845 130 9177 (Monday-Friday 10am-4pm)

Textphone: 0870 603 9176 Email: advice@dlf.org.uk. www.dlf.org.uk

The Disabled Living Foundation is a national charity providing practical up-to-date advice and information on many aspects of living with disability for disabled and elderly people and their carers.

InconTact (National Action on Incontinence)

United House, North Road, London N7 9DP

Tel: 020 7700 7035 Fax: 020 7700 7045

Email: info@incontact.org Website: www.incontact.org

Incontact provides support and information for people with bladder and bowel problems. They publish user-friendly information and a quarterly newsletter.

There is a network of local groups and helplines.

The Parkinson's Disease Society of the United Kingdom

215 Vauxhall Bridge Road, London SW1V 1EJ

Tel: 020 7931 8080 Fax: 020 7233 9908

Helpline: 0808 800 0303 (Monday-Friday 9.30am-5.30pm)

Email: enquiries@parkinsons.org.uk www.parkinsons.org.uk

The Parkinson's Disease Society works with people who have Parkinson's, their families and carers. The mission of the Society is the conquest of Parkinson's disease and the alleviation of the distress it causes, through effective research, education, welfare and communication

The Royal College of Nursing Continence Care Forum

20 Cavendish Square, London W1M 0AB

Tel: 020 7409 3333 Fax: 020 7647 3435. www.rcn.org.uk

The RCN Continence Care Forum is a network for nurses with an interest in continence. The Forum circulates up-to-date information and guidelines to members to enable them to give research-based care to patients.

Further Reading

The Continence Foundation has a number of leaflets including:

Adult Bedwetting (leaflet) Advice on enuresis. (December 1999)

The Misbehaving Bladder (leaflet) About 'Urge Incontinence'. Includes suggested plan of management and 5-day bladder chart.

Men in Focus; Better Prostate Help (leaflet) Basic anatomy, introduction to problems with the testes, penis, prostate and fertility (March 1995)

The Pelvic Floor and Stress Incontinence (information sheet) Pelvic floor exercises and reinforcing techniques such as biofeedback, electrical stimulation and use of devices. (2000)

Penile Sheaths (information sheet) When (and when not) and how to use incontinence sheaths (1997)

Reusable Bedpans (information sheet) Advantages and disadvantages, types and use. (1997)

Single copies of the above are provided free of charge if you send a stamped addressed envelope. Ask for a copy of the Foundation's complete publications list.

The Foundation can also supply the following books (postage and packing included):

Coping Successfully with Prostate Problems by Rosy Reynolds (Sheldon Press, London, 1993) Covers all important issues for men with prostate problems. £6.99 + p&p

Bowel Control: Information and Practical Advice by Christine Norton and Michael Kamm (Beaconsfield Publishers, 1999). Illustrated short book giving details of bowel function, what can wrong, treatments and ways of coping. £5.95 + p&p.

Managing Incontinence: A Guide to Living with Loss of Bladder Control by Cheryle Gartley (Souvenir Press, London, 1998). By a group of American professionals and people living with and managing the problem. For men and women of all ages. £8.95 + p&p

Women's Waterworks: Curing Incontinence by Pauline Chiarelli (Neen Healthbooks, Dereham, Norfolk, 1991). A positive and encouraging view of stress incontinence. £6.50 + p&p.

The Parkinson's Disease Society also publishes a range of information:

Facing the Future An introductory guide to Parkinson's disease and the Parkinson's Disease Society (Parkinson's Disease Society, revised 2001) Free

Moving On An A-Z of Parkinson's for those who have had the condition for some time (Parkinson's Disease Society, 2002) Free

The Drug Treatment of Parkinson's Disease (Parkinson's Disease Society, revised 2001) Free

Parkinson's Disease and Diet (Parkinson's Disease Society, 2001) Free

Parkinson's and Dental Health (Parkinson's Disease Society, revised 2000) Free

Living with Parkinson's Disease Increasing mobility, improving speech and aids to daily living (Parkinson's Disease Society, 1992) £2.50

Parkinson's at Your Fingertips by Dr Marie Oxtoby and Professor Adrian Williams (Class Publishing, 2001) £14.99

NB: Postage must be paid, even on free items. Please send a cheque for £1.00 for 1-5 items; £2.20 for 6-10 items. Please make cheques available to PDS Sales Ltd.

To order please contact: Sharward Services, Westerfield Business Centre, Main Road, Westerfield, Ipswich, Suffolk IP6 9AB; tel: 01473 212115. They can also provide a list of all PDS publications.

The Disabled Living Foundation can supply:

Flying High – a practical guide to air travel for elderly people and people with disabilities (DLF, 1994) £2.50 (inc. p&p)

Equipped for living – a guide to equipment designed for elderly people and people with disabilities (DLF, 1996) £35.00 (inc. p&p)

PDS Publications Response Form

To ensure that the PDS is providing as good a service as possible, we like to find out what readers think of publications. The Society would be extremely grateful if you would take the time to complete this form, copy it and email it to bcormie@parkinsons.org.uk. Thank you.

Are you: (please circle)

Someone with Parkinson's: I have had Parkinson's for _____ years.

- A carer for someone with Parkinson's.
- A relative of someone with Parkinson's
- A friend of someone with Parkinson's
- A professional working with people with Parkinson's

The name of the publication: LOOKING AFTER YOUR BLADDER AND BOWELS IN PARKINSONISM

Where did you get the publication from? (please circle)

Sharward Services Information Day PDS Branch Hospital
Doctor's Practice Pharmacy/Chemist Other

How useful have you found the publication?

(please circle a number: 1 is not very useful, 7 is very useful)

1 2 3 4 5 6 7

Which section did you find most helpful?

Which section did you find least helpful?

Are there any topics you felt should have been covered but weren't?

.....

Have you found the the publication easy to read / use?

.....

Any other comments on this publication?

.....

Is there another related topic which you think the PDS should provide a booklet/factsheet on?

.....

Many thanks for your help. You do not have to fill out your details below, but if you do so, it will help us ensure we give a better service in future.

Name:

Date of Birth:

Address:

.....**Postcode**

Telephone:.....**E-mail**.....

Are you a PDS member? (*please circle*) **Yes No**

Would you like information on becoming a PDS member? **Yes No**

The Parkinson's Disease Society of the United Kingdom is registered under the Data Protection Act and all information you supply through this response form will be treated under the terms of the Act. The PDS will hold this data on its own database, and will not release it to any commercial organisation.

The information supplied will be used for monitoring services.