Welcome to today's Webinar

Your Presenter is: Katherine Smith
Your Facilitator is: Chris Porter

Acknowledgement

We acknowledge and pay respect to the traditional custodians past and present on whose lands we meet today.

We acknowledge the deep feelings of attachment and the relationship of Aboriginal people to country and respect the cultural authority of the elders in each community.
Bladder Changes in MS
What’s Normal?

What is the Urinary Tract?
Bladder dysfunction associated with multiple sclerosis is caused by the interruption of nerve pathways / impulses that control the passing of urine (micturition).

Bladder dysfunction is one of the most common symptoms associated with multiple sclerosis. Surveys have indicated that 60 - 90% of people with multiple sclerosis have bladder dysfunction at some stage.
1. Failure to store (detrusor overactivity)

2. Failure to empty - doesn’t empty properly (retention-detrusor failure)

3. A bladder that combines the 2 types of dysfunction as above (detrusor sphincter dyssynergia)

What Happens in a Bladder Assessment?

“*We need something for his verbal incontinence. He has a bladder control problem.*
Types of Bladder problems in MS

. FAILURE to STORE  Overactive bladder

.FAIlure to EMPTY

COMBINATION of BOTH  Detrusor Sphincter Dysynergia

Unstable or Overactive Bladder: Treatment

- Anticholinergic medications:
  - Oxybutnin (Ditropan) (Oxytrol patches)
  - Tolterodine (Detrusitol)
  - Solifenacin (Vesicare)
  - Mirabegron (Betmiga)

- Botox injection
Retaining Urine: Symptoms

- Frequency
- Urgency
- Recurrent urinary tract infections
- Occasional overflow incontinence
- Getting up at night

Detrusor Sphincter Dyssynergia: Symptoms

- Frequency
- Urgency
- Recurrent urinary tract infection
- Sudden flooding incontinence
- Getting up at night to pass urine
Detrusor Sphincter Dyssynergia: Treatment

- Medication
- Clean, intermittent catheterisation
- Permanent Indwelling Catheter (Urethral or Supra Pubic)

Urinary Tract Infection: Symptoms

- Burning
- Stinging
- Concentrated, smelly or cloudy urine
- Passing small amounts of urine
- Increased passing of urine at night
- Urgency
- Frequency
- Fever

Fatigue
Worsening of MS Symptoms
Return of recent symptom
Some Simple Things to Help Reduce Infections

- Drink plenty of clear fluid
- Do not restrict fluids
- Add lemon to water
- Cranberry
- Probiotics
- Keep antibiotics to a minimum

Basic First Aid for Bladder Problems

- Review caffeine intake
- Review fluid intake
- Elevate feet
- Avoid constipation
- One change at a time
- Diet and exercise
- Talk to a doctor, a MS Nurse or a continence nurse
Recommendations

Multiple Sclerosis Limited

Other Helpful Titbits

- Helpful internet sites:
  - [www.continence.org.au](http://www.continence.org.au)
- Useful apps for smart phones:
  - Wheelmate - tells you where the nearest accessible toilet is to your current location
  - Cathnow - an alarm reminds you to catheterise
  - National Public Toilet Map
Further Advice

- MS Connect 1800 042 138
- National Continence Helpline 1800 330 066
- General Practitioner

Summary

- Bladder - How does it work
- How MS affects the bladder
- First aid
- Where to get help
In the Library & Publications section of our website you can find information about:

- MS Library services
- How to borrow both eBooks and print books on topics such as wellness, and managing multiple sclerosis and its symptoms
- Accessing our online library catalogue
- MS publications, including *Intouch* magazine, email newsletters, booklets and information sheets

Visit our website for more information **www.ms.org.au**
Multiple sclerosis may cause a myriad of symptoms and varies greatly from person to person. The authors demystify the illness and offer practical solutions and guidance based upon their extensive combined clinical and research experience.
The NDIS is the Biggest social reform changing the way supports and services are purchased and delivered for people with a disability

- The NDIS has commenced rolling out across NSW, ACT, Victoria and Tasmania – it will occur in different ways across the regions for people under 65 years of age
- MS is here to help you understand what the NDIS means, and assist you to prepare for a planning meeting
- We have resources available on our website www.ms.org.au click on the large NDIS button
- MS is registered with NDIA to deliver Support Coordination (all regions), Residential Respite, Social Support Day Program (Vic) Exercise physiology and personal training (NSW) Specialist Continence Assessment (NSW), Physiotherapy and Occupational Therapy (NSW and Vic).

Want to learn more? Please call MS Connect on 1800 042 138
Basic First Aid for Bladder Problems

Knees higher than hips
Lean forward and put elbows on knees
Bulge abdomen
Straighten spine
Master Locksmith Access Key (MLAK)

The Master Locksmiths Access Key (MLAK) is an innovative system that enables people with disabilities to gain 24/7 access to a network of public facilities.

The MLAK system has been fitted to elevators at railway stations, accessible toilets in Council municipalities and National Parks and in adaptive playground equipment (Liberty Swing - see below) across Australia.

People with a disability are able to purchase an MLAK master key which will open all toilets, playgrounds and other facilities which are fitted with this specially designed lock.

MLAK keys are available for purchase from Business Members of the Association. To find your nearest Master Locksmith, please make use of our Locksmith Search facility.

Who’s Eligible?

Eligibility is restricted to people who have a disability or have written authority from:
- a doctor
- a disability organisation
- community health centre
- the owner or management of a building with an accessible toilet on site

MLAK Facilities

Spinal Cord Injuries Australia maintains a directory of MLAK-enabled facilities across Australia.

Further Information

For further information, please contact the Master Locksmiths Association (03) 9338 8822 or Spinal Cord Injuries Australia on (02) 9661 8665 or 1800 819 775

National Public Toilet Map

The National Public Toilet Map shows the location of more than 14,000 public and private public toilet facilities across Australia. Details of toilet facilities can also be found along major travel routes and for shorter journeys as well. Useful information is provided about each toilet, such as location, opening hours, availability of baby change rooms, accessibility for people with disabilities and the details of other nearby toilets.

The National Public Toilet Map is also available for Apple’s iPhone. Just go to the App Store on your iPhone or use iTunes to download the National Public Toilet Map App. It’s free!

Liberty Swings

The Liberty Swing is a world-first Australian innovation – a swing that allows children in wheelchairs the opportunity to experience the joy of having a swing in the park.

The Liberty Swing can only be utilised with the use of the MLAK Key. If you require a key, please see your nearest Master Locksmith.

Looking for a Liberty Swing in your State or want further information? Visit the Liberty Swing Website or download the PDF below.
Bladder

Managing your bladder

A guide for people with MS
We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

This book has been provided free by the Multiple Sclerosis Trust, a small UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

**MS Trust information service**

*Helping you find the information you need*

The MS Trust offers a wide range of publications, including a newsletter *Open Door*, which provides an ongoing update on research and developments in MS management. In addition it contains articles from people with MS and health professionals.

For a full list of MS Trust publications, to sign up for *Open Door* and much more visit our website at [www.mstrust.org.uk](http://www.mstrust.org.uk)

**Freephone:** 0800 032 3839
(Lines are open Monday – Friday 9am–5pm)

**Email:** infoteam@mstrust.org.uk

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Introduction
Around 75 in every 100 people with MS experience bladder problems and these can have a big impact on life. However this is an area where successful treatment is available and straightforward lifestyle changes can make a real difference.

This book aims to give you an insight into why bladder problems can be part of MS, and provides a practical approach to helping you successfully manage your bladder problems.
It explores:

- how to monitor symptoms and recognise factors that might make them worse
- simple strategies that can improve your bladder problems
- treatment options that might be relevant to you
- how working in partnership with the appropriate health professionals can be the key to finding the approach that works best for you.

It includes comments from people with MS who know what it is like to live with bladder problems and draws on the experience of health professionals including MS specialist nurses and continence advisors.

Toilet taboo – talking about bladder problems
Toilet talk is common when we have young children but we don’t expect to have to think about it again in later life. Many people feel a sense of shame and embarrassment about bladder problems and feel awkward raising them with health professionals.
Research has shown that six out of ten people aged 40 or over with bladder problems have never discussed these with a doctor or nurse.

‘Fear of other people’s reactions is what can stop you talking about bladder problems but for me being honest and open really helped’

It is OK to talk about this aspect of life and many people are pleased to be able to share their stories.

‘Out with very close friends I was talking about my bladder problems when the couple close by asked if they could join us, they were so relieved that someone was talking about this openly and wanted to share their experiences’

All health professionals should understand that MS has an impact on how the bladder works so don’t be shy in raising this. Many hospitals and local primary care services have a continence advisor, or continence nursing service, that deals specifically with bladder and bowel problems. In some areas you may be able to refer yourself directly to continence services, or else your MS specialist nurse or GP can make a referral.

Your MS specialist nurse, GP or continence advisor are all experienced in dealing with bladder problems and should be able to put you at your ease.

How to start the conversation – what people say ...

‘I’ve got problems with water works’

‘I just tell it like it is – I feel it’s best to be honest’
‘I tend to just say “I can’t pee”’

‘Say whatever comes to mind! Depends who it is!’

When should I contact a health professional?
If you are worried about how your bladder problems are affecting your life, if things have changed or you have any questions about medication you are taking do not hesitate to contact your health professional. Specifically this might be if:

- you experience urine leakage, and you avoid important activities because of it
- you often feel urgency to urinate and rush to a bathroom, but sometimes don’t make it in time
- you go to the toilet much more often than you used to, during the day and at night
- going to the toilet is painful or your urine has an unusual smell
- you feel the need to urinate, but you’re unable to
- you notice that your urine stream is getting weaker, or you feel as if you haven’t fully emptied your bladder.

What will happen at my appointment?
When you talk to your health professional it is important to be clear about your symptoms and how long they have been affecting you. You could tell them how your bladder problems affect your life, for example making things difficult at work. Keeping a diary of your bladder symptoms and sharing it can help you to describe this (see page 17 for more on keeping a bladder diary).
Some people think that bladder problems are an inevitable part of ageing or after having children – this is not necessarily the case and not all bladder problems are caused by MS.

Here are some of the common things that can cause bladder issues:

- enlarged prostate in men
- pregnancy and childbirth can weaken pelvic floor muscles in women
- infection in the urinary tract (water infection)
- abdominal surgery
- caffeine and alcohol consumption.

Your health professional will take a full history of your symptoms, and they might ask you to keep a detailed bladder diary for a short period of time. They might also carry out the following investigations.

**Urine testing** – a ‘dipstick test’ is used to test a sample of urine and detect any infection known as a urinary tract infection. Your health professional will ask for a sample of urine. This is tested for bacteria using a small, chemically treated stick (dipstick) that is dipped into the urine sample. If bacteria are present it will change colour.

**Check for efficient bladder emptying** – if there is no sign of a urinary tract infection, the amount of urine left in your bladder after urinating will be measured. This is carried out with a simple ultrasound scanner.

If there is less than 100ml left after the bladder has been emptied, then the symptoms are more likely to be due to problems storing urine.
If there is more than 100ml left after emptying, then the symptoms are likely to be due to problems with emptying the bladder.

The results will enable your health professional to understand the cause of the problem and to work with you to find the most appropriate approach to treatment.

**How the bladder works**

The bladder has two main functions:

- Storing urine
- Emptying urine at an appropriate time

The kidneys filter the blood to collect waste products and create urine, which is then stored in the bladder. The bladder is a bag-like muscle (the detrusor muscle) that can expand and contract. When urine reaches a certain level, nerve endings in the bladder wall are stimulated and send a signal to the part of the spinal cord that controls the bladder emptying reflex.

This area of the spinal cord then sends messages to the brain, making you aware of the need to empty your bladder. These messages can be controlled by the brain until there is an opportunity to get to a toilet. When a suitable occasion arises, the brain sends messages back to the spinal cord reflex centre and onto the bladder, telling the bladder to contract and the urethral sphincter (the muscle at the bottom of the bladder that acts like a tap or valve) to relax. This allows urine to flow out through the urethra, the tube that connects the bladder to the
outside of the body. Health professionals call this voiding or micturation, we might call this peeing or urinating.

- an adult will usually go to the toilet between six and eight times a day depending on the level of fluid intake
- a healthy bladder has a capacity of between 300–500ml of fluid, equivalent to between half a pint and a pint and the urge to urinate is felt when the bladder is around two thirds full
- the bladder only contracts at emptying
- the bladder is rarely completely empty, with about 10% of capacity left after a visit to the toilet.
What can happen in MS?
MS can damage areas of the spinal cord or brain that play a part in controlling your bladder function and the symptoms you experience will depend on the damage that has occurred. Bladder problems can be divided into two types; those relating to the storage of urine and those relating to emptying of urine.

- **Storage problems** include urgency (the need to go to the toilet immediately) and frequency (needing the toilet often) during the day and night (nocturia). Occasional incontinence may also occur, where bladder control is lost and urine leaks out.

- **Emptying problems** include hesitancy (difficulty passing urine) and retention (a feeling of incomplete bladder emptying).

Some people experience a combination of these symptoms.

**Urgency and frequency**
You have a sudden urge to go to the toilet or are unable to hold on and reach the toilet in time.

*‘I feel as though my bladder has a life of its own’*

You need to use the toilet more than eight times a day, sometimes as soon as half-an-hour after already going.

These symptoms result from problems with storage of urine. The bladder becomes overactive and has a tendency to spasm or contract unpredictably and sometimes uncontrollably.
Messages are interrupted between the bladder emptying reflex in the spinal cord and the part of your brain that has control over when you empty your bladder. This means that reflexes tell the bladder muscle to contract as soon as it starts filling.

**Investigations**

Check for infection – as symptoms from urinary tract infections can be similar to those of other bladder problems – the dipstick test is used for this.

Check volume of urine left in the bladder after emptying (using ultrasound) – if this is less than 100ml problems are most likely to be due to urine storage.
Treatment options

Medication

Antimuscarinic drugs block the messages that start bladder contractions and so reduce how frequently someone needs to empty their bladder; they are also thought to reduce sensations of urgently needing to reach the toilet. These drugs are taken as tablets or, in some instances, administered through skin patches. Drugs include oxybutynin (Ditropan, Lyrinel XL), tolterodine (Detrusitol, Detrusitol XL), solifenacin (Vesicare), fesoterodine (Toviaz), trospium (Regurgin, Flotros). It can take up to four weeks to see the full benefits of treatment. Side effects can include constipation, dry mouth, and dry eyes in some people. Studies have shown that solifenacin and trospium produce fewer side effects.

Mirabegron (Betmiga) is a drug with a different mode of action and is available if antimuscarinics haven’t been effective or if the side effects are difficult to tolerate.

Desmopressin is a synthetic hormone that regulates the production of urine and is effective in treating day and night time frequency. It may be suggested if other drugs don’t work well. Desmopressin is available as tablets or nasal spray. Use is limited to once in 24 hours and it is not licensed for use in people over 65.

Bladder injections

Botulinum toxin type A (botox) is licensed as a treatment for overactive bladder due to MS where antimuscarinic treatments have not been effective. Botulinum toxin stops nerve conduction to muscles and can freeze the contraction of muscles. Studies
have indicated that this treatment improves urinary continence in people with MS. One study also indicated that botulinum toxin injections significantly reduced the incidence of urinary tract infections.

The procedure involves around 30 injections into the bladder wall from the inside. The doctor will use a fine tube, also containing a very small telescope, inserted through your urethra into your bladder to give the injections. This is usually carried out under local anaesthetic. The benefits generally last between 6 and 12 months after which the procedure can be repeated.

This treatment affects bladder emptying and so people will need to carry out clean intermittent self-catheterisation (see page 14 for more on catheters).

‘This was the best thing for me – it means I’m in control of my bladder at last’

Nerve stimulation
Where antimuscarinic medications have not been effective and someone doesn’t want to try botulinum toxin, percutaneous tibial nerve stimulation (PTNS) may be offered.

An electric current is passed through a small needle inserted into the posterior tibial nerve in the ankle, which stimulates the nerves around the bladder and pelvic floor.

It requires at least 12 weekly sessions lasting 30 minutes each.

Effects do not last long after the sessions have stopped and more sessions may be needed.
Hesitancy and retention
You don’t feel as though your bladder has emptied fully when you’ve been to the toilet.

The flow of urine is interrupted or slow, or starting to pass urine takes longer than normal.

‘I can be absolutely desperate to go to the loo and once I get there – I can’t go!’

These symptoms occur because there are problems with emptying the bladder. Typical experiences include a reduced flow or an interrupted stream of urine, often accompanied by a feeling of not completely emptying the bladder.

For some people, these symptoms may also be combined with feelings of needing to find a toilet quickly and often. This can lead to urine leaks in spite of earlier efforts to empty the bladder.

There are several possible causes for this difficulty in emptying the bladder:

• The area of the spinal cord that controls the bladder emptying reflex becomes damaged. As there is no reflex to urinate, the bladder becomes very full but you are unaware of how full it is, so leakage of urine may occur.

• Messages from the brain are confused, so that when the bladder muscle contracts to start emptying, the valve which allows urine out of the bladder (the urethral sphincter) closes the outlet at the same time, effectively blocking or interrupting the bladder’s attempts to empty. This lack of coordination between the different muscles is called dyssynergia.
For some people while urine may be easy to pass and may flow normally, the bladder does not empty properly (this is known as retention). The area of the spinal cord which controls the emptying reflex becomes damaged and as a result the bladder muscle stops contracting before the bladder is empty.

Scarring in the reflex area of the spinal cord interrupts the instruction to empty the bladder.

**Investigations**

*Check for infection* – as symptoms from urinary tract infections can be similar to those of other bladder problems – the dipstick test is used for this.
Check volume of urine left in the bladder after emptying (using ultrasound) – if this is greater than 100ml problems are most likely to be due to bladder emptying.

**Treatment options**

**Catheters**

Clean intermittent self-catheterisation (CISC) is the term used to describe passing a catheter into the bladder via the tube that connects the bladder to the outside of the body (the urethra) – draining off urine, and then removing the catheter. This is a procedure that you carry out yourself. It is ‘intermittent’ because this normally takes place several times a day using disposable catheters. The procedure should be taught by a nurse or continence advisor. Using a catheter can seem daunting at first but you will be fully supported by your health professionals.

**Benefits of intermittent catheter use** – using a catheter can give you better control over your bladder leading to improved confidence and less need to ensure that toilets are closely available. Using an intermittent catheter can also reduce the number of urinary tract infections by ensuring that the bladder is fully emptied.

‘*Using catheters means my bladder empties properly, and I get less of those awful water infections*’

‘*The best thing I have used. I can empty my bladder before I go to bed and have a good night’s sleep*’
Possible drawbacks – using an intermittent catheter can seem daunting at first because you might be anxious or embarrassed but specialists will provide reassurance and support. This technique does require someone to have good manual dexterity. Where clean intermittent self-catheterisation is difficult to manage safely, an indwelling catheter may be recommended. These are only used after less invasive methods have been exhausted. Indwelling catheters are either inserted via the urethra or through the abdominal wall when they are known as suprapubic catheters and remain in place. It can transform life but regular review and support is required.

‘Suprapubic catheter is fantastic for the waterworks – and saves energy by not having to get to the loo in time, 10 times a day’

Suprapubic vibration
There is some evidence to suggest that a vibration device or buzzer, such as the Queen Square bladder stimulator, placed over the pubic area can help the sphincter (valve) to relax and improve emptying if hesitancy is a problem.

Bladder accidents – incontinence
Many people with MS experience continence difficulties, some of which can cause occasional incontinence. Fear of having an accident can be one of the most worrying things. There are many different types of products available to help you manage this which can be valuable as a backup whilst you are undergoing treatment and for some people these may also be useful in the long-term.
These include continence pants and pads, which come in a variety of sizes and shapes, washable and disposable pads. There are also a number of products such as penile sheaths for men (also known as external catheters or conveens) that can help contain urinary leakage, and urinals for women that you can use when you are out and about. These are non-invasive and discreet. More information about all of these products is available from your local continence service, from the Bladder and Bowel Foundation and from the Continence Products Advisor website. (See sources of help and support page 24).

If you need to get to the toilet in a hurry, clothing that’s easy to undo may also help prevent accidents.

‘I’ve found that zips or Velcro instead of buttons on flies are a big help’

**Urinary tract infection (UTI)**

UTIs are common in MS. It is important that urinary tract infections are detected early and treated appropriately as they can worsen other MS symptoms. For example a urinary tract infection is one of the most common causes of worsening of spasms or stiffness; it can precipitate a relapse or make thinking difficulties worse.

People with a UTI may experience some or all of the symptoms below, although for some people there are no symptoms at all:

- frequent urge to urinate
- painful or burning sensation when urinating
generally tired or washed out most of the time
painful bladder or abdomen even when not urinating
passing a small amount of urine even though there is an urge to pass more
milky or cloudy urine that smells unusual
high temperature.

To check for a UTI, your health professional will ask for a sample of urine. This is tested for bacteria using a small, chemically treated stick (dipstick). This is dipped into the urine sample and if bacteria are present it will change colour.

Urinary tract infections are treated with a course of antibiotics. If symptoms persist you many need to try a different antibiotic. Drinking plenty of liquids to flush out the bladder or increasing the frequency of self-catheterisation may also help.

**Getting to know your bladder**

**Keeping a bladder diary**

This can give you an overview of how your bladder problems affect you over time. You can share it with your health professionals to demonstrate accurately what your bladder patterns are.

Write down what you had to drink, eat, any medication you take, when you go to the loo, and any problems with stopping or starting.

If you make any changes, for example the amount of caffeine you drink or starting a new medication, the diary can help you to see how this affects your bladder symptoms.
It can be useful to know how much a cup/glass/mug holds as sometimes we believe we are drinking a lot more than we actually are.

You might use quite a formal chart –

<table>
<thead>
<tr>
<th>Time</th>
<th>Food or drinks</th>
<th>Toilet visits</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>7am</td>
<td>Cup of tea</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9am</td>
<td></td>
<td>Yes</td>
<td>Needed to rush</td>
</tr>
</tbody>
</table>

Or something more informal.

I write briefly what I’m doing differently – eating, drinking or exercising.

There are also apps available to enable you to monitor this on your mobile phone – (see sources of help and support page 24).

Tips to improve bladder function

There are simple lifestyle changes that can make a real difference to your bladder problems.

My MS specialist nurse told me to cut down on caffeine and I just couldn’t believe the difference it made.

Food and drink

Drinking too much can make bladder symptoms worse – increasing the number of visits to the toilet and the urgency to urinate. On the other hand drinking too little can lead to concentrated urine that irritates the bladder and creates a good environment
for infection. The general advice is to drink around one to two litres, or six to eight glasses, of liquid per day (more if the weather is hot or if exercising). Food and drink that can irritate the bladder and are best avoided include:

Drinks that contain caffeine – drinks such as coffee, tea, green tea, hot chocolate can cause irritation directly to the bladder lining. 
Alcohol – particularly white wine. 
Fizzy drinks – carbonated and highly coloured drinks have been shown to worsen some bladder symptoms. 
Acidic fruit and juices – citrus fruits including grapefruit, orange, lime, lemons and tomatoes. 
Spicy foods – studies suggest that people who avoid spicy foods, like curry, chilli pepper and cayenne pepper, may reduce their bladder symptoms.

Record when you eat or drink any of these and see if they affect you.

Weight 
Being overweight can increase pressure on the pelvic floor muscles and can result in stress incontinence.

Smoking 
Nicotine in cigarettes can irritate the bladder.

‘Changing little things can make a big difference’

Pelvic floor excercises 
The pelvic floor is a sheet of muscles that extend from the tail bone (coccyx) at the bottom of the spine to the pubic bone (at the front). They form the ‘floor’
to the pelvis and support the bladder and bowel. Pelvic floor muscles give you control when you urinate. They relax at the same time as the bladder contracts (tightens) in order to let the urine out. In MS neurological damage can result in weakness to the pelvic floor as a result of poor transmission of messages to the muscles by damaged nerves, mainly within the spinal cord. However this can also be made worse by other factors such as having children, getting older or having surgery in this region of the body. Where bladder symptoms are mild, pelvic floor exercises can be helpful. Men and women can do pelvic floor exercises.

It will take several weeks of regular exercise to regain strength in your pelvic floor muscles.

**Pelvic floor exercises**

You can feel your pelvic floor muscles if you try to stop the flow of urine when you go to the toilet.

To strengthen your pelvic floor muscles, sit comfortably and squeeze the muscles 10–15 times in a row.

Do not hold your breath or tighten your stomach, buttock, or thigh muscles. When you get used to doing pelvic floor exercises, you can try holding each squeeze for a few seconds.

**‘Holding on’ – bladder training**

The aim of bladder training is to increase the amount of time between going to the toilet. You gradually increase the time between urinating (this can be just by five minutes). It may take weeks or months to be effective but your continence advisor or MS
specialist nurse can put together a timetable to support you to achieve this.

‘When you go to the toilet, wait for a minute or so and try to go again, you may find a little more comes out and this can reduce the frequency of visits to the toilet’

Other approaches
Hyperbaric oxygen therapy
Hyperbaric oxygen (HBO) therapy involves breathing oxygen through a mask in a pressurised chamber, similar to a diving bell. Treatment usually consists of an initial course of around 20 sessions, each lasting an hour, spread over one month. Follow-up treatment is then needed at less frequent intervals. Although anecdotal evidence suggests that some people find it helpful, particularly for fatigue and bladder symptoms, research has failed to find scientific evidence that it is effective for MS. In the UK, hyperbaric oxygen therapy is available through most MS Therapy Centres (see sources of help and support page 24).

Working with your health professionals
Ideally before starting any treatment for bladder problems you should have the opportunity to consider all the different treatment options, ask all the questions you need to and discuss any concerns you may have. It is also really valuable to have realistic expectations of what the treatment can offer and what the drawbacks may be. Knowing clearly what you would like the treatment to achieve can be helpful in ensuring that you and your health
professionals are working together towards the same goal.

‘I want to be able to see a film at the movies without having to go to the toilet half way through’

It can be useful to think of questions in advance and take them to your appointment for example:

- how long will it take to see any response?
- when will we review how things are going?
- what if the treatment doesn’t work?
- how can I get in touch if I have any problems? Is there a direct number or email?

If you don’t understand what was said do ask for an explanation. You can also ask for copies of any letters sent between your GP and other health professionals including hospital consultants. This keeps you informed and helps you to remember what was said.

You should be able to discuss or review your treatment and management at regular intervals or when circumstances change. This can include changing your mind about treatment.

‘If at first it doesn’t succeed try, try and try again! Don’t be afraid to ask your MS specialist nurse or GP to change your medication if you feel its not working’

It is important to continue with treatment but if it’s not working ask what’s next. It can take some time to find the approach that works best for you.
Living well with bladder problems
Self esteem and depression
Bladder problems can have a major impact on self esteem, which might already have been affected as a reaction to all that living with MS brings. According to continence nurses, as many as seven out of ten people with incontinence are affected by depression. Depression involves persistent sadness lasting more than two weeks, accompanied by other symptoms such as an altered sleep pattern, feelings of hopelessness, reduced energy and the inability to concentrate and to take pleasure in anything. If this is how you are feeling talk to your MS specialist nurse or GP as there are many ways to successfully treat depression.

Work
If you have a diagnosis of MS you are covered by the Equality Act 2010 and your employer is required to make reasonable adjustments to the work place to ensure that you are not put at a disadvantage because of your diagnosis.

It is up to you whether or not to disclose your diagnosis of MS but if you are making frequent or longer toilet breaks that others have noticed, this might be the time to tell your employer. Requesting that you have a desk near to the toilets can be seen as a reasonable adjustment.

Sexuality
Worrying about wetting yourself can be a sexual turn off. However going to the toilet before sex, or self–catheterising can help with this. Knowing that your bladder has been emptied can make you feel more
relaxed and ease the worry. Talking about your fears with your partner can be really helpful.

Sources of help and support

People

MS specialist nurse – MS specialist nurses provide specialist clinical advice and support to people with multiple sclerosis. They often act to coordinate services for people with MS, referring someone on to a doctor, therapist, or other appropriate services. To find your MS specialist nurse see the map of MS services on the MS Trust website. 

www.mstrust.org.uk/map

Continence advisor – continence advisors are experienced, qualified nurses who have undertaken specialist training to help people with continence problems. Many services accept self referral or ask your GP or MS specialist nurse to refer you.

Specialist physiotherapist – physiotherapists experienced in the assessment and treatment of neurological conditions. They can devise and support you with exercise, pelvic floor and bladder training programmes. Your GP or MS specialist nurse can refer you.

Urologist – doctors who specialise in treating disorders of the urinary tract such as bladder and continence problems. Urology also covers disorders of the male reproductive system such as erectile dysfunction.
Organisations

Bladder and Bowel Foundation
The Bladder and Bowel Foundation is a charity providing information and support for people with all types of bladder and bowel related problems and their families, carers and health professionals. They have a confidential helpline staffed by specialist continence nurses and physiotherapists.
Helpline: 0845 345 0165
www.bladderandbowelfoundation.org

Cystitis and Overactive Bladder Foundation
The Cystitis and Overactive Bladder Foundation has message boards to enable people to support each other online and also offers an advice line.
Helpline: 0121 702 0820
www.cobfoundation.org

Multiple Sclerosis Therapy Centres
MS Therapy Centres are local charities that provide a range of non drug therapies for symptom management. Therapies offered by Centres vary but often include hyperbaric oxygen therapy and physiotherapy as well as support for people with MS and their families. To find your nearest Therapy Centre see the map of MS services on the MS Trust website.
www.mstrust.org.uk/map

Disability Rights UK
Disability Rights UK are responsible for the National Key Scheme (NKS) that was previously run by RADAR. For a small charge, a key is provided that gives people with a disability access to many locked public toilets around the country. A guide to the location of toilets in the NKS scheme is available to purchase.
www.disabilityrights.org
Products
Continence Product Advisor
The Continence Products Advisor website is a not for profit collaboration between the International Consultation on Incontinence and the International Continence Society. The website provides evidence based information on a wide range of continence products.
www.continenceproductadvisor.org

PromoCon
PromoCon is a national service, working as part of Disabled Living, which offers product information, advice and practical solutions to both health professionals and people who have continence difficulties.
Helpline: 0161 607 8219
www.promocon.co.uk

Toilet card
A toilet card, sometimes called a ‘no waiting card’ or a ‘just can’t wait card’, is a discreet credit card sized card which states that the holder has a medical condition and needs to use the toilet urgently. The card will not guarantee preferential treatment but most places will usually try to help. Produced by the Bladder and Bowel Foundation.

Mobile phone apps
Apps have been developed to help locate the nearest toilet, for example the National Key Scheme app and to keep track of bladder function – bladder diary apps.
Resources from the MS Trust

MS Trust Information Service
If you have specific questions on any aspect of MS, contact our team of information officers on 0800 032 3839 or infoteam@mstrust.org.uk

MS Trust books and factsheets are free and can be ordered by ringing 01462 476700 or by email at info@mstrust.org.uk. All titles can be read or ordered online at www.mstrust.org.uk/pubs

Keep up to date with news about research and the world of MS by signing up for Open Door, the MS Trust’s free quarterly newsletter, or our weekly email alerts. Ring 01462 476700, email info@mstrust.org.uk or signup online at www.mstrust.org.uk/in-touch.

Other resources
- A-Z of MS – this covers a wide range of information about symptoms, management and sources of support www.mstrust.org.uk/a-z
- Exercises for people with MS – www.mstrust.org.uk/exercises
- Map of MS services – includes the locations of MS specialist health professionals including MS specialist nurses and support www.mstrust.org.uk/map
- Diet factsheet
- Depression factsheet
- Managing your bowels: a guide for people with MS (book)
- MS and me: a self-management guide to living with MS (book)
- Sex and MS: a guide for men (book)
- Sexuality and MS: a guide for women (book)
About the editor

Lynn Fox, Information Officer, MS Trust.
The MS Trust is a UK charity for people with MS, their family and friends. The MS Trust Information Service offers a personalised enquiry service; produces a wide range of publications including Open Door, a quarterly newsletter; and provides web based information.

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