



# Living with NMO

## Bladder and Bowel Issues





The Walton Centre in  
Liverpool and John

The Walton Centre   
NHS Foundation Trust

*Excellence in Neuroscience*



Oxford University Hospitals   
NHS Trust

Radcliffe Hospital in Oxford are recognised as  
specialist NHS centres in the diagnosis and care of  
patients with Neuromyelitis Optica (NMO) in the UK

Please contact either centre if you have any further  
concerns regarding your diagnosis or symptoms.

This booklet can be provided in other formats including  
large print or as an audio file. Please contact either  
specialist centre for details or go to [www.nmouk.nhs.uk](http://www.nmouk.nhs.uk)

**NMO Service**  
Walton Centre Foundation Trust  
Lower Lane  
Fazakerley  
Liverpool L9 7LJ  
Contact: 0151-529-8357  
[nmo.advice@thewaltoncentre.nhs.uk](mailto:nmo.advice@thewaltoncentre.nhs.uk)

**NMO Service**  
John Radcliffe Hospital  
West Wing  
Headley Way  
Oxford OX3 9DU  
Contact: 01865-231905  
[nmo.advice@ouh.nhs.uk](mailto:nmo.advice@ouh.nhs.uk)



**NMO SPECTRUM-UK**  
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**NMO SPECTRUM-UK**  
working to support the NHS and  
sufferers of NMOSD throughout  
the UK.

No **MO**re Suffering Alone

# Introduction

Approximately 80% people who have had transverse myelitis (TM), a rare condition involving inflammation in the spinal cord, will experience bladder and/or bowel problems at some time. These symptoms can be difficult to talk about and have a big impact on everyday life. However, with the right information and support, the majority of bladder and bowel problems can be successfully managed to improve your quality of life.

Continence is defined as the individual's ability to control his or her bowel or bladder functions and retain urine or faeces until a suitable time and place is found.

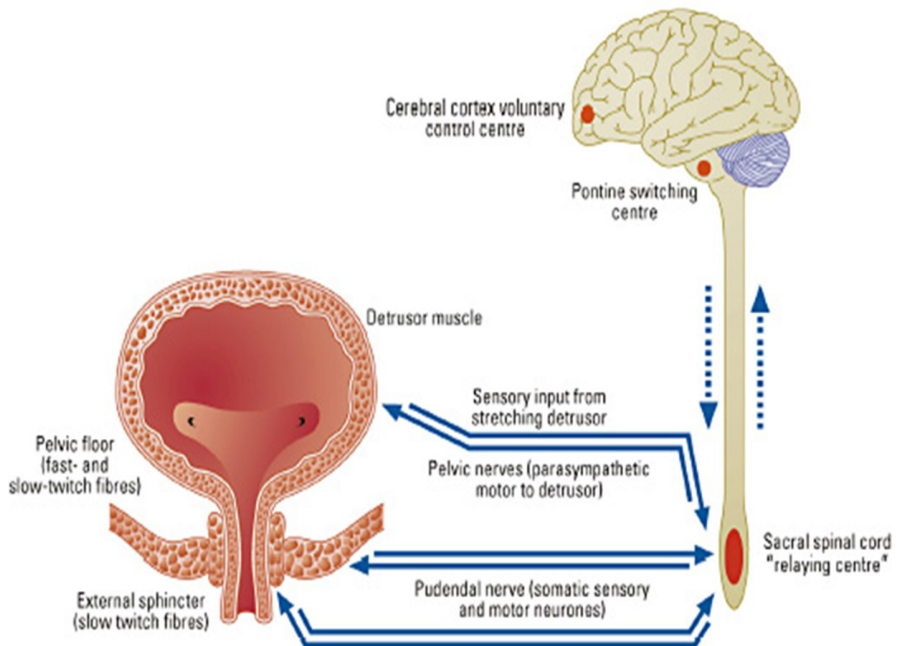
**This booklet aims to give you information on:**

- \* cause of bladder and bowel problems in NMO
- \* offers some practical advice
- \* treatment options on managing these problems

# Biology of the problems of Myelitis

The bladder has 2 main functions

- \*Storing urine
- \*Emptying urine at a convenient and appropriate time



Urine is created in the kidneys by filtering waste out of the blood. This urine is then carried down to the bladder where it is stored for elimination at a convenient time and place. The bladder is a stretchy balloon of muscle which expands as it fills.

The nerve endings in the base of the bladder are stimulated as it fills and they send a message to the brain to say that you need to pass urine. One of two things then happens in a normal bladder.

Either:

- \* You find a suitable place and empty your bladder. The bladder muscle (detrusor) contracts to squeeze out the urine and the sphincter relaxes to allow the urine out
- OR:

- \* Your brain sends messages to stop the bladder emptying until a suitable time and place is found. The detrusor muscle relaxes and the sphincter stays closed.

In a person with **Transverse Myelitis** these messages can be interrupted leading to issues with emptying the bladder. This can cause retention of urine and incomplete emptying of the bladder. It can also lead to the bladder leaking or spontaneously emptying.



# Bladder Symptoms

**These are a few examples of what people say:**

- \* “I have to rush to get to the toilet” (urgency)
- \* “I spend all day running back to the toilet” (frequency)
- \* “I have to go again a few minutes after I think I’ve finished” (double emptying)
- \* “I think I need to go, but when I get there it takes me ages to start” (hesitancy)
- \* “I sometimes can’t control my bladder and leak urine” (leakage)
- \* “I don’t feel like I’m emptying my bladder” (retention)
- \* “I’m up all night going to the toilet’ (nocturia)



# Quality of life and bladder issues in NMO

50% of people with Neuromyelitis Optica (NMO) are significantly affected by urinary symptoms. The bladder symptoms affect a person's quality of life, the most distressing of these being:



- \* ability to travel
- \* embarrassment eg. having to change their underwear
- \* employment
- \* social interaction
- \* family interactions
- \* worried to leave the house
- \* personal relationships
- \* cost of equipment/cleaning

# Management

Although you may feel embarrassed, it is worth discussing your bladder symptoms with the nurse or doctor. There are several options available to manage

symptoms effectively depending on the issue.



Medications

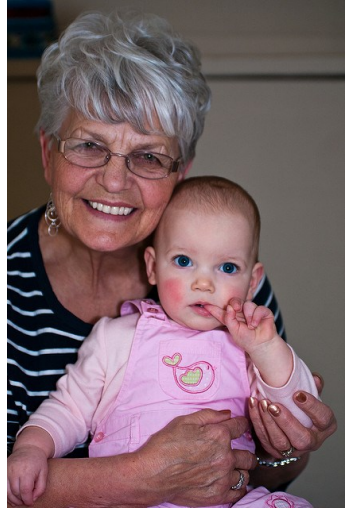
(called Antimuscarinics) may be given where suitable to calm the bladder and give you more time to get to the toilet. Other medications can help slow urine production during the night.

There are also a range of medical devices which can help manage incontinence. These include a urinary sheath for men which fits over penis and drains the urine into a leg bag whilst keeping the wearer dry.



# Intermittent Self-Catheterisation

When people are unable to empty the bladder they may be taught to catheterise themselves. Intermittent self catheterisation (ISC) can be carried out up to 4-6 times per day and sometimes less. ISC can be done in any toilet, it is both convenient and discreet and can greatly improve your quality of life.



Although catheters are an option, indwelling or supra pubic catheters are usually a last resort due to the risk of infection.



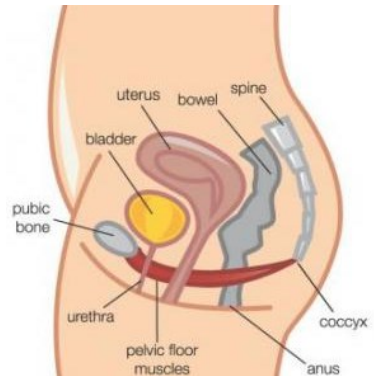
Pads and padded underwear work well for many people and there are a large range of products available.

## What can I do to help myself?

- \* Drink 6-8 glasses of fluids every day, preferably water or cordial. People often think they should avoid drinking because it makes them need the toilet more, however by restricting fluids, the concentrated urine irritates the bladder and makes you need to go more!
- \* Avoid drinks with caffeine in them such as tea, coffee and cola or drink decaffeinated versions.
- \* Try retraining your bladder if you are having to go to the toilet a lot and don't have an infection. You can do this by delaying going to the bathroom by a few minutes each time you feel the urge to pee. Increase the length of time gradually until you are up to around 3 hours between toilet visits. This trains the bladder to hold more urine and become less sensitive to small amounts of urine.
- \* Avoid constipation.
- \* Keep a diary to track any triggers which make you need to go to the toilet more often
- \* Carry out pelvic floor exercises twice everyday

# How to do pelvic floor exercises

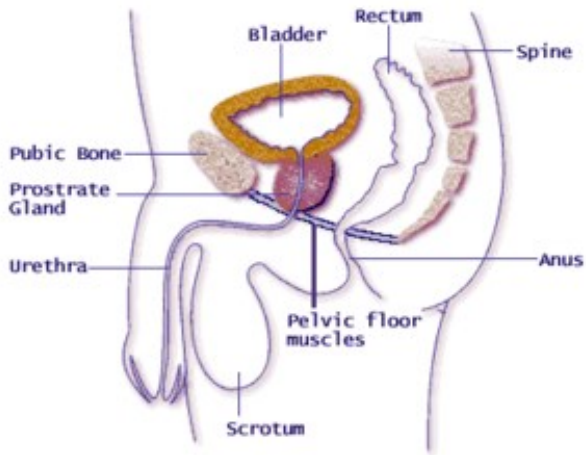
**Women** You can feel your pelvic floor muscles if you try to stop the flow of urine when you go to the toilet. However, it is not recommended that you regularly stop your flow of urine midstream, because it can be harmful to the bladder.



To strengthen your pelvic floor muscles, tighten the pelvic floor and hold up to 10 seconds. Repeat this 10 times in the morning and at night. It is also important to strengthen the short acting muscles that snap shut when we sneeze or cough. You need to do the same exercise but only hold for a second and do two sets of 10 twice a day.

You should soon start to notice the results. Your incontinence should improve, as well as the sensitivity you experience during sex. You should carry on doing the exercises, even when you notice them starting to work.

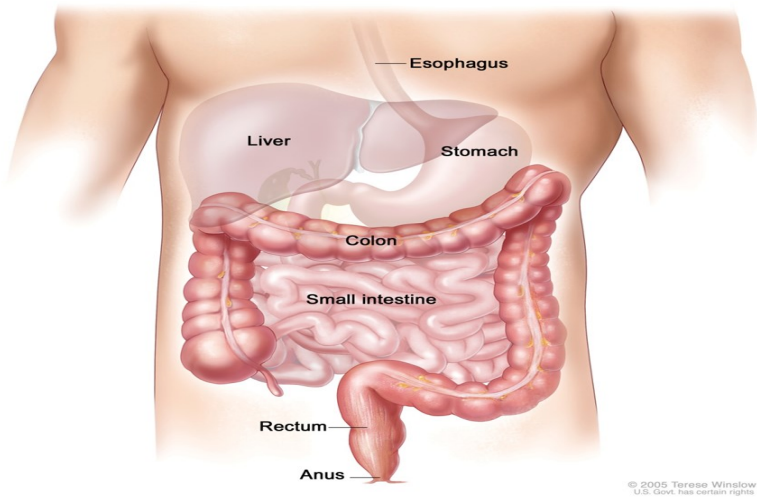
**Men** When emptying the bladder try to stop or slow the flow. This technique can help men locate their pelvic floor muscles. Avoid performing this technique as a regular exercise to avoid interrupting the normal flow of urine. Using this technique once a week can improve continence.



Try to tighten the muscles in and around the anus as if trying to avoid passing wind. The buttocks should stay relaxed and breathing should remain regular.

Stand in front of a full length mirror and watch as you try to use your pelvic floor muscles to lift your scrotum upwards slightly and retract or draw the penis inwards. This action should be visible in the mirror.

# The bowel and Transverse Myelitis



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## What can happen in NMO and Transverse Myelitis?

Transverse myelitis (TM) is inflammation of the spinal cord. Any inflammation here causes swelling which presses on the nerves in the spine and disrupts the messages. The last two nerves on the spinal cord control bladder and bowel. Any swelling above this can affect the bowel, causing loss of sensation in the rectum and/or control of the anal sphincter resulting in constipation and/or incontinence.

The bowel has 2 major functions:

- \* Digesting food and absorbing nutrients into the blood stream
- \* Eliminating waste products at a convenient and appropriate time

Starting at the mouth and ending at the anus, the digestive system includes the mouth, oesophagus, stomach, small and large intestines (known as the bowel). The end of the large bowel is a section known as the rectum. This pouch is where faeces are temporarily stored prior to emptying. Sensors in the rectum send messages to the brain making you feel the urge to go to the toilet. These sensory nerve endings are sensitive enough to distinguish between wind, solids and liquids. Bowel habits vary from person to person from once every 3-4 days to several times a day.

# Constipation

Constipation is defined as passing hard stools with excessive effort usually less than three times a week. Being constipated can cause discomfort, flatulence and bloating, tiredness, fatigue and loss of appetite.

In NMO, the bowel can cause slower passage of faeces. The longer the faeces is in the large bowel, the dryer it becomes making it more difficult to pass. Sensory loss in the rectal area can also contribute to constipation as the person is unaware of the need to the toilet and the faeces dries and hardens in the rectum. Weakness of the anal sphincter and pelvic floor can contribute to this issue. Occasionally, the faeces becomes

so hard that watery diarrhoea bypasses it however the hard faeces stays



# **What can I do to help myself?**

What you eat and drink has a massive impact on your bowel. Eating regularly helps the bowel as it keeps it stimulated. Skipping meals has the opposite effect and makes the bowel sluggish.

Ensure you drink plenty of fluids. Current guidelines recommend 6-8 glasses of water per day but juice, cordial, skimmed milk and decaffeinated tea/coffee are fine

Try to establish a good routine by going to the toilet about 30 minutes after breakfast as this is when the urge to open your bowels is strongest

Take regular exercise as this strengthens the muscles and contractions within the bowel. Even walking for 15 minutes a day will help.

Correct posture - How you sit on the toilet can affect how easily you are able to empty your bowels. The correct position for doing this is with your knees higher than you hips. You can easily do this by resting your feet on a step or small stool.





Make sure you get enough fibre in your diet as this helps push the contents of the bowel along. Eat more fibre. There are two kinds of fibre, soluble and insoluble, both are important. Soluble is from fruit like bananas or apples, nuts, grains such as oatmeal, root veg such as carrots and potatoes and beans/pulses. Soluble fibre helps to bulk your poo and keep it soft whilst also having benefits for your heart. Insoluble fibre, found in wholemeal rice and bread also bulks and is important in moving the contents of the bowel along.

## Management - Medication

A good diet high in fibre with plenty of fluids is the key to preventing constipation. Sometimes however these are not enough and medications are required.

**Laxatives** - often bought over the counter, should only be used as a short term solution:

- **Bulk forming laxatives** - such as Fybogel work like fibre you get from your diet by increasing the bulk of the faeces, however you need to drink 2 litres of fluid a day for this to work well.
- **Stool softeners** - such as docusate work by softening the faeces, making it easier to pass
- **Osmotic laxatives** - such as Movicol work by delivering fluid to the large bowel that cannot be absorbed by the gut. It is then absorbed by the stool making it softer. It is important that these are taken exactly as per instructions or they will not work.
- **Stimulant laxatives**— such as senna cause stronger contractions in the bowel pushing the faeces along.

# Management - Continence Products

There are several products available to help with bowel incontinence. Most are available on the NHS but you would need a referral from your doctor or nurse to access the continence team in your area for assessment and advice

**Anal plugs** - these are used to help stop leakage from the anus. There are two types available: a soft expanding foam plug which swells when it comes into contact with liquid; and a soft silicone design with two discs which sit either side of the anus and are connected with a thin tube of silicone and effectively seals the anus until the next time you need to open your bowel. These can be used for 12 hours or more depending on the type.



# Management - Continence Products

**Anal irrigation** - uses warm water to 'flush out' the hardened faeces which can become stuck in the large colon. This is quite useful for people who have limited or no sensation in the rectum or for those lacking the capacity to push the faeces out. It can be used every other day to prevent build up



**Continence pads** - are a commonly used method to control anal leaking and are available on the NHS. Manufacturers of these products will quite often send samples out to try. Many are very discreet and washable varieties are available.

## Other help available

### **‘Just can’t wait’ toilet cards**

These are available from the bladder and bowel foundation at a cost of £5. These can be shown to allow you to go to the front of the queue at public toilets.

### **Radar Keys:**

These keys unlock the 9000 disable toilets located at public areas, restaurants, pubs and office blocks around the country. You can obtain one for around £5 from your local authority or specialist disabled centres



# Useful Links

## **General information**

[www.continence-foundation.org.uk/](http://www.continence-foundation.org.uk/)

[www.bladderandbowelfoundation.org/](http://www.bladderandbowelfoundation.org/)

## **Radar key:**

<http://www.radarkeys.org/>

## **‘Just can’t wait’ toilet card:**

[www.bladderandbowelfoundation.org/forum/register](http://www.bladderandbowelfoundation.org/forum/register)

## **More information on bowel incontinence**

[http://www.nhs.uk/Conditions/Incontinence-bowel/  
Pages/Treatment.aspx](http://www.nhs.uk/Conditions/Incontinence-bowel/Pages/Treatment.aspx)

## **Can I get products on the NHS?**

[http://www.nhs.uk/chq/Pages/can-i-get-incontinence-  
products-on-the-nhs.aspx](http://www.nhs.uk/chq/Pages/can-i-get-incontinence-products-on-the-nhs.aspx)

## **Bladder re-training**

[http://www.nhs.uk/Livewell/incontinence/  
Urgeincontinencerealstory.aspx](http://www.nhs.uk/Livewell/incontinence/Pages/Urgeincontinencerealstory.aspx)

## **Help stopping leaks**

<http://www.nhs.uk/Livewell/incontinence/>

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Tricia joined the team in 2017 having worked on the day ward here administering Rituximab. Her varied background includes critical care, A&E and Midwifery.

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