



Living with NMO

Bladder and Bowel



www.nmouk.nhs.uk





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

NMO Service

Walton Centre Foundation Trust
Lower Lane
Fazakerley
Liverpool L9 7LJ

Contact: 0151-529-8357

nmo.advice@thewaltoncentre.nhs.uk

NMO Service

John Radcliffe Hospital
West Wing
Headley Way
Oxford OX3 9DU

Contact: 01865-2311905

nmo.advice@orh.nhs.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

Disclaimer

We have made every effort to ensure that information in this publication is correct. We do not accept liability for any errors or omissions as policy and practice may change. Should you require medical advice as a result of reading the information contained within this site you should seek such advice from a registered medical practitioner

About the authors:

Sam Linaker - NMO Nurse Specialist

Sam trained as a Continence Nurse Advisor in 2010 as part of her role as an MS Nurse. She initially joined the Liverpool NMO team as a Urology Nurse but transitioned over to NMO Nurse Specialist in November 2016. Sam is keen to ensure that all of our patients have access to help and support with continence should they need it.

Kerry Mutch - NMO Advanced Nurse Practitioner

Kerry spent 9 years as an MS Nurse Specialist Nurse, after gaining experience in many other areas of nursing, including neuro rehabilitation. Kerry was instrumental in setting up the NMO Nursing service in 2010 and has worked tirelessly to ensure equal access to the specialist services for NMO patients across the UK.

Useful Links

General information

www.continence-foundation.org.uk/
www.bladderandbowelfoundation.org/

Radar key:

www.radarkeys.org/

‘Just can’t wait’ toilet card:

www.bladderandbowelfoundation.org/forum/register

More information on bowel incontinence

www.nhs.uk/Conditions/Incontinence-bowel/Pages/Treatment.aspx

Can I get products on the NHS?

www.nhs.uk/chq/Pages/can-i-get-incontinence-products-on-the-nhs.aspx

Bladder re-training

www.nhs.uk/Livewell/incontinence/Pages/Urgeincontinencerealstory.aspx

Help stopping leaks

www.nhs.uk/Livewell/incontinence/Pages/10waystostoptheleaks.aspx

TM Society

<http://www.myelitis.org.uk/>

Spinal Cord Injury Association (SIA)

www.spinal.co.uk

Introduction

Approximately 80% people who have had transverse myelitis (TM), a rare condition causing 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.

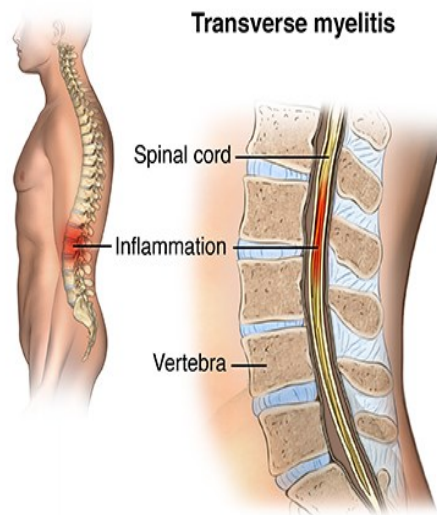
This booklet aims to give you information on:

- * The cause of bladder and bowel problems in NMO.
- * Practical advice to living with continence problems.
- * Treatment options on managing these problems.

What happens in NMO and Transverse Myelitis?

Transverse myelitis (TM) is inflammation (swelling) of the spinal cord. The last two nerves of the spinal cord control bladder and bowel.

Inflammation disrupts the electrical signals that go to and from the brain and bladder or bowel causing loss of sensation and issues with emptying the bladder or bowel resulting in either incontinence of urine/faeces **OR** retention of urine or constipation.



Continence

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

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 approx £5 from your local authority or specialist disabled centres



Continence Products

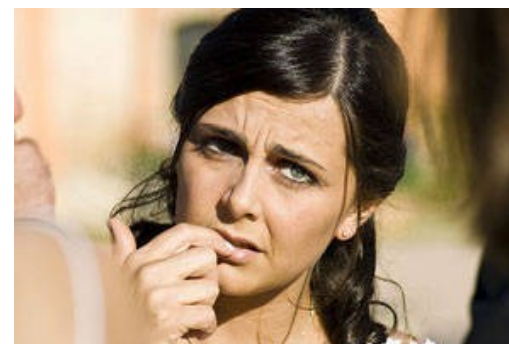
Anal irrigation - uses warm water to 'flush out' the hardened faeces which can become stuck in the large colon. This is quite useful for people who have limited or no sensation in the rectum or for those unable to push the faeces out. It can be used every other day to prevent build up.



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.

Quality of life and bladder/bowel issues in NMO

80% of people with NMO are significantly affected by urinary or bowel symptoms, that affect a person's quality of life, the most distressing of these are:



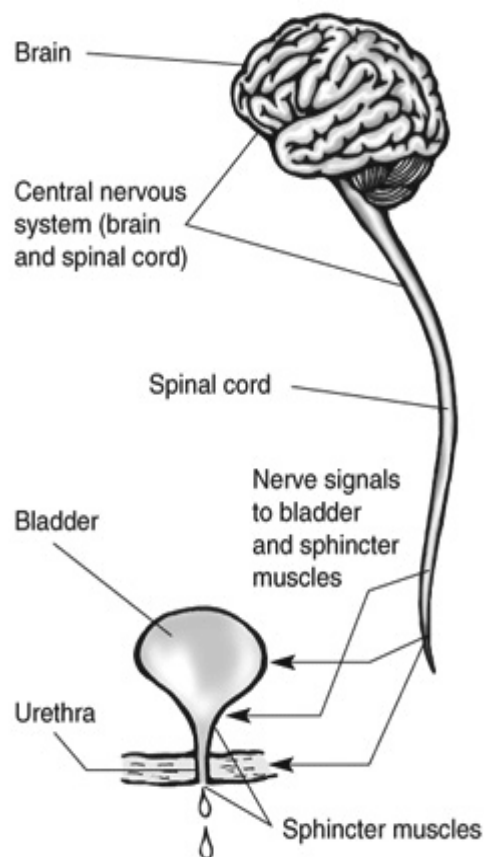
- * Restrictions in ability to travel.
- * Embarrassment e.g. having to change their underwear.
- * Employment.
- * Social interaction.
- * Family interactions.
- * Worried to leave the house.
- * Personal relationships.
- * Cost of equipment/cleaning.

Bladder and 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. The 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.



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 - 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.

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 happen 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).



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.

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 your hips. You can easily do this by resting your feet on a step or pile of magazines.

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 possible irritants to bladder such as drinks with caffeine (coffee, tea, coke), citrus fruit, spicy foods or artificial sweeteners.
- * Keep a diary to track any triggers which make you need to go to the toilet more often.
- * 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. This trains the bladder to hold more urine and become less sensitive to small amounts of urine.
- * Carry out pelvic floor exercises twice everyday.
- * Avoid constipation.

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 anti-muscarinic e.g. oxybutynin, solifenacin) 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 (e.g. desmopressin).

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

Constipation

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

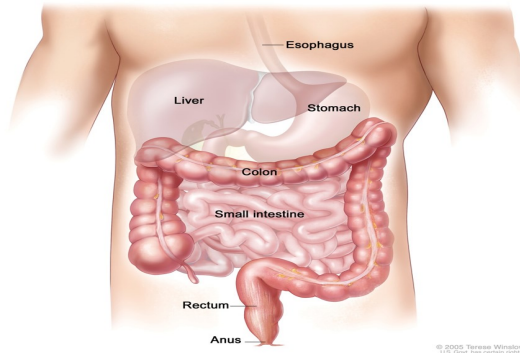
In NMO, the bowel movements are slow. The longer the faeces is in the large bowel, the dryer it becomes making it more difficult to pass. Sensory loss in the rectum can also contribute to constipation as the person is unaware of the need to open bowels and the faeces dries and hardens. Weakness of the anal sphincter and pelvic floor can contribute to this issue. Occasionally, the watery, partially formed stools that build-up behind the hard stools causing diarrhoea alternating with constipation.



Bowel and Myelitis

The bowel has 2 major functions:

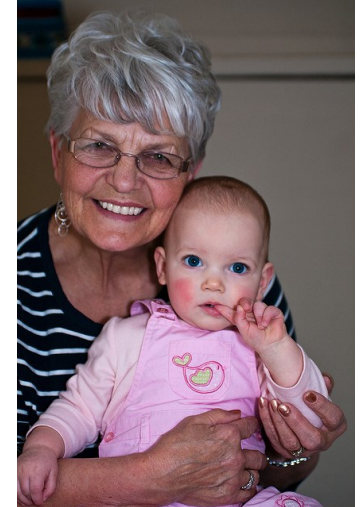
- * Digesting food and absorbing nutrients into the blood stream.
- * Eliminating waste products at a convenient and appropriate time.



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 nerve endings are sensitive enough to distinguish between wind, solids and liquids. Bowel habits vary from person-to-person.

Catheters

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.



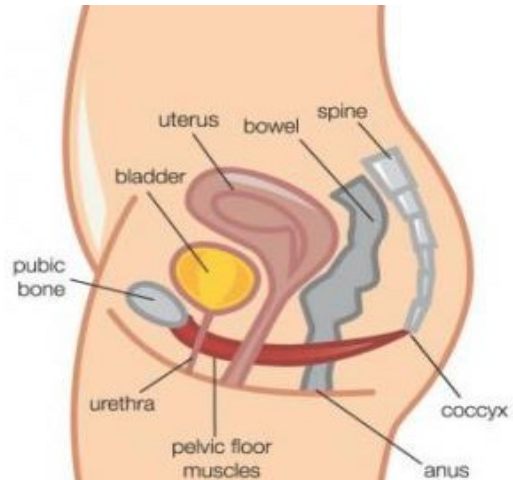
Urethral or supra-pubic catheters are usually a last resort due to the risk of infection.



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

How to do pelvic floor exercises

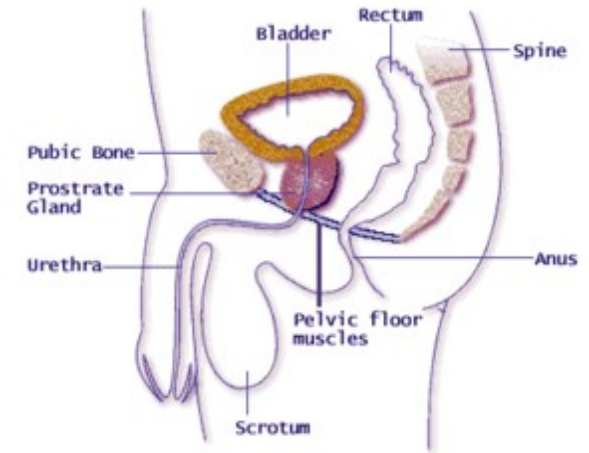
Women You can feel your pelvic floor muscles if you try to stop the flow of urine when you go to the toilet. However, it is not recommended that you regularly stop your flow of urine midstream, because it can be harmful to the bladder.



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.