



Experts in MS Bladder and Bowel Pathway Webinar

Questions and Answers

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Experts in MS

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Understanding the need

What are the best sources of information to support a business case for the development of an MS continence service?

Include the cost of Non-elective admissions for MS patients in your area for continence related conditions.

Unplanned admission consensus committees or similar have lots of information around generic business cases that you adapt for use.

Benchmark against other local Health Boards or services to help identify performance gaps and see what else is currently in place.

Contact areas that have had success setting services up and request information.

Include the Patient Reported Outcome Measures and Patient Reported Experience Measures data

What are the steps people can take to develop bowel and bladder services and deliver on the pathway?

Step 1

The first step is to understand the need in your area using a variety of tools to assist in benchmarking current services and identifying gaps. Gather as much relevant data as possible including PREMS and PROMS (see above answer) to analyse the current service and how it is performing.

Step 2

Develop links and involve colleagues in this process including continence teams, IPC leads, MS Nurses and other key stakeholders.

Step 3

Finally, develop a business case to implement the pathway in your service.

What are the current opportunities in the health care system that could support developing a conversation on continence and MS?

You can get support to raise continence service issues from several sources, depending where you work, including the Association for Continence Advice, All Wales Continence Forum, Chronic illness awareness, UACC, MS Society, MS Trust and current service development in NHS England as well as Infection and Prevention Control Leads.

Some useful websites and contacts:

[Association for Continence Advice](#)

[Unplanned Admissions Consensus Committee](#)

[MS Society Experts in MS](#)

[MS Trust](#)

What's the strongest case for change to implement this pathway – cost of emergency admissions, impact on quality of life or pressure on NHS workforce?

All of them are applicable. Certainly capacity is a big issue in the NHS – finding sufficient staff to monitor patients. So, preventing patients from going into hospital with UTI's and other continence related conditions is a very strong case for change. There's also the cost savings made as well.

Quality of life is also a really big issue for people with MS. If you have UTI's and other bladder problems that's a significant issue. It can have an impact on their independence and employment. By initiating the pathway, it'll help to improve Quality of Life impact for individuals, reduce emergency admissions, decrease duplication of work, reduce pressure on workforce and contribute to more communication between professionals leading to more cohesive care.

Implementing the Pathway

How can we implement the Pathways into our clinics?

The first thing to do is look at how patients are going through your system now because from that you'll be able to highlight where you might have bottlenecks for seeing patients.

Have a look at the data that shows how patients are using the services: whether they're going into hospital, whether you've got lots of UTI's, whether you've got lots of problems.

Once you've got that data, have a look at how you can do a service improvement. Lots of services are looking at things like quality, looking at reducing hospital admissions and Pathways. One of the big issues around the MS bladder is that patients go into hospital quite frequently with UTI's. We know a lot of services are looking at UTI management now.

Look at what your pathway is now and using data, develop a stakeholder group of interested people. They can work with you to start looking at that pathway implementation.

Your stakeholder group might be people from your MS service, your Bladder and Bowel service, your Quality Lead within the ICB or the Trust that you're working in and people living with MS. With this kind of group you can identify how to develop the pathway as a quality improvement initiative.

For more information about the Pathway here are some useful links:

Link to the Consensus Document

Link to Bladder Pathway Document

MS Society Professional Network- professionalnetwork@mssociety.org.uk

You can join our Professional Network for help and support with this.

Sue Thomas - sue.thomas@healthcare-consulting.org.uk

Sue Thomas was the chair of the pathway consensus group.

Is the pre clinic questionnaire suggested for bladder and bowel symptoms or any other symptoms too?

A pre clinic questionnaire generally includes more than just continence care but is a helpful tool as part of the pathway. Below is an example of a pre-clinic assessment questionnaire that is sent to all patients in advance of their appointment for them or their family/carers to complete and bring to clinic/available for home visits. It helps the person with MS direct the initial conversation. It also highlights to the healthcare professional the key priorities and issues that need addressing. It has been helpful to address some of the invisible symptoms that are often more difficult to bring up verbally in clinic, they can be written and that opens up the opportunity for this conversation. The second benefit that has been found is the ability to gather the standardised information through the form; for example current medication, recent monitoring results, other investigations non-MS related; which releases more crucial face-to-face time in clinic.

A more specific continence related pre clinic questionnaire may be something that the group look at in the future.

[Take a look at an example of a pre-clinic questionnaire](#)

How could a service support awareness raising of continence and MS continence services?

A service could run an online or in person awareness session for people living with MS and their families or carers.

You could promote awareness sessions by reaching out to the Neuro/MS specialist service that sees people in their area and ask their comms team and/or MS team to let people know the session is running. You can also advertise to people in local MS groups, networks and charities.

This is how a pilot awareness session is happening in the Liverpool area. Evaluating the pilot will help support future awareness raising.

E-mail ruth.austen-vincent@mssociety.org.uk for more information about the pilot awareness sessions.

Managing Bladder and Bowel Continence

Is there a "known" timeline for how many years Botox injections work for bladder?

Botox usually has a life of 6-12 months, although it can vary from person to person, and then the procedure needs to be repeated. This has been repeated for some individuals with no decline in efficacy. There are reports of use for up to 12 years with no bladder damage, but there are no long-term studies recommending how long Botox can be continually used for.

In the consensus document and pathway I can't see any mention of Autonomic Dysreflexia (AD) risk, especially if individuals have an MS lesion around T6. Is this a missed opportunity to highlight this potential risk as it is often not recognised by health professionals in acute settings?

Potentially, this can be taken back to the group to see if an algorithm could be inserted into pathway to identify/treat Autonomic Dysreflexia (AD).

The group was aware that AD is something that can potentially happen to people with MS, but it's not as common as in spinal injuries. AD does have an NHS Improvement Patient Safety Alert Official Classification Paper. It is a big issue for patients that are at risk of it and a reference to that Patient Safety Alert would need to go into any Bowel Pathways that are there. There's been a recent push to make professionals aware of the risks associated with AD and treatment available.

What are your thoughts about access to Tibial Nerve Stimulation for people living with MS?

Tibial nerve stimulation is usually classed as a third line treatment for people with bladder urgency. It should be offered when conservative/pharmacological treatments have failed. It can also be used for faecal incontinence. Whilst there is guidance to follow with regards to use / efficacy of PTNS there are also contraindications (see below).

Contraindications: Do not use on patients with pacemakers or implantable defibrillators, patients prone to excessive bleeding, patients with nerve damage that could impact either percutaneous tibial nerve or pelvic floor function, or on patients who are pregnant or planning pregnancy.

This means it may be unsuitable for individuals who live with MS. But, the clinician would need to assess the individual person with MS and then decide if it's appropriate.

What's the best way to prevent hospital admissions for urinary tract infections?

The following are key factors to prevent hospital admissions for urinary tract infections:

Educate patients in conservative measures that they can do themselves like fluid consumption, Correct fluids prevent constipation.

Identify changes to their bladder symptoms.

Provide a UTI pack to self – monitor.

Arrange regular bladder scanning at outpatient's clinic or scan if bladder symptoms change or there's a history of UTI's.

Initiate and review Intermittent Self Catheterisation (ISC) at appropriate times including when there is a change in presenting urinary symptoms. The review should include a review of the patient's technique, the frequency of ISC and check the equipment is still appropriate as this may need to vary with symptom presentation.

In your experience, what are the best ways to support people in discussing bladder and bowel problems with their health care practitioners and with their close friends and family?

We need education for professionals to be more confident in addressing issues. We also need education for individuals and family members about presenting symptoms and how they can be addressed. We can all raise awareness about MS, bladder and bowel conditions and the treatment available. And we can develop empathy across all stakeholders by providing space for people to discuss this. We can create support networks to tackle the stigma that's still associated with these conditions.

[Managing Bladder Problems](#)

[Managing Bowel Problems](#)

Useful Resources

Documents

[Expert Opinion Consensus: Management of bladder dysfunction in people with Multiple Sclerosis](#)

[Bladder Pathway](#)

[Self-Assessment Tool](#)

Websites

[Read about our panel member Sue Thomas and her healthcare consultancy](#)

[Find MS Society bladder and bowel information for people with MS and their family](#)

[Find out more about the NeuroResponse service](#)

[Visit Revive MS Scotland website to find out more about their services](#)

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We're the MS Society.

Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

Contact us

MS National Centre

020 8438 0700

info@mssociety.org.uk

MS Society Scotland

0131 335 4050

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MS Helpline Freephone

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 **Let's stop MS together**