

EXPERT OPINION CONSENSUS DOCUMENT

Management of bladder dysfunction  
in people with multiple sclerosis

## CONSENSUS PANEL AUTHORS

Chair, Sue Thomas, Independent Healthcare Consultant

Joan Bradley, Lead Nurse, MS and Rehabilitation, The Hillingdon Hospitals NHS Foundation Trust

Trishna Bharadia, Health Advocate and Patient Engagement Consultant, The Spark Global; MS Patient Advocate (Orchid ID: 0000-0003-3633-729X)

Ian Pomeroy, Consultant Neurologist, The Walton Centre NHS Foundation Trust, Liverpool

Megan Roberts, Head of Health Professionals Programmes, MS Trust

Ruth Stross, Multiple Sclerosis Specialist Nurse, Surrey Downs Health and Care, Epsom and St Helier University Hospitals NHS Trust

Agne Straukiene, Consultant Neurologist, Honorary Consultant Neurologist, Plymouth Hospitals NHS Trust

Mark Webb, Disability and Diversity Campaigner and Head of Communications, Shift.ms

Ann Yates, Director of Continence Services, Cardiff and Vale University Health Board

Jane Young, Nurse Consultant, Bladder and Bowel Service, Central and North West London NHS Foundation Trust

## REVIEWER PANEL

Colin Bannon, retired GP and patient with MS

Simon Fulford, Consultant Urological Surgeon, James Cook University Hospital, Middlesbrough

Gavin Giovannoni, Professor of Neurology, Queen Mary University of London

Natasha Hoyle, Neurosciences Pharmacist, Sheffield Teaching Hospitals NHS Foundation Trust

Priya Khanna, Consultant Microbiologist, London North West University Hospitals NHS Trust

Frank Lee, Consultant Urological Surgeon and Neurourologist, Royal National Orthopaedic Hospital, London

Debbie Quinn, Policy Advisor, UK Multiple Sclerosis Specialist Nurse Association (UKMSSNA)

Margaret Solomons, Multiple Sclerosis Specialist Nurse, Central London Community Healthcare NHS Trust, Harrow

Sarah White, Lead Multiple Sclerosis Clinical Nurse Specialist, St George's University Hospitals NHS Foundation Trust

## DECLARATION OF INTEREST

Sue Thomas has received speaker honoraria from Hollister and is a consultant for Hollister. Joan Bradley has received speaker honorarium from Hollister. Trishna Bharadia, Ian Pomeroy, Megan Roberts, Ruth Stross, Agne Straukiene, Mark Webb, Ann Yates and Jane Young have no interests to declare.

Suggested citation: Thomas S, Bradley J, Bharadia T, Pomeroy I, Roberts M, Stross R, Straukiene A, Webb M, Yates A, Young J. Expert opinion consensus document. Management of bladder dysfunction in people with multiple sclerosis. *BJN* 2022; 31 (3 Suppl 3), S1–32

Editor and Associate Publisher: Tracy Cowan

Project Manager: Angela Shaw

Medical Writer: Penny Gray

Subeditor: Francesca Ramadan

Head of Projects: Camila Fronzo

Publishing Director: Andrew Iafrazi

Design: Fonthill Creative

Published by: MA Healthcare Ltd, St Jude's Church, Dulwich Road, London, SE24 0PB, UK

Tel: +44 (0)20 7501 6726. Web: [www.markallengroup.com](http://www.markallengroup.com). Email: [andrew.iafrati@markallengroup.com](mailto:andrew.iafrati@markallengroup.com)

© MA Healthcare Ltd 2022

All rights reserved. No reproduction, transmission or copying of this publication is allowed without written permission. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, mechanical, electronic, photocopying, recording, or otherwise, without the prior written permission of MA Healthcare Ltd, or in accordance with the relevant copyright legislation.

Cover Image: [stock.adobe.com/vectorlia](https://stock.adobe.com/vectorlia)

**MA Healthcare**

# Contents

<b>Foreword: a call to arms—the need for updated guidance</b>	<b>S4</b>	<b>Management</b>	<b>S14</b>
Sue Thomas		<b>Behavioural measures</b>	<b>S14</b>
<b>Foreword: patients' perspective—vision and insight</b>	<b>S5</b>	<b>Management of impaired voiding</b>	<b>S15</b>
Trishna Bharadia and Mark Webb		Clean intermittent self-catheterisation	S15
<b>Management of the neurogenic bladder in people with MS</b>	<b>S6</b>	Other measures	S15
		Long-term catheterisation	S16
<b>Consensus methodology</b>	<b>S7</b>	<b>Management of overactive bladder symptoms</b>	<b>S17</b>
Literature review	S7	Antimuscarinics	S17
<b>Pathophysiology of multiple sclerosis</b>	<b>S7</b>	Other drug treatments	S18
		Botulinum toxin type A	S19
<b>Burden of lower urinary tract dysfunction in multiple sclerosis</b>	<b>S9</b>	Self-management	S20
Health and care burden	S9	<b>Prevention and management of infection: key recommendations</b>	<b>S20</b>
Psychosocial impact	S10	<b>Behavioural management of stress incontinence</b>	<b>S21</b>
<b>Guidance and policy changes since 2009</b>	<b>S11</b>	<b>Surgical treatments</b>	<b>S21</b>
<b>Assessment of lower urinary tract dysfunction in PwMS</b>	<b>S11</b>	<b>Medical devices</b>	<b>S23</b>
Multidisciplinary assessment	S11	<b>Conclusion</b>	<b>S23</b>
Patient engagement and collaboration	S12	<b>Recommendations</b>	<b>S24</b>
Ongoing care and surveillance	S13	<b>References</b>	<b>S27</b>

# Foreword: a call to arms—the need for updated guidance

**D**espite the fact that a UK consensus guideline on bladder management in multiple sclerosis (MS) has been available for over a decade (Fowler et al, 2009), it is not always routinely used. Furthermore, the National Institute for Health and Care Excellence (NICE) MS guideline (NICE, 2019) recommendation that everyone with MS should receive an annual health review, which might signpost to any bladder dysfunction, is not always adhered to, mainly due to capacity issues (Thomas et al, 2021).

Bladder problems can have a significant impact on people with MS (PwMS), their families, the NHS and society overall. Some 10% of hospital emergency admissions in PwMS are urinary tract infections (Multiple Sclerosis Academy, 2020). This lack of focus on an issue that can be effectively managed is unacceptable. The evidence cited in this document shows that proactive management of the neurogenic bladder can improve patient outcomes.

At present, so many PwMS are failing to receive appropriate management and are left thinking bladder issues are inevitable and untreatable, and that they have to 'live with the problem'. Therefore, MS specialists wanted to reconsider the Fowler et al (2009) consensus guidelines: first, to re-examine the evidence base and new developments within the changing NHS landscape; and second, to raise awareness of the need for a regular bladder assessment for PwMS.

This update of the Fowler et al (2009) consensus document makes the case for actively seeking out and managing bladder problems. This could be achieved through patient education, recognition of early symptoms, incorporation of bladder assessment into the regular MS review and standardised care pathways that are joined up between acute and community services. However, we also must be aware that health inequalities exist, and many PwMS still do not have regular reviews, potentially resulting in bladder problems being missed, which may lead to hospital admission. This places a huge economic burden on the NHS: NHS Digital data shows that emergency admissions for MS alone in 2019/20 cost the NHS almost £98 million ([www.wilmingtonhealthcare.com](http://www.wilmingtonhealthcare.com)).

There is an urgent need to ensure bladder assessments are undertaken by competent professionals and that appropriate management strategies are put into place to deal with problems. This will require education on bladder assessment for MS teams, as well as more dedicated time for monitoring patients, and improvements in joint working between MS, continence and urology teams. MS nurses are already overstretched in their day-to-day work (MS Trust, 2019), so an appropriate skill mix within teams is needed to increase efficiencies and build workforce capacity.

The updated guidelines presented here touch on the many facets of managing the MS bladder and the need to offer people a holistic service to improve their quality of life, as well as their neurological outcomes, while also reducing unnecessary and preventable utilisation of healthcare services. The guidelines not only overview the gold standard for bladder management, but also are a call to arms to MS teams, NHS providers and commissioners and the MS community, to think differently, work differently and make bladder management a priority.



**Sue Thomas,  
Panel Chair**

# Foreword: patients' perspective—vision and insight

**B**ladder dysfunction can be one of the more difficult MS symptoms to manage, not least because of the impact it can have on patients' confidence and self-esteem. These symptoms are frequently associated with stigma, either perceived or real. Bladder dysfunction is one of the most common symptoms of MS, with one in ten PwMS reporting it at the initial MS diagnosis (Panicker et al, 2020).

As two people living with MS who experience bladder symptoms to varying degrees, we know first-hand how this can lead to distress and isolation, and can impact on one's work, personal and social life. We recall the initial confusion and embarrassment. Yet, today, we still hear examples of patients being met with bewildering terminology as they try to come to terms with this challenge.

It is vital that healthcare professionals are aware of the optimal pathways for the treatment and care of PwMS with bladder complications, taking into consideration the individual's circumstances, their outcome wishes and quality of life.

For this reason, we both felt it important to be involved in the development of this updated consensus guidance on the management of bladder dysfunction in PwMS in the UK. We see the need to reduce the impact of urinary tract infections on patients and hospitals; to ensure patients can understand and explore management options and can confidently self-manage, where appropriate; and to provide clear, understandable and accessible information on bladder dysfunction.

Underpinning this is the need for better collaboration between PwMS and healthcare professionals, so that shared decision-making can take place. Improving communication, establishing joint education initiatives, co-creating information and solutions, and opening a space for dialogue is a great start. It is important to both of us, and to the community we support as best we can, that healthcare professionals are able to better understand what it is like for PwMS living with bladder dysfunction. Patients feel more invested in their own health management if they are being listened to and considered.

We hope this updated consensus document will help to

guide you towards the provision of optimal care for your patients, and that it will lead the way to better experiences and outcomes for all those living with MS who experience any form of bladder dysfunction.



**Trishna Bharadia,**  
Health Advocate and  
Patient Engagement  
Consultant, The Spark Global  
and MS Patient Advocate



**Mark Webb,**  
Disability and Diversity  
Campaigner and Head  
of Communications,  
Shift.ms

# Management of the neurogenic bladder in people with MS

## ABSTRACT

The neurogenic bladder is associated with an increased risk of urinary tract infection (UTI), which is a leading cause of hospital admission in people with multiple sclerosis (PwMS) and thus imposes a significant health economic burden on the NHS. The last UK consensus document on the management of the bladder in multiple sclerosis (MS) was published in 2009. This document, based on a consensus panel meeting discussion and literature search, updates that guidance. It presents new, evidence-based recommendations relating to the assessment of the lower urinary tract in PwMS, first- and second-line treatments of impaired voiding, and medications for overactive bladder symptoms. There is also guidance on how to promote patient self-management, including the use of home testing kits and patient-initiated follow-up. A key recommendation is the need for a national bladder pathway for PwMS. The consensus panel had a multidisciplinary membership and included two PwMS with first-hand experience of bladder problems.

**M**ultiple sclerosis (MS) affects over 130 000 people in the UK: approximately 1 in every 500 (Thomas et al, 2020) and 190 in every 100 000 in England (Public Health England (PHE), 2020). It is the most frequently occurring progressive neurological disease in young people, with a mean age of onset of 30 years (Phé et al, 2016a), affecting three to four times as many women as men (Bientinesi et al, 2020). Lower urinary tract (LUT) dysfunction is one of the most common and distressing effects of MS (Phé et al, 2016a). One in ten people with MS (PwMS) reports these symptoms at the time of initial diagnosis (Panicker et al, 2020); prevalence increases with the duration and severity of the condition, correlating to the extent of damage to the spinal cord, with nearly all patients affected after 10 years (Panicker et al, 2015a; Tornic and Panicker, 2018).

Bladder dysfunction in PwMS has a wide-ranging negative impact on patients' quality of life (Browne et al, 2015; Lakin et al, 2021). Common characteristics of the neurogenic bladder, such as impaired bladder function, high intravesical pressures, urinary retention and need for catheterisation, also significantly increase the risk of urinary tract infection (UTI), which is one of the leading causes of emergency hospital admissions, particularly in patients with more severe disease, constituting a significant burden on the NHS (Thomas et al, 2020a; Multiple Sclerosis Academy, 2020). Moreover, symptoms may often

be overlooked, in part because patients may be reluctant to talk about them, but also because healthcare professionals may not ask (Browne et al, 2015; Wang et al, 2018).

The UK consensus on management of the bladder in multiple sclerosis, published in 2009 (Fowler et al, 2009), made three main recommendations regarding the assessment of lower urinary tract (LUT) symptoms (in PwMS, alongside several specific recommendations on treatment interventions:

1. Dipstick urinalysis should be undertaken in all those with new symptoms of bladder dysfunction
2. Post-void micturition residual (PVR) volume should be measured by ultrasound in all patients with bladder symptoms prior to treatment or if there is reason to suspect incomplete bladder emptying
3. Urodynamic investigations with filling cystometry and pressure/flow studies of voiding should not be routine, but instead conducted only in patients who are refractory to conservative treatment, or who are bothered by their symptoms and want to undergo further investigations (Fowler et al, 2009; NHS Supply Chain, 2019).

A number of policy and guidance documents have suggested improvements to bladder and bowel services in recent years. In 2019, NHS England (NHSE) commissioned the National Bladder and Bowel Health project (NBBH) to improve continence care across the health and care system (NHS Supply Chain, 2019).

The NBBH, in turn, is aiming to implement recommendations of the 2018 Excellence in Continence

Care (EICC) report (NHS England, 2018), in line with the NHS Plan (NHS England, 2019).

However, a recent report from the Pelvic Floor Society highlights a continuance of wide variations in the provision and quality of continence care across services (Collie et al, 2021), which may be exacerbated by underfunding (Orrell et al, 2013). Anecdotally, a survey run as part of the MS Trust virtual conference in February 2021 found that around half of MS nurses and allied health professionals did not feel confident about managing bladder problems in PwMS (Thomas, 2021b).

## There's quite a lot of policy around [bladder and bowel services], but not a lot happening'

*MS independent consultant*

With support from Hollister, the *British Journal of Nursing* (BJN) and the *British Journal of Neuroscience Nursing* (BJNN) hosted a virtual meeting, attended by a multidisciplinary group of expert practitioners in MS and patient advocates, to review and update the 2009 UK guidance in the light of more recently published clinical and qualitative research, assess progress in the field, share examples of good practice, agree potential updates to the 2009 recommendations, and consider possible ways of improving the implementation of care for PwMS with bladder dysfunction. This report presents the results of the discussion.

## CONSENSUS METHODOLOGY

### Literature review

The consensus panel represented the various disciplines involved in the assessment and management of bladder issues in PwMS, and the two patient advocates both had personal experience of MS-associated bladder problems. All had extensive clinical experience in this field and were already advocating the need to improve service provision for PwMS.

A literature search of the PubMed database, using the search terms 'multiple sclerosis' and 'bladder', was conducted in advance of the meeting. This identified over 400 papers, including national and international guidelines. From this, the panel chair selected a reading pack for the panel, comprising both full-length versions and abstracts of 36 papers, to help them prepare for the discussion and to identify an evidence base for the meeting's agenda and the subsequent consensus recommendations. After the panel meeting, the panel and sponsor identified additional evidence to support the consensus document.

Where required, additional references were sought post the meeting and provided to the panel. The consensus methodology is illustrated in *Table 1*.

**Table 1. Methodology used for this consensus document**

<ul style="list-style-type: none"> <li>■ Review of the literature</li> <li>■ Analysis of the current state (health service need and policy)</li> <li>■ Selection of key papers for discussion in the consensus panel meeting and citations in the document</li> </ul>
<p><b>Consensus meeting</b></p> <ul style="list-style-type: none"> <li>■ Discussion of the key papers selected</li> <li>■ Identification of additional evidence</li> </ul>
<p><b>Post-consensus meeting</b></p> <ul style="list-style-type: none"> <li>■ Further additional evidence identified by panel and sponsor</li> <li>■ Consolidation of consensus statements</li> </ul>
<p><b>Preparation of the consensus document</b></p> <p><b>Review of the consensus document</b></p> <ul style="list-style-type: none"> <li>■ Reviewed by consensus panel</li> <li>■ Reviewed by review board</li> </ul>
<p><b>Final document approved by consensus panel and review board</b></p> <ul style="list-style-type: none"> <li>■ Development of the algorithm</li> </ul>

## PATHOPHYSIOLOGY OF MULTIPLE SCLEROSIS

Scientific understanding of the pathophysiology of MS has not changed substantially since the publication of the 2009 UK consensus guidance. Both the underlying causative mechanisms and mechanisms responsible for disease progression remain obscure (Zéphir, 2018; Stys and Tsutsui, 2019), inhibiting the development of potential new treatments (Stys and Tsutsui, 2019).

A 2013 report on the epidemiology and pathophysiology of the neurogenic bladder by Ginsberg (2013), which appears to be one of the most recent updates, broadly aligns with the recommendations of Fowler et al (2009). The report clarifies the function of the LUT: to store urine at low pressures without leakage and allow voiding at appropriate times under conscious control (Ginsberg, 2013).

The storage phase involves inhibition of parasympathetic activity and active relaxation of the detrusor muscle to allow low pressure storage, with sympathetic contraction of the urethral sphincters via the pudendal nerve preventing leakage.



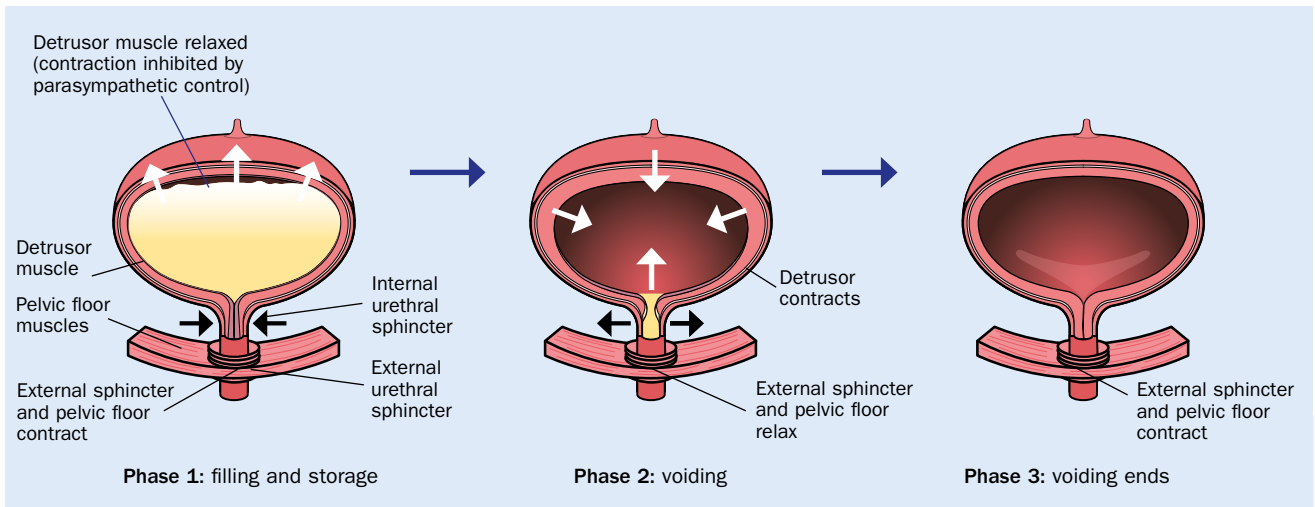


Figure 1. Normal cycle of bladder filling and voiding

In the voiding phase, the micturition reflex is triggered by sensory information from the bladder, and inhibition of sympathetic activity leads to detrusor muscle contraction, synchronised with relaxation of the pelvic floor muscles and urethral sphincter. *Figure 1* shows the normal cycle of bladder filling and emptying.

Bladder function is controlled via three voiding centres, which can all be affected in PwMS (*Figure 2*):

- Sacral centre, at spinal cord S2-S4 levels, which controls voiding at a reflex level
- Pontine micturition centre, in the brain stem, which coordinates relaxation of the external sphincter with bladder contractions
- Cerebral cortex centre, which controls voiding at a conscious level (Ginsberg, 2013).  
Ginsberg (2013) uses an anatomical system for

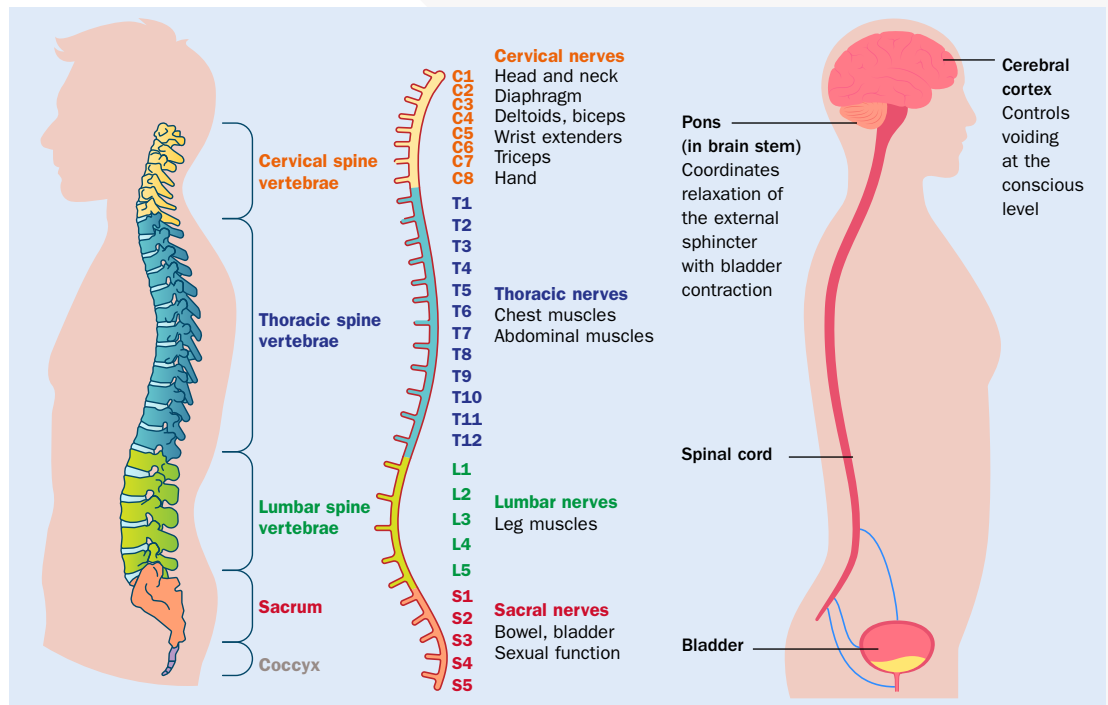


Figure 2. The three voiding centres that control bladder function



classification of neurogenic bladder, based on the site of the neural lesion(s) and the consequent effect on the central nervous system. As such, this does not reflect the severity of MS. The pattern of LUT dysfunction and the resulting symptoms depend on the distribution of lesions in the brain and spinal cord (Tornic and Panicker, 2018). Lesions above the brainstem may lead to uninhibited bladder contraction, detrusor overactivity or detrusor areflexia in some patients, but high bladder pressure should not develop if sphincter activity is coordinated.

By contrast, complete suprasacral spinal cord lesions can lead to detrusor-sphincter dyssynergia (DSD), where the bladder and the sphincter do not work together, and detrusor overactivity, with resulting urinary urgency and incontinence. This can lead not only to obstructive voiding and incomplete emptying, but also high pressures and the potential for damage to the kidneys (Ginsberg, 2013). Sacral cord lesions typically lead to detrusor areflexia with variable sphincter disturbance, usually with a resting sphincter tone that cannot be voluntarily controlled. This can result in overflow incontinence, experienced as small amounts of leakage all the time. *Figure 3* illustrates the correlation between distribution of lesions in the brain and spinal cord with symptoms and outcomes.

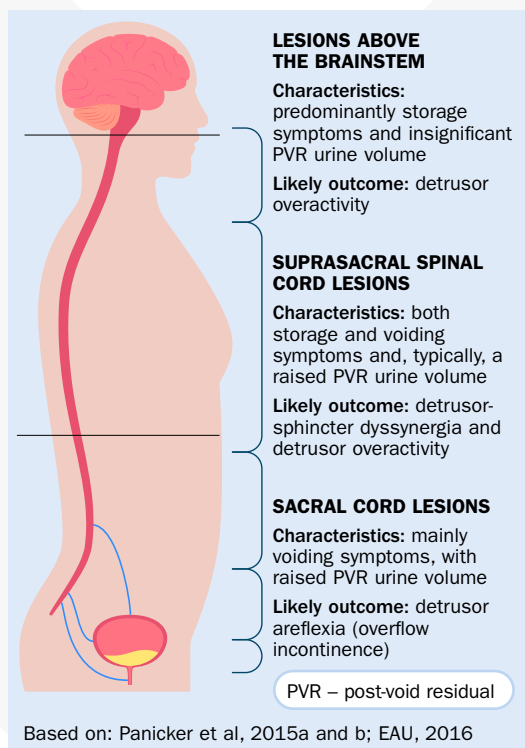
As with presentation, management will differ considerably, depending on the lesion location. Therefore, a thorough early assessment is essential to protect the kidneys, particularly when MS is advanced, and to optimise management and quality of life (Ginsberg, 2013).

## BURDEN OF LOWER URINARY TRACT DYSFUNCTION IN MULTIPLE SCLEROSIS

### Health and care burden

The prevalence of MS in the UK is reported to have risen since the 1990s (MacKenzie et al, 2014). Estimates in 2019/20 are based on The Health Improvement Network (THIN) primary care database, a system used by GPs for recording patient information. Extrapolation of numbers of PwMS within the THIN dataset to the general population gives a UK-wide estimate of 130 740 PwMS, which equates to 198 per 100 000 population; this is 1 in every 500 people, with 6600 new diagnoses of MS each year (PHE, 2020; Thomas et al, 2020a). MS is also the most common cause of neurological disability in the working-age population; employment is affected even at low levels of disability, measured on the expanded disability status scale (EDSS), with levels of disability progressing over the disease course (Giovannoni et al, 2016).

LUT symptoms affect around two-thirds of PwMS, with a recent meta-analysis of 12 studies revealing a pooled



**Figure 3. Pattern of lower urinary tract dysfunction and position of lesions in the brain and spinal cord in patients with multiple sclerosis**

prevalence of 68.4% (self-reported) and 64.0% (urodynamic) (al Dandan et al, 2020a). Nevertheless, renal failure is rare in PwMS, with Lawrenson et al (2001) reporting a rate ratio of renal failure of 0.5–2.2 for women with MS, when compared with the general population. Pooled results for LUT symptoms are given in *Table 2*.

Bladder dysfunction in PwMS increases significantly over the disease course and with the progression of disability (Tepavcevic et al, 2017; Nazari et al, 2020). In a 6-year follow-up study of 93 PwMS, the proportion of patients with one or more symptoms of bladder dysfunction increased from a baseline level in men of 48.1% to 51.9% at 3 years and 71.4% at 6 years' follow-up, with corresponding values for women of 45.5% at baseline, and 50.0% and 66.7% at 3 and 6 years' follow-up, respectively (Tepavcevic et al, 2017). Moreover, the presence of this dysfunction in both women and men was significantly correlated with increasing physical disability, reductions in health-related quality of life (HRQoL) and sexual dysfunction (Tepavcevic et al, 2017).

LUT dysfunction is also a significant contributor to emergency hospital admissions in PwMS, with considerable associated costs to the NHS. Hospital episode statistics

**Table 2. Pooled prevalences of lower urinary tract symptoms by measurement method used**

Self-reported assessment	Urodynamic diagnoses
Urinary frequency: 73%	Neurogenic detrusor overactivity: 43%
Urinary urgency: 64%	Detrusor sphincter dyssynergia: 35%
Incomplete bladder emptying: 61%	Voiding dysfunction with detrusor sphincter dyssynergia: 35%
	Detrusor underactivity associated with detrusor sphincter dyssynergia: 27%

Source: Al-Dandan et al (2020a) supplementary information

(HES) data shows that, in 2019/20, UTI was the cause of emergency admission for 9.5% of PwMS' hospital stays, incurring an average cost of £2710 per emergency admission, with a total cost of £7.9 million ([www.wilmingtonhealthcare.com](http://www.wilmingtonhealthcare.com)).

Analysis of 5 years' HES data at University College London Hospitals NHS Trust identified 52 PwMS presenting with UTI (Li et al, 2020a). The 25 female and 27 male patients (with a mean age of 60 years) had 112 emergency department (ED) presentations and 102 hospital admissions for UTI; 24 PwMS presented multiple times; they were more likely to be male and older, with progressive MS, high levels of disability and more frequent antibiotic resistance (Li et al, 2020a). A European retrospective cohort study revealed consistent findings (Cabreira et al, 2020). Some 44 PwMS (41.5% of the cohort) were readmitted to hospital during the 6 years of the study, with a rate of 11% within 30 days post-discharge, mainly on account of infections (58.5%) (Cabreira et al, 2020). Neurogenic bladder was the most common comorbidity in these patients (47.7%), with progressive MS and treatment with second-line drugs (natalizumab/fingolimod) the main predictors of readmission within 30 days of discharge ( $p=0.016$  and  $p=0.022$ , respectively) (Cabreira et al, 2020).

### Psychosocial impact

Bladder dysfunction creates multi-level disruption in the lives of PwMS, interfering with sleep, travel outside the home and sexual relationships, among other aspects of daily life (Browne et al, 2015; Lakin et al, 2021). Bladder problems contribute to debilitating sleep disturbance (Strober et al, 2015) and are significantly correlated with fatigue (Lin et al, 2019), daytime sleepiness (Tudor et al, 2020) and depression (Tudor et al, 2020). Despite these detrimental impacts, patients can often be reluctant to seek help, in part because of the social stigma associated with bladder dysfunction (Elstad et al, 2010; Southall et al, 2017) and may choose to self-manage their symptoms (Browne et

al, 2015). Many suffer in silence, as they are unaware of potential treatment options (al Dandan et al, 2020b).

Even in those PwMS who receive treatment, satisfaction can be very low (Wang et al, 2018). A large-scale study of PwMS with bladder, bowel and sexual symptoms, performed with those on the North American Research Committee on Multiple Sclerosis (NARCOMS) registry, showed consistent associations between the severity of disability—determined using the patient-determined disease steps (PDDS) rating scale, MS relapse in the preceding 6 months and catheter use—and being affected by these symptoms, with only one-third of patients being completely satisfied with treatment for any of them (Wang et al, 2018). A large-scale, two-centre study of PwMS with urinary incontinence in Europe reported consistent findings, concluding that current treatments for LUT symptoms are often inadequate (Zecca et al, 2016). In addition, the perceptions of disease impact differ between PwMS and healthcare professionals (Vermersch et al, 2020)—for example, PwMS are more bothered by non-physical, invisible symptoms of MS, whereas neurologists overestimate the impact of physical symptoms and their impact on activity (Marin et al, 2021).

Personal testimonies from PwMS on the consensus meeting panel supported the findings from the published literature in all aspects: the considerable negative impact on daily living; the associated stigma and difficulty in talking about these issues; the particular challenges for men and ethnic minority communities; and the fear of concomitant UTIs in the course of MS disease progression.

**6 You do worry. You end up having to plan a lot more. I always want to know where the bathrooms are when I'm travelling'**

*Patient advocate panel members*

## GUIDANCE AND POLICY CHANGES SINCE 2009

Recent years have seen the publication of a number of policy and guidance documents on the management of bladder and bowel health and MS more generally. In 2019, NHS England (NHSE) established the NBBH to improve continence care across the healthcare system (NHS Supply Chain, 2019). The project aims to research and implement the EICC guidance 2018 (NHS England, 2018), and to meet the collective objectives of understanding patients' needs, improving patient safety and outcomes, agreeing national standards and promoting best practice.

Parallel to this, the National Neurology Advisory Group (NNAG) has developed an optimum pathway for PwMS, in consultation with specialist MS healthcare professionals, patient groups and PwMS (NNAG, 2019). This covers the spectrum of MS care, from referral to specialist assessment, drug treatment, symptom management and advanced and specialist components of care. It also considers barriers to and enablers of implementation, and provides guidance for disease-modifying service provision and primary care practice. Although it emphasises the need for bladder management, this is not discussed in detail. However, in a subsequent consensus document, the Neurology Academy/MS Academy highlight the additional need for explicit sub-pathways to address priority issues for PwMS, such as bladder and bowel management, in order to provide holistic care (Thomas et al, 2021a).

For the most part, provision of services for PwMS falls short of these ideals. Both MS care and bladder and bowel services are inconsistent, with considerable inequalities in access to care (NHS England, 2018; Collie et al, 2021), insufficient funding and resourcing (Orrell et al, 2013; Thomas et al, 2021a; 2021b) and a lack of integration between the two (Thomas, 2021a; 2021b).

## ASSESSMENT OF LOWER URINARY TRACT DYSFUNCTION IN PwMS

### Multidisciplinary assessment

LUT symptoms in PwMS need to be assessed and monitored at all stages of the patient's journey. In addition, patients need to be provided with good information and support (NICE, 2012a). The consultant neurologist and MS nurse specialist should take a detailed clinical history, which should include questions about urinary tract, bowel and sexual dysfunction, as well as neurological symptoms and quality of life (NICE, 2014; European Association of Urology (EAU) Guidelines, 2016). An evaluated neurourological algorithm for assessing LUT symptoms in PwMS has been proposed by Domurath et al (2020).

## MS specialist nurses need to aim to reduce variations in bladder care received by PwMS. They can help achieve this by ensuring that possession of the required nursing competencies and expertise is acknowledged as the key to improving standards'

*MS nurse specialist panel members*

Because of the multifactorial nature of MS, PwMS require coordinated care from a multidisciplinary team (MDT), including neurologists, MS specialist nurses, physiotherapists and occupational therapists, bladder and bowel specialists, psychologists and GPs. The service should include a dedicated single point of contact for each patient, who is responsible for coordinating care and helping to access services (NICE, 2014; NHS England, 2018). The Therapists in MS (TiMS) self-assessment form is designed to be used pre-clinic to help PwMS identify the key areas they want to cover during their consultation, and is a useful tool to provide to PwMS at the referral stage (TiMS National Working Group, 2021).

Any PwMS with LUT symptoms should be under the care of a health professional with the competency to assess or refer to the specialist bladder and bowel team (Continence Care Steering Group, 2014). As standard, assessment and investigation should include (NICE, 2012a; Continence Care Steering Group, 2014; EAU, 2016):

- Clinical assessment of urinary tract and bowel symptoms, neurological symptoms and sexual dysfunction
- Functional assessment of the impact of neurological conditions on factors affecting the management of LUT dysfunction, such as mobility, manual dexterity, social support and home environment
- Pelvic floor function testing with vaginal and/or rectal examination, if clinically indicated—for example, to assess prolapse
- Urinalysis by dipstick, microscopy, culture and urinary tract ultrasound scan. Note that dipstick urine is not recommended for catheterised patients and those aged over 65 years. If the patient is symptomatic, consider implementing the steps outlined in *Box 1*
- Requesting patients and/or their family members/carers to complete a 'bladder diary'—a record of fluid intake, urinary frequency and volume of urine passed—for at least 3 days
- Measurement of the urinary flow rate, if applicable

### Box 1. Options for urinalysis procedures in symptomatic patients with lower urinary tract syndrome

If the patient is symptomatic at assessment (increased MS symptoms or pain), send a catheter specimen urine (CSU) or midstream specimen of urine (MSU) directly for microscopy, culture and sensitivity (MC&S). Treat with antibiotics, if necessary, before the results are received. Also, consider atrophic vaginitis if there is vaginal or bladder irritation, vulva dryness, tenderness or traces of blood

Source: Flores and Hall, 2020

- Measurement of the PVR using an ultrasound scanner
- Paying special attention to potential red flags, such as haematuria (either visible or non-visible and non-explained) (NICE, 2021a), recurrent UTI and sepsis, which need to be referred for urgent investigation. The patient must be monitored and referred to urology for cystoscopy in case these prove to be indicators of bladder cancer.

Criteria for referral to urology are given in *Table 3*. Urodynamic investigations should not be routinely offered, as most PwMS have a low risk of renal complications (NICE, 2012a).

Validated questionnaire tools, such as the International Consultation on Incontinence Modular Questionnaire (ICIQ), can be helpful in assessing the impact of urinary symptoms on quality of life (Avery et al, 2004; EAU, 2016). Idiomatic/idiometric questionnaires designed specifically for assessing PwMS are likely to capture PwMS experience most accurately (Schwartz et al, 2020).

The results of a pilot study by Li et al (2020b) suggest that a symptom-based screening questionnaire may be useful for distinguishing PwMS in whom PVR measurement is required when facilities for measuring PVR volumes are not available.

Measurement of PVR is essential to confirm or exclude impaired voiding, as this may not be obvious from the patient's clinical history, and a high PVR

volume predisposes patients to recurrent UTIs (Panicker, 2020). A consistently raised PVR volume of more than 100 ml is commonly taken as a cut-off point at which clean intermittent self-catheterisation (CISC) should be initiated following receipt of informed patient consent (Phé et al, 2016a), although there is neither was consensus on this nationally or internationally, nor a definition of what constitutes a significant PVR (Domurath et al, 2020; Panicker et al, 2020). Anecdotally, the panel were aware of clinicians who set a PVR cut-off volume of 100, 150 or 200 ml, and there is a considerable amount of inconsistency in practice. These views are supported by an evaluation of neuro-urological assessment in PwMS (Domurath et al, 2020). The investigators found PVR cut-off values of 100–300 ml in different guidelines or used by convention in different studies and centres. In a painstaking process for developing an algorithm for neurogenic urinary tract dysfunction assessment in MS, they settled on a PVR volume threshold of  $\geq 70$  ml, confirming its prognostic value using logistic regression and demonstrating a good correlation between PVR  $\geq 70$  ml and abnormal urodynamic findings (Domurath et al, 2020). Nevertheless, more research is needed to provide a firm evidence base for PVR measurement evaluation. Finally, renal function should be checked when measuring PVR.

Women of childbearing age who have MS should be offered pre-pregnancy counselling, which should be repeated at least annually (Dobson et al, 2019). Although bladder symptoms may worsen in the latter stages of pregnancy, and for the first 3 months postpartum, this is rarely a cause for concern, as pregnancy itself is not associated with long-term worsening disability in PwMS (Dobson et al, 2019). It is important to provide reassurance and information on this, as it can be a cause of considerable anxiety in this patient group.

## 6 It is crucial that MS specialist nurses engage in good-quality conversations with patients in a sensitive way, especially when significant decisions are required'

*MS nurse specialist panel members*

### Patient engagement and collaboration

Good communication between PwMS and healthcare professionals can help promote treatment adherence and enhance the patient experience and outcomes

**Table 3. Criteria for referral to urology**

- Presence of haematuria (NICE, 2012a)
- Symptomatic of significant incomplete bladder emptying
- Deterioration of the upper urinary tract, although this is rare
- Presence of recurrent urinary tract infections and/or symptoms that have not responded to management in primary care or by a neurologist

(Motavasseli et al, 2018; Celius et al, 2021). Conversely, poor communication can contribute to poor treatment adherence and dissatisfaction with care (Vermersch et al, 2019; Celius et al, 2021). Bladder issues can be embarrassing for patients, making them reluctant to seek help (Browne et al, 2015); if healthcare professionals also fail to raise the topic, this can further contribute to inadequate patient care (Brucker et al, 2017). Overcoming these barriers requires that bladder issues are addressed early by healthcare professionals, with care, sensitivity and empathy, in line with NICE guidelines on the components of good patient care (NICE, 2012b).

**6 PwMS often say that they find discussions with health professionals complex and daunting, and that both they and health professionals often appear to avoid them. These conversations require skilful handling, expertise and competency from the MS specialist nurse involved. They can be supplemented with provision of high-quality resources and signposting to approved evidence-based websites**

*MS nurse specialist panel members*

A number of new initiatives may be helpful in supporting PwMS and their families. For example, the NBBH project is developing programmes and educational materials on bladder and bowel health (Booth et al, 2021). Promotion of self-management is also important, as this can contribute considerably to patients' sense of wellbeing and empowerment (Celius et al, 2021). Therefore, service development should factor in many patients' ability to self-manage their bladder symptoms (Browne et al, 2015) and determine how to support this.

Activities that can aid engagement and collaboration with patients can include:

- Talking to and learning from patients who are up to speed with online resources and technological solutions, such as mobile phone apps and peer-support networks like Shift.ms buddy (Shift.ms, 2021)

- Ensuring that translations of educational material are clear, accurate and respect cultural sensitivities
- Providing educational resources on MS to children of families affected by the condition, as this can aid family understanding and increase confidence (Thomson et al, 2021). One example is the Digesting Science website ([www.digestingscience.co.uk](http://www.digestingscience.co.uk)), which helps teach young children about MS in general and bladder problems specifically
- Supplying home urine tests for UTI, along with the relevant education and information on application: this may help to rule out this infection when patients are experiencing symptoms suggestive of a relapse and reduce GP visits and emergency hospital admissions (Thomas and Stross, 2021).

**6 Improved education is essential for healthcare professionals in primary care, particularly GPs and practice nurses'**

*(Booth et al, 2021)*

#### **Ongoing care and surveillance**

European Association of Neurology (EAU) guidelines recommend regular close surveillance of bladder dysfunction in PwMS throughout each patient's lifetime (EAU 2016). NICE guidelines recommend that these patients should undergo a comprehensive review (including bladder function) at least once a year (NICE, 2014). The panel consensus was that bladder symptoms should be reviewed at this annual MS review to identify red flags and any deterioration in symptoms that might require adjustment of treatment.

Provision of patient self-management strategies can be extremely valuable in enabling ongoing care and should be supported as much as possible. Examples are the use of home urine tests and self-management resources, such as the Squeezy app ([www.squeezyapp.com](http://www.squeezyapp.com)).

Implementation of patient-initiated follow-up (PIFU) might run alongside the annual review or provide an alternative approach in line with the recent NHS EICC guidance, although the patient must be provided with information on when and how to seek help (NHS England, 2018; Thomas, 2021b). However, PIFU is not suitable for all PwMS, and the individual's suitability for this must be assessed beforehand. Regular monitoring, combined with audit, can highlight opportunities for improving bladder and bowel services and patient outcomes (Metcalf and Owen, 2021).



‘The ability to self-refer could be a game changer because so much time can be lost in the referral process itself’

*Patient advocate panel member*

‘Good patient education is an important factor for self-referral to be successful, though it’s not going to be for everyone’

*Specialist clinician panel member*

## MANAGEMENT

The goals of management for PwMS with a neurogenic bladder are to achieve urinary continence, improve quality of life and protect the upper urinary tract (EAU, 2016). Patients may present primarily with symptoms of urinary storage dysfunction—that is, an overactive bladder, voiding dysfunction, or both. A wide range of treatments is available, and, as each person’s presentation will be unique, management needs to be individualised.

Table 4 outlines the treatment options for LUT dysfunction in PwMS. In addition, a NICE pathway on LUT symptoms in men is available (NICE, 2021b), although it is not specifically designed for those who also have MS.

## BEHAVIOURAL MEASURES

Behavioural measures, such as bladder retraining, pelvic floor exercises and fluid adjustment, may be helpful for some PwMS with LUT symptoms (Phé et al, 2016a; Bientinesi et al, 2020). NICE recommends behavioural management programmes, such as bladder retraining, but notes that evidence for such interventions is slim (NICE, 2012a). A 2015 Cochrane review concluded that weight loss in women who are overweight may help, and that evidence for other lifestyle interventions, such as reducing caffeinated and fizzy drinks, is lacking (Imamura et al, 2015). A prospective study involving 200 PwMS concluded that the relationship between urinary symptoms, fluid intake and fluid restriction is complex (Tam et al, 2020). Although fluid restriction is common in PwMS, it is not associated with a reduction in the severity of LUT symptoms. Likewise, drinking caffeinated drinks has a minimal effect on symptoms. The authors concluded that modifying fluid intake may not contribute greatly to reducing LUT symptoms (Tam et al, 2020).

The expert panel considered pelvic floor muscle training as the first-line treatment for LUT dysfunction, including stress urinary incontinence (SUI), in line with NICE guidelines (2012a; 2019). Instruction on

**Table 4. Treatment options for lower urinary tract dysfunction**

### Behavioural measures

- First-line treatment: pelvic floor exercises
- Other treatments: bladder retraining, fluid adjustment\*, weight loss, prevention of constipation

### Impaired voiding/chronic retention of urine

- First-line treatment: clean intermittent self-catheterisation (CISC)
- Second-line treatment: long-term catheterisation (when CISC is not feasible)

### Overactive bladder symptoms

#### ■ First-line treatments:

Antimuscarinic drugs (anticholinergics): these were considered the first-line treatment, but their associated anticholinergic burden (side effects such as dry mouth, constipation, blurred vision and cognitive impairment) can affect patient adherence to treatment (Panicker and Fowler, 2015a; 2015b; Phé et al, 2016a; Tornic and Panicker, 2018; Lisibach et al, 2021)

Newer antimuscarinics, such as solifenacin, tolterodine and fesoterodine, have a lower side-effect profile, and thus are preferable to older antimuscarinics like oxybutynin (Herschorn et al, 2010; Tornic and Panicker, 2018)

Darifenacin and trospium chloride are particularly suitable for patients with advanced disease (Phé et al, 2016a; Tornic and Panicker, 2018)

#### ■ Other drugs:

Mirabegron (beta-2 receptor agonist): as yet, there are limited data on its efficacy, but it has no anticholinergic side effects and good tolerability

Desmopressin: for the treatment of daytime urinary frequency and nocturia. Common side effect is hyponatraemia

#### ■ Other treatments:

Cannabinoids: can be effective (Phé et al, 2016a; Tornic and Panicker, 2018; Bientinesi et al, 2020), but more research is needed

Botulinum toxin type-A: effective second-line treatment for PwMS who are unresponsive to or cannot tolerate antimuscarinics (NICE, 2012a)

\*Although potentially helpful, this is unlikely to reduce symptom severity

how to perform this should be offered by trained staff who are competent to assess pelvic floor strength. If a patient does not benefit from self-directed exercises, they should be referred on to a pelvic floor physiotherapist or appropriately trained nurse for at least 3 months of supervised pelvic floor muscle training (Continence Care Steering Group, 2014).

## MANAGEMENT OF IMPAIRED VOIDING

### Clean intermittent self-catheterisation

Clean intermittent self-catheterisation (CISC) is first-line treatment for PwMS who are unable to empty their bladder (EAU, 2016; Tornic and Panicker, 2018). Based on extensive clinical experience, many MS nurses consider CISC to be the gold standard treatment for this indication. The panel recommends more original research should be undertaken to determine at what point CISC should be recommended, based on the PVR rate.

CISC has been shown to significantly improve quality of life, enhance independence and reduce episodes of incontinence and the impact of LUT symptoms in PwMS (Castel-Lacanal et al, 2013; Vahr et al, 2013; EAU, 2016), with the added benefit that they are able to self-manage and retain independence (Yates, 2016a).

Patient adherence to CISC can often be poor (Motavasseli et al, 2018; Zachariou et al, 2020). Several studies provide insight into the barriers to CISC and possible ways of overcoming them (Motavasseli et al, 2018; McClurg et al, 2019; Zachariou et al, 2020). Some examples are given in Table 5.

Zachariou et al's study (2020), published as an European Association of Urology (EAU) congress abstract, found that, of 61 PwMS prescribed CISC, only half of these were adherent, most of them female (22/31)—a finding consistent with the experience of the consensus panel. PwMS with a higher frequency of CISC and less spontaneous micturition were more often adherent, whereas those who experienced a blocking sensation during catheterisation, who needed to change their position in order to catheterise, or who suffered from mood disorders, were less adherent (Motavasseli et al, 2018; Zachariou et al, 2020). Furthermore, the prospect of CISC can be daunting for some PwMS, who may need time to come to terms with it before starting treatment (McClurg et al, 2019).

Being taught and supported by a competent, skilled healthcare specialist how to perform CISC will help reduce the risk of CISC-associated UTI, as will teaching the technique in the patient's home (Yates, 2013; 2016a; Logan, 2020).

Good success in learning CISC can be expected, regardless of age, provided patients have the manual dexterity, mobility and cognitive abilities needed (Hentzen et al, 2018; Haddad et al, 2021).

The risk of CISC-associated UTI is chief among patient's concerns, and its development in the early stages could deter PwMS from continuing with the procedure (McClurg et al, 2019). When a patient is learning how to undertake the procedure, use of strategies and products (as indicated) designed to minimise the risk of UTI, coupled with the use of a 'no touch technique' should help address such concerns and thus improve patient adherence (McClurg et al, 2019; Phé et al, 2016b; EAU, 2016). Key strategies for promoting adherence to CISC are listed in Table 5. Ongoing support from both healthcare professionals and the patient's family will have a positive effect, as will any improvement in symptoms, (McClurg et al, 2019).

### 6 Patients who were initially concerned about CISC often found it gave them a new independence and increased their confidence to socialise, work and exercise, with fewer infections.'

*Specialist clinician panel member*

A recent systematic review and meta-analysis of 25 randomised controlled trials of catheters used for intermittent self-catheterisation, involving 1233 patients with neurogenic voiding impairment, found that ready-to-use, single-use catheters were associated with a lower incidence of UTI than reusable catheters and patient satisfaction was highest for the pre-activated hydrophilic-coated catheter (Ye et al, 2021).

Nevertheless, there are times when reusable catheters could be more convenient, such as when taking a large supply of single-use catheters on holiday is cumbersome, although this does involve transporting cleaning equipment as well (Avery et al, 2018).

Panel recommendations for the management of PwMS who first experience recurrent UTIs after starting CISC due to incomplete bladder emptying are outlined in Table 6.

### Other measures

There are no effective drugs for the treatment of underactive bladder (Osman and Chapple, 2018). The EAU guideline on neuro-urology cautions that parasympathomimetics, such



**Table 5. Strategies for improving adherence to clean intermittent self-catheterisation**

- Alleviate patient fears and anxieties about the procedure in the initial consultation
- Provide the patient with accessible anatomical information about the bladder, and how complications, including infection, can occur
- Explain how CISC is designed to reduce the risk of infection and improve quality of life
- Inform the patient about the process of clean intermittent self-catheterisation, including no-touch technique. This can be done verbally, in writing and/or with visual aid
- Repeat this education, as required
- Promote patient choice in terms of catheter selection, with a focus on comfort, individual preference, ease of use and prevention of infection

Source: Balhi and Khalil Mrabet, 2020

**Table 6. Panel recommendations for the management of patients who develop recurrent UTIs after starting clean intermittent self-catheterisation**

- Check their technique is correct: hand hygiene, frequency of application and use of lubrication
- Check the catheter length is suitable for the patient. Is it long enough to drain the bladder?
- Explain how CISC is designed to reduce the risk of infection and improve quality of life
- Only consider prophylactic antibiotics if all other options have been ruled out. Antibiotic prophylaxis should be reviewed every 6 months (NICE, 2018)
- Given the lack of evidence on the use of prophylactic antibiotics for this indication, consider referral to a urologist to ensure appropriate microbiological diagnostics

as bethanechol and distigmine, should not be prescribed for this indication (EAU, 2016).

NICE (2012a) recommends that alpha-adrenoceptor blockers, which help relax the bladder muscles, should not be offered as a treatment for impaired voiding caused by neurological conditions. However, there is anecdotal evidence that alpha-blockers can benefit women with LUT symptoms. These drugs should only be prescribed and administered by a doctor or specialist nurse with expertise in bladder dysfunctions

and with the competency to assess the above bladder problems correctly.

Some patients with incomplete bladder emptying and detrusor overactivity may find the use of a vibrating bladder stimulator (also called a 'buzzer') helpful, as it stimulates reflex bladder contraction. However, the evidence for this is very limited (Prasad et al, 2003).

### Long-term catheterisation

Long-term catheterisation should be offered as a second-line treatment to PwMS with voiding dysfunction that is no longer responsive to CISC or who are no longer able to manage it, or where this therapy is not feasible (Phé et al, 2016a). It can also be offered to patients experiencing side-effects, such as symptomatic urine infections or overflow incontinence, from significant incomplete emptying. The European Association of Urology (BAUS) guideline recommends avoiding indwelling transurethral and suprapubic catheterisation 'whenever possible', due to risks and limitations (EAU, 2016), which can increase morbidity. These risks are listed in *Table 7*. Long-term indwelling urethral catheters should be avoided, due to the risk of urethral injury.

To help reduce this risk, several publications present guidance for increasing the safety of long-term catheterisation (Holroyd, 2021; Hall et al, 2020; European Network for Safer Healthcare, 2021; Wileman et al, 2021; Reid et al, 2021).

Suprapubic catheterisation is preferred over the transurethral route because of its reduced potential for associated complications, including urethral trauma and UTIs (Phé et al, 2016a; Yates, 2016b), its increased acceptability and comfort for patients, and the greater ease afforded during sexual intimacy (Yates, 2016b; Tornic and Panicker, 2018).

This is generally regarded as a safe procedure, although there is a small risk of bowel injury during insertion, which may be reduced if the bladder is fully distended and palpable. Ultrasound-guided insertion is recommended by BAUS (Harrison et al, 2011) and should therefore be used in those in whom the bladder cannot be readily palpated (Hall et al, 2020). Use of a local anaesthetic for insertion in these patients is not advised. Urinary suprapubic catheter kits, which have been shown to reduce catheter-associated urinary tract infections (CAUTI) in the acute setting by up to 80%, may also be considered (Cartwright, 2018; European Network for Safer Healthcare, 2021).

When discussing long-term catheterisation, patients should always be offered the suprapubic option. Silicone catheters are generally preferred over latex, as they are less

susceptible to encrustation and less likely to induce an allergic reaction (EAU, 2016; Tornic and Panicker, 2018). Following insertion, a suprapubic catheter must stay in place for 4–6 weeks, depending on local guidelines, which should be sufficient time for the tract to become established (Wileman et al, 2021).

Anecdotal evidence indicates that use of open-ended catheters can reduce the risk of blockage when this has a tendency to occur.

Catheter management plans or ‘catheter passports’, although not yet widely used, can improve the provision of information to patients and nurses, thereby helping to reduce the risk of infection and supporting patients’ transition from hospital to home (Holroyd, 2021; Prieto et al, 2020). In their consensus document, the BAUS and nurses (BAUN) recommend that all patients should have a catheter passport (Reid et al, 2021). For each catheterisation, a date should be set for renewal or trial without catheterisation (TWOC), depending on individual need (Holroyd, 2021). Reid et al (2021) outline consensus recommendations for the management of complications of long-term indwelling catheters.

Learning to accept a long-term catheter can take many months (Geng et al, 2012); however, the evidence suggests they do not have a detrimental effect on quality of life (Fowler et al, 2014; Yates, 2016b).

Always refer to local guidance or policy on referral pathways for long-term catheterisation, and initial implementation.

Catheter valves can provide an alternative to urine drainage bags (NICE, 2012a). They are indicated for those who:

- Can undergo long-term catheterisation without the need for a drainage bag
- Have failed TWOC
- Have normal renal function
- Require bladder retraining before long-term catheter removal (Carr, 2019)
- Fear that continuous free drainage might lead to a painful, contracted bladder.

Use of catheter valves can help facilitate normal bladder function (filling and emptying). As the catheter is intermittently flushed with urine, there is a reduced risk of loss of bladder capacity (Reid et al, 2021), blockage and risk of infection (Sabbuba et al, 2005; Carr, 2019). There is also a reduced risk of cross-infection, as they are usually applied by the patient (NICE, 2012a).

Patients should be followed up either annually or biennially by either a urologist or neurologist, with assessment including uroflowmetry and renal ultrasound.

**Table 7. Risks associated with long-term catheterisation**

- Associated with an increased risk of catheter-related urinary tract infection (CAUTI); the longer the catheter remains in place, the greater the risk
- Their presence can promote biofilm formation, which can prove resistant to antibiotics and the body’s immune system
- As the bladder does not empty with continuous drainage, bacteria are not flushed away
- The increased risk of infection has an associated health economic cost
- A plan should be in place for early removal, wherever possible

Source: Simpson, 2017

**‘Because I now have a suprapubic catheter and I’m able to drink so much water, it’s the first time I’ve been off antibiotics for about 7 or 8 years. I’m thoroughly resistant to trimethoprim now’**

*Quote from the PwMS on the consensus meeting panel*

## MANAGEMENT OF OVERACTIVE BLADDER SYMPTOMS

### Antimuscarinics

Antimuscarinic drugs, previously known as anticholinergics, have long been established as the first-line treatment for symptoms of neurogenic overactive bladder (NICE, 2012a; EAU, 2016). However, the evidence base for their use in PwMS is very limited (Phé et al, 2016a; Bientinesi et al, 2020), and most recommendations are extrapolated from their use in other neurological and non-neurological disorders (Bientinesi et al, 2020). Systematic reviews do not support the use of any one antimuscarinic drug, so the main consideration in choosing between them for PwMS is their side effect profile, which can include dry mouth, constipation, blurred vision and, particularly for the older antimuscarinics, cognitive impairment; collectively termed the anticholinergic burden, these are known to affect adherence (Panicker and Fowler, 2015a and b; Phé et al, 2016a; Tornic and Panicker, 2018; Lisibach et al, 2021). Box 2 summarises assessment of the anticholinergic burden.

The panel consensus was that the use of older antimuscarinics, such as oxybutynin, should be avoided, as they cross the blood–brain barrier and thus have the

### Box 2. Assessing the anticholinergic burden

Regrettably, no gold standard exists for assessing the ‘anticholinergic burden’—the cumulative negative effect of taking one or more anticholinergic drugs (Lisibach et al, 2021). Different services use different scales of varying quality, and validation studies of the four most often investigated clinical outcomes (cognition, delirium, mortality and falls) have shown contradictory results (Lisibach et al, 2021). Of 19 anticholinergic burden scales identified in an extensive literature search, the anticholinergic cognitive burden (ACB) and German anticholinergic burden scale (GABS) were rated the highest quality (Lisibach et al, 2021).

When a person with multiple sclerosis presents with lower urinary tract symptoms, their medications prescribed should be reviewed, in case the dosage and/or drug interactions are contributing to this outcome.

potential to cause central nervous system side effects (NICE, 2012a). The newer antimuscarinics, such as solifenacin, tolterodine and fesoterodine, are associated with a much lower risk of side effects in general, so would generally be preferable (Herschorn et al, 2010; Tornic and Panicker, 2018). Darifenacin and trospium chloride have a beneficial neurological adverse event profile, so might be considered in PwMS with more advanced disease (Phé et al, 2016a; Tornic and Panicker, 2018). Treatment should be started with a low dose, which can subsequently be raised, depending on the patient’s response and occurrence of side effects. Two different antimuscarinics would usually be tried before a second-line treatment is considered (Tornic et al, 2018).

Non-pharmacological options for this indication also exist. Tibial neuromodulation (electrical stimulation of the tibial nerve), which can be used as an alternative to or in combination with antimuscarinics, has been found to be a safe and effective treatment for the overactive bladder (Panicker, 2020; Karademir et al, 2005; Peters et al, 2010; Sancaktar et al, 2010; Vecchioli-Scaldazza et al, 2018). The stimulation results in neuromodulation of the sacral nerve plexus that controls bladder function (Bhide et al, 2020). Application methods include percutaneous needle electrode and transcutaneous surface electrode; wireless implantable stimulators are in development (Bhide et al, 2020).

Other options are hyperbaric oxygen and intravesical vanilloids. Although there is some anecdotal support for the use of hyperbaric oxygen to manage bladder symptoms, there is no robust research evidence to support this. A meta-analysis found that intravesical vanilloids might be effective for treating neurogenic lower urinary tract dysfunction, but there are concerns about its safety profile (Phé et al, 2018).

Figure 4 illustrates a treatment pathway for PwMS presenting with LUT symptoms.

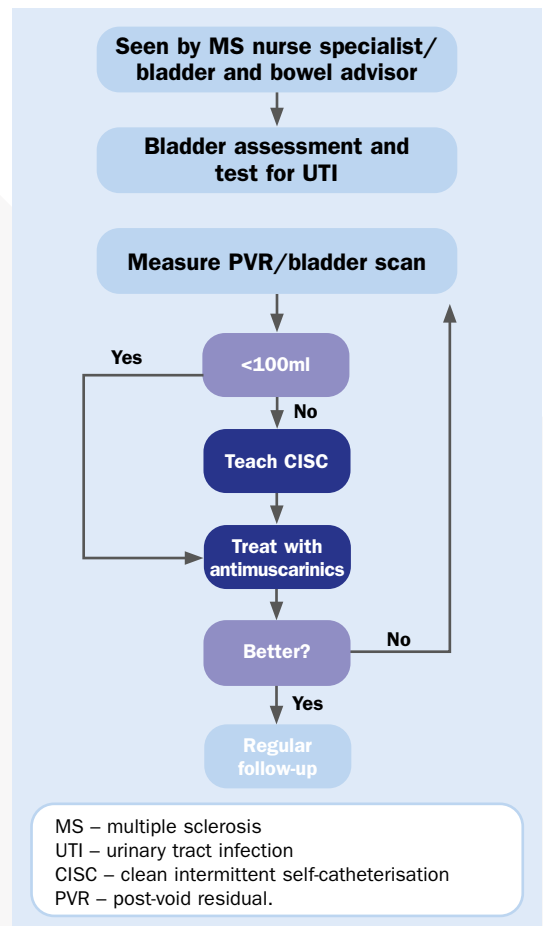


Figure 4. Treatment pathway

### Other drug treatments

The  $\beta_3$ -receptor agonist, mirabegron, is being increasingly used in combination with or as an alternative to antimuscarinics for the treatment of overactive bladder (Tornic and Panicker, 2018). Data on its efficacy and safety in PwMS are limited (Tornic and Panicker, 2018). However, critically, it is devoid of anticholinergic side effects (Panicker, 2020) and has good tolerability; potential adverse reactions are hypertension, palpitations and headache (Tornic and Panicker, 2018).

Given as a single agent in a randomised controlled trial, mirabegron demonstrated significant improvements in patient-reported outcomes and urodynamic variables in patients with neurogenic detrusor overactivity (NDO) associated with MS or spinal cord injury (Krhut et al, 2018). In an open-label study involving PwMS with NDO who had failed solifenacin therapy, 12 weeks’ treatment with a combination of mirabegron and desmopressin was associated with significant improvements in urinary

### Box 3. Key components of a continence care bundle

Although, as yet, there is no national continence care bundle, its development and implementation would benefit patients with multiple sclerosis (PwMS). Hillingdon Hospitals NHS Foundation Trust has developed a local continence care bundle. The key components of this bundle, in relation to patients with PwMS, are:

- Assessment
- Dipstick urinalysis
- Pre- and post-void bladder scanning
- Maintenance of a bladder diary, as well as frequency and volume charts, alongside the provision of bladder self-help information

frequency, urgency and episodes of incontinence (Zachariou et al, 2017). Furthermore, 12 months' combination treatment with mirabegron and solifenacin in patients with overactive bladder in a randomised, multicentre trial led to a greater improvement in symptoms than with either drug alone, for all ages (Gratzke et al, 2018; Mueller et al, 2019).

The synthetic vasopressin (antidiuretic hormone), desmopressin, is effective for the treatment of nocturia in PwMS with overactive bladder symptoms (Fowler et al, 2009; Tornic and Panicker, 2018). Hyponatraemia is a common side effect, followed by urinary retention and headache, thus sodium levels need to be monitored at 6-monthly intervals as a matter of course, and more frequently in those at increased risk of hyponatraemia (women, older patients and those with pre-existing cardiac disease or elevated 24-hour urine volumes) (Fowler et al, 2009; Tornic and Panicker, 2018). It should not be used more than once every 24 hours (Fowler et al, 2009; Tornic and Panicker, 2018).

Cannabinoids may be effective for treating LUT symptoms in some PwMS, and are well tolerated (Phé et al, 2016a; Tornic and Panicker, 2018; Bientinesi et al, 2020). Moreover, a review has suggested they may be useful in treating a broad range of MS symptoms in tandem (Fernández et al, 2020). However, the evidence base for cannabinoids in the treatment of neurogenic bladder is 'highly inadequate' (Bientinesi et al, 2020), a view supported by others (Phé et al, 2016a; Tornic and Panicker, 2018). Therefore, more high-quality studies are needed to reach definite conclusions (Abo Youssef et al, 2017). Tetrahydrocannabinol-cannabidiol (THC/CBD) oromucosal spray is licensed to treat

### Home testing kits

In 2019–2020, there were 690 emergency admissions for patients with multiple sclerosis (PwMS) in the Surrey area. At the start of the COVID-19 pandemic, the team was concerned that there would be an increase in hospital admissions in PwMS with a urinary tract infection (UTI). To address this, in 2020, Ruth Stross, Multiple Sclerosis Nurse Specialist, in collaboration with Sue Thomas, MS Academy and MS Trust, developed a home urine test kit for use by PwMS at Surrey Downs Health and Care service. Patients self-collect urine at home and email the service for the results. This is designed:

- For patients with a suspected UTI
- For patients taking disease-modifying therapy that requires urine testing
- To rule out UTI if there is a suspected relapse.

The test kit comprises a letter, instructions, a dipstick, pot and envelope. It is designed to be simple and easy to use (no training is required).

Patients email the results to the MS coordinator, who feeds them to the clinical team. Patients with abnormal results are asked to take a sample to their GP for further testing.

The testing kit has been peer reviewed by local MS nurse specialists and practitioners, and has been endorsed by the MS Trust and MS Academy.

Patients feedback includes:

- 'I like having the kit at home, as find it really difficult to give a sample at the GP and I think with practice it will just become easier.'
- 'As for the testing kit, an uneventful experience that does indeed mean the process takes minutes, not hours. I debated its cost effectiveness compared to the test in hospital approach, but suspect it is a good solution all round, especially when considering my reduced environmental impact from not driving just to have the test.'

symptoms of spasticity in PwMS, but no cannabinoid is licensed for symptoms of overactive bladder (Phé et al, 2016a; Fernández et al, 2020).

### Botulinum toxin type A

Bladder wall injections of botulinum toxin type A (onabotulinumtoxin A) are well established as a second-line treatment for neurogenic detrusor overactivity (Tornic and Panicker, 2018), with proven efficacy in phase 3 randomised controlled trials (Schurch et al, 2005; Cruz et al, 2011; Ginsberg et al, 2012) and systematic reviews (Mehta et al, 2013, as reported in the EAU guidelines (2016)). Efficacy

is retained with repeated injections (Ginsberg et al, 2017), although declines with the progression of MS (Tornic and Panicker, 2018). This is a specialist procedure, requiring 20–30 injections via cystoscopy, usually under local anaesthesia (Panicker et al, 2015b). The most frequent adverse effects are urinary retention and UTIs (EAU, 2016), thus most people need to use CISC following treatment. NICE accordingly recommends offering botulinum toxin type A to PwMS with symptoms of overactive bladder that are unresponsive to antimuscarinics, or in whom antimuscarinics are poorly tolerated (NICE, 2012a), with the caveats that healthcare professionals should explain the need for catheterisation beforehand and ensure that people are able and willing to manage such a regimen if urinary retention develops following treatment (NICE, 2012a).

It is worth noting that Khavari et al (2019) conducted an intriguing small-scale study involving fMRI imaging to measure brain activity concurrently with urodynamic studies in 12 women with MS prior to and after treatment with botulinum toxin A. The results identified botulinum toxin-treatment activation of most motor and sensory brain regions involved in bladder dysfunction (Khavari et al, 2019). The demonstration of active brain involvement in neurogenic overactive bladder suggests a potential for phenotyping patients to optimise therapy; this would require confirmation in further studies (Khavari et al, 2019).

**Some people with MS are starting to veer away from antimuscarinic because they're finding out about the cognitive impact ... I was offered them but decided not to take them I've seen a lot of talk online by patients who said they were going to talk to their teams about changing their drugs because of the anticholinergic burden. It's so important to ensure that people with MS are made aware of the issues so that they can make an informed decision'**

*Quote from the PwMS on the consensus meeting panel*

### Self-management

Some LUT symptoms, such as nocturia, can be self-managed by patients, supplementing therapeutic approaches, prescribed by specialists, for what is often a complex presentation. Self-management will require a holistic assessment, engagement and collaboration with patients, provision of clear and accessible patient information, and ongoing follow-up and support. It can be helpful to direct people to local and online sources of advice and information. More literature and evidence is required on this topic. As an example,

*Table 8* outlines the principles of self-management for nocturia in PwMS, which can be undertaken alongside specialist interventions. *Figure 5* illustrates a self-management pathway, recommended by the panel.

### PREVENTION AND MANAGEMENT OF INFECTION: KEY RECOMMENDATIONS

Stagnant urine, caused by the bladder not emptying fully, can provide a good environment for bacterial proliferation and, thus, UTIs; as such, these infections are common in PwMS. UTI symptoms can be confused with other MS symptoms such as fatigue. If left untreated, they can be a trigger for spasticity or cause a relapse, which may lead to sepsis. *Table 9* summarises the key components of management of CAUTIs and UTIs.

Complementary options for self-management include cranberry juice, probiotics and d-mannose supplements, for which there is anecdotal but not much research evidence on their efficacy.

Other non-antibiotic management options include use of urinary antiseptics, alkalinising agents and sodium hyaluronate; all are considered promising, but require

**Table 8. Key components of self-management of nocturia**

- Restrict fluid intake before bedtime
- Empty the bladder before bedtime
- Restrict caffeine, carbonated drinks and alcohol intake in the evenings
- Take diuretics 5–6 hours before bedtime
- Optimise the sleeping environment
- Pelvic floor exercises and practise urge suppression techniques
- Moderate exercise, if indicated
- Weight loss, if indicated

Source: Yates, 2017



large-scale studies to support initial findings, and none have been evaluated on just PwMS cohorts. Suitable for use as a treatment and prophylaxis, the urinary antiseptic methenamine hippurate was found by a Cochrane review of 13 studies to have a good safety profile, no antimicrobial resistance and to reduce the risk of recurrent UTIs in patients with a normal renal tract (Lee et al, 2012). Although its mode of action is not fully understood, urinary alkalinisation has been reported to reduce symptoms of dysuria and UTI recurrence; unfortunately, a Cochrane review identified 172 studies for appraisal, but none met its inclusion criteria (O’Kane et al, 2016). Instillation with sodium hyaluronate can protect the bladder mucosal glycosaminoglycan (GAG) layer, and thus epithelium, from bacterial virulence factors and biofilm formation. Again, there is supporting evidence for this (Madersbacher et al, 2013; Vedanayagam et al, 2013; Batura et al, 2019), but these need to be substantiated by large-scale studies (Bonkat et al, 2021).

## BEHAVIOURAL MANAGEMENT OF STRESS INCONTINENCE

Stress urinary incontinence (SUI), leakage of urine associated with physical exertion, coughing or laughing, is a common comorbidity in PwMS, and typically not related to the MS disease process (Gelfand, 2014). It is roughly twice as common in women as in men, though prevalence estimates vary. Nazari et al (2020) report a prevalence of SUI symptoms in women and men of 33.8 and 17.2%, respectively, figures that are in line with those in the wider UK population (Pelvic Floor Society, 2021). An overall prevalence of 56% is frequently reported, and it often occurs together with overactive bladder symptoms, as mixed urinary incontinence (MUI) (Phé et al, 2016a) and with bowel problems and sexual dysfunction, two other disorders that affect the pelvic floor (Mahajan et al, 2014).

Pelvic floor exercise for SUI is discussed above. Drug treatment should not be given for neurogenic SUI (EAU, 2016). Therefore, patients who do not respond to at least 3 months of pelvic floor muscle training are generally recommended for surgery (NICE, 2019; Panicker, 2020). It is important to provide PwMS with information on all the treatment options at this stage (Bombieri and Freeman, 2003; Continence Care Steering Group, 2014)

## SURGICAL TREATMENTS

Surgical treatments have a limited but valuable role in the management of bladder dysfunction in PwMS. The vast majority of such patients can be successfully managed with conservative means (oral medication, intravesical

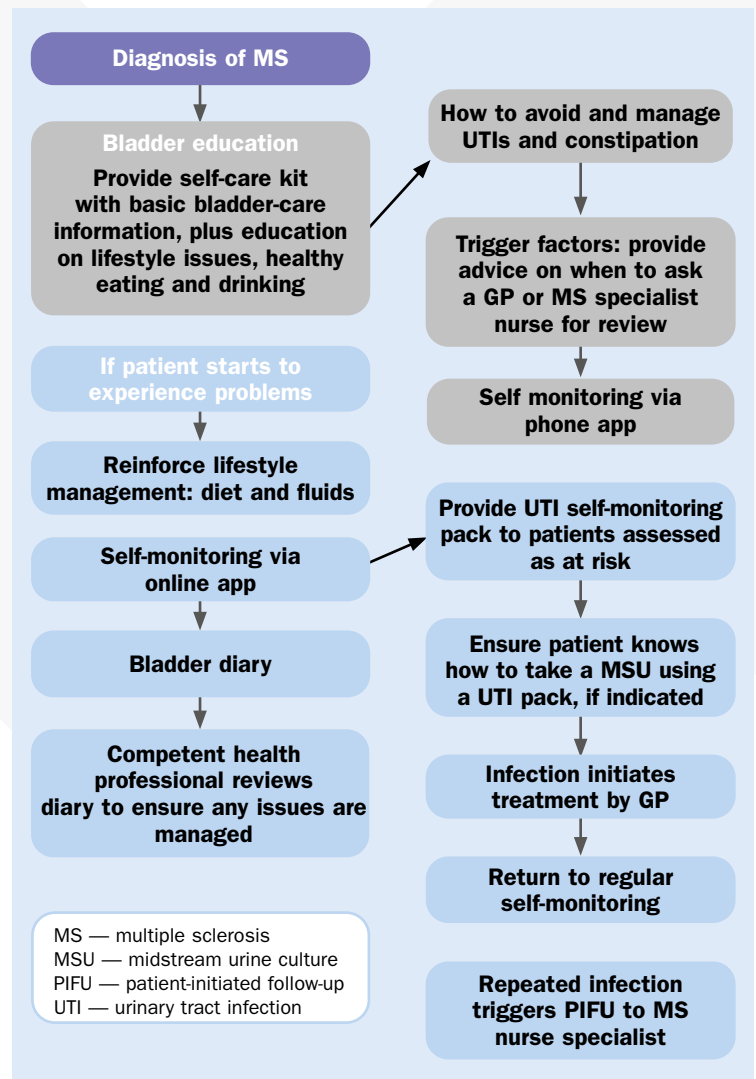


Figure 5. Self-management pathway

botulinum toxin injections and CISC). However, there are a number for whom these measures will be insufficient, and who will benefit from surgery.

Sacral neuromodulation is a recognised treatment for idiopathic detrusor overactivity and non-obstructive retention of urine. It has been used in PwMS and some small case series have reported good results, but the results are variable and it is not yet a recommended treatment (Rahnama'i, 2020). It may be considered an option in patients who have failed to respond to intravesical botulinum toxin injections.

PwMS with stress urinary incontinence should be offered the same surgical treatments (periurethral bulking injections, autologous fascial slings, colposuspension and

implantation of artificial urinary sphincter) as patients without MS who have this disorder (NICE, 2012a).

Intramural injection of bulking agent can be considered for patents with SUI when surgical treatments are either

not suitable or acceptable, subjected to informed patient consent. This includes women who wish to delay definitive surgery until after they have had children (McGowan et al, 2020). These agents create additional bulk to the urethral submucosa, to help promote closure at rest (McGowan et al, 2020). The procedure can be conducted under local anaesthetic and is in line with the recommendations of expert practitioners (Panicker et al, 2015). NICE (2019) notes a lack of evidence on the long-term efficacy and safety of bulking agents, but also that many women find such treatment helpful (Bombieri and Freeman, 2003), and that it may avoid the need for more invasive surgery, such as surgical mesh implantation, which caused painful side effects in some women (Baroness Cumberlege Report, 2020).

In PwMS who have neurogenic detrusor overactivity resistant to oral medication and botulinum toxin injections, augmentation cystoplasty may be appropriate. It may also be appropriate to simultaneously create a continent catheterisable abdominal stoma (Mitrofanoff) to facilitate CISC. Cystoplasty should only be offered to patients able to perform CISC and who are likely to be able to continue with this, eg those with adequate hand function and low probability of progression that will prevent them self-catheterising in future. In suitable patients, good results are reported (Kalkan et al, 2019).

Some PwMS become intolerant of catheters due to frequent catheter blockages and/or urinary infections leading to sepsis, stone formation and/or urethral erosion and frequent peri-catheter leakage. In such cases, insertion of a suprapubic catheter and injection of botulinum toxin may resolve the problems. If this does not, then formal urethral closure with permanent bladder drainage via a suprapubic catheter or the formation of an ileal conduit urinary diversion should be considered. If an ileal conduit is created, simultaneous simple cystectomy to prevent the future risk of pyocystis should be considered.

Transvaginal urethral closure has a high failure rate with 10% requiring secondary revision and 4% needing an ileal conduit to achieve continence (Eckford et al, 1994).

Ileal conduit urinary diversion is a major procedure, but there is good evidence that in PwMS it is an effective option with similar perioperative morbidity rates (26%) and long-term complication rates (31%) as in patients with other indications (Akakpo et al, 2020). Minimally invasive surgical approaches with laparoscopy and robotic assistance may further reduce morbidity without compromising effectiveness (Guillotreau et al, 2012).

Many PwMS express concern that having surgery and anaesthetics may provoke relapse of their MS. Studies

**Table 9. Management approaches for catheter-associated urinary tract infections and urinary tract infections**

Catheter-associated urinary tract infections (CAUTIs)	Urinary tract infections (UTIs)*
Multidisciplinary collaboration is essential	Signs and symptoms should be assessed on the day of presentation
Patient education is vital to ensure that patients and their families can make informed decisions about catheter selection and use. They also need to be aware of the difference between asymptomatic and symptomatic bacteriuria	On the same day, a clean midstream urine sample should be obtained, tested with a dipstick and a culture and susceptibility (C&S) sought
Local guidance and policy are needed to promote a standardised approach to prevention and management among different settings	In the case of CAUTI, a sample should be taken from the sampling port and sent for culture and the catheter changed as soon as possible
Documentation should be consistent within different local settings	Following this, antibiotic therapy should be initiated, and treatment determined based on patient history and presentation
Increase access to bladder scanners, along with training on how to use them	Patient should be told to phone if no improvement in 48–72 hours  Some 24–48 hours after presentation, if urine culture is negative, discontinue antibiotic therapy; if positive, adjust antibiotics as required
	A follow-up appointment (or telephone/online video review) should take place 14–21 days after the start of the antibiotic treatment. Repeat urine culture is only required if patient is symptomatic or pregnant. Consider undertaking a repeat dipstick test, particularly if the presence of blood or protein has been detected in the initial dipstick test
	Assess for recurrent UTIs at 6 months (two infections) and 12 months ( $\geq$ three infections) (Multiple Sclerosis and Management of Urinary Tract Infection, Clinical Practice Guideline, 2013)

\*Key recommendations for patients in primary care  
Source for CAUTIs: Public Health England, 2021



have not found an increase in relapse rates associated with surgery and anaesthesia (De Lott et al, 2020). When PwMS require surgery, this should be carried out in centres which regularly undertake anaesthesia and surgery on PwMS. In such centres, the staff will be familiar with all the issues associated with MS and be able to care for PwMS appropriately.

## MEDICAL DEVICES

There is a wide and growing range of medical devices to help control and/or collect urine leakage and preserve patients' comfort and dignity when incontinence persists despite treatment, or decreasing mobility restricts people's ability to use a regular toilet. These include urinary sheaths and body-worn urinals for men, intravaginal tampons or pessaries and intraurethral mechanical devices for women, hand-held urinals for outdoor use for both sexes, bed urinals for both sexes, pubic pressure devices, such as certain briefs and toileting aids, such as toilet raisers and toilet frames (Lipp et al, 2014; Abrams et al, 2016). While patients and healthcare practitioners may find many of these devices useful, evidence for their value is often missing or poor (Lipp et al, 2014; Abrams et al, 2016), and NICE cautions against intravaginal and intraurethral devices for the management of urinary incontinence in women, other than for occasional use as necessary (NICE, 2019). Individual assessment by a bladder and bowel specialist team or community nurse is always important to ensure the best fit for a person's needs.

Smart devices will undoubtedly see increasing take-up over the coming decade, both for auto-injection treatment and monitoring (Marziniak et al, 2018; Mountford, 2018). Some provide patient advice and education, while others facilitate self-management, MS disease screening and remote assessment and monitoring via smartphone apps—an area with considerable scope for development (Mountford, 2018). Bladder and bowel nurse practitioners on the panel were finding the NHS 'Squeezy' app invaluable for PwMS who needed pelvic floor muscle exercise training, while one of the neurologists was piloting remote management and consultation with their PwMS patients, with promising early results.

## CONCLUSION

Although there has been much progress since publication of the Fowler UK consensus document in 2009, with, for example, the emergence of treatments with a lower anticholinergic burden for an overactive bladder, there is still some way to go to address the escalating health and economic burden posed by LUT dysfunction in PwMS.

The incidence of hospital admissions for UTIs is increasing, with potentially devastating consequences for patients. There are also worrying reports of regional variations in specialist continence care offered to PwMS.

As the risk of LUT dysfunction increases with the severity and duration of MS, a multifaceted, multidisciplinary patient-focused approach is clearly needed to address this. The recommendations presented here offer strategic direction, with a call for a bladder management pathway to be integrated into the optimum MS care pathway, which should lead the way to more collaboration between MS and continence care services, with improved protocols for referrals. It is hoped this will help address unwarranted variations in care offered to PwMS with bladder problems. Central to good outcomes is the panel's recommendation that all PwMS should be offered a structured self-management plan supplemented with educational and health professional support.

The panel recommendations presented here offer a route map whereby the multidisciplinary team and PwMS can work together to address the problems highlighted throughout this document. The effectiveness of such an approach can be assessed by ongoing audit of recurrent admissions of PwMS with UTI and/or sepsis, which will help build a framework for future innovation.

It is hoped this latest UK consensus document will build on the achievements of the Fowler publication, and help mitigate the risk of LUT dysfunction and UTI among PwMS.

## RECOMMENDATIONS

RECOMMENDATIONS	ACTIONS	OWNERS	TIMESCALE
<p><b>Self-management</b></p> <p>Offer PwMS a bladder self-management programme</p>	<p>Present a bladder self-management programme comprising a written personalised action plan, supported with education</p> <p>Provide access to online bladder management apps or other accessible educational materials; these can support self-management, as well as help people understand problems that may arise and seek timely help</p> <p>Ensure PwMS have information and contact details so they can access services in a timely manner. Include advice on how to contact their HCP if problems develop or deteriorate (patient-initiated follow-up)</p> <p>Provide PwMS with a home urinalysis and MSU test kit with instructions for use to support prompt UTI management</p>	<p>Local MS and bladder and bowel services</p> <p>Commercial providers; MS services; National Bladder and Bowel Health Project</p> <p>Integrated care systems; primary care networks</p> <p>Integrated care systems; primary care networks</p>	<p>Within 6 months of publication of this consensus document</p>
<p><b>MS continence care bundle</b></p> <p>Develop a continence care bundle to standardise practice</p> <p>A care bundle is a collection of 3–5 key evidence-based process measures or interventions that are known to improve care if consistently performed (Box 3, page S19). A continence care bundle can also include provision of lifestyle information and literature on bladder management awareness.</p> <p>Care bundles have been demonstrated to contribute to improvements in care quality and safety</p>	<p>Each MS and continence service should implement the continence care bundle</p> <p>Undertake a structured clinical assessment of the bladder if bladder symptoms are reported by the patient or identified at the annual MS review, or the patient develops LUT dysfunction.</p> <p>The clinical history should include:</p> <ul style="list-style-type: none"> <li>■ Urinary tract symptoms</li> <li>■ Bowel symptoms</li> <li>■ Sexual dysfunction</li> <li>■ Comorbidities</li> <li>■ Use of prescription/other medications and therapies.</li> </ul> <p>Also, check for:</p> <ul style="list-style-type: none"> <li>■ Red flags: haematuria, recurrent infections, loin pain and biochemical evidence of deteriorating renal function</li> <li>■ Infection: dipstick and MSU, if indicated</li> </ul> <p>Measure the PVR:*</p> <ul style="list-style-type: none"> <li>■ 100 ml: recommend CISC management (gold standard)</li> <li>■ &lt;100 ml: treat with antimuscarinics (anticholinergic burden caution)</li> <li>■ Offer support post-CISC to maintain adherence *(see Figure 4 on page S18)</li> </ul> <p>Referral criteria for specialist urology review should be available to the MS nurse specialist</p> <p>PwMS with LUT symptoms should be under the care of an HCP with the competency to assess or refer to the specialist bladder and bowel team (CCSG, 2014)</p> <p>Systems should be in place to improve CISC uptake</p> <p>Undertake an annual review of CISC technique, including frequency of application and suitability of the catheter. Promote use of no-touch technique. Refer to a urologist if there has been a history of UTIs that have not responded to treatment</p>	<p>Bladder and bowel services or MS clinical nurse specialist</p> <p>National agreement through the NAAG</p> <p>International Continence Society</p> <p>Promotion through patient organisations, charities and non-profit organisations, such as the MS Society, MS Trust, Neurological Alliance and MS Academy</p>	<p>Within 12 months</p>

<p><b>Promote NNAG MS optimum pathway</b></p> <p><b>Implement local bladder management pathways</b></p> <p>Pathways can improve outcomes in PwMS, optimise the skills of neurologists and MS nurse specialists in the management of MS and avoid service duplication (Fuller, 2021)</p> <p>Local pathways should take into account access to specialist bladder and bowel advisers and other services</p>	<p>MS services should implement a bladder management pathway</p> <p>Implementation of the pathway could identify the need for additional workforce capacity</p> <p>Pathway audit can highlight a range of opportunities for improving bladder and bowel management services and thus patient outcomes (Metcalf and Owen, 2021)</p>	<p>MS optimum pathway: NNAG</p> <p>Local MS and bladder and bowel pathways: promote examples of good practice in pathway implementation via the MS Trust, MS Society, MS Academy and Shift.ms</p>	<p>Within 12 months</p>
<p><b>IT solutions for care</b></p> <p>Use of technology should be integral to the delivery of continence care.</p> <p>Technology should help facilitate self-care, connect patients and caregivers, and enable providers to monitor progress and troubleshoot problems</p>	<p>Deploy new technologies to enhance MS (Fuller, 2021) and continence services. Ensure these are available to PwMS</p> <p>Where clinically appropriate, offer virtual consultations in line with the NHS Long Term Plan (NHS, 2019) and the ambitions of the Outpatient Transformation Programme. To ensure equity of access to care, face-to-face appointments should be offered when clinically indicated or requested</p> <p>Consider using an online questionnaire to take a patient's history prior to a consultation. An alternative approach will be needed for those with no internet access or limited literacy</p> <p>Provide patients with access to telephone helplines, which can improve efficiency and capacity, and digital apps and evidence-based information on approved websites, which can support self-management. Apps and approved websites can also provide comprehensive resources and education</p> <p>When developing local/regional solutions, consider the role of private providers in improving support, efficiencies and maintain quality should</p>	<p>NHSE/1</p> <p>MS/continence services</p> <p>Bladder and bowel providers</p>	<p>Within 12 months</p>
<p><b>Education</b></p> <p>Ensure bladder dysfunction is part of ongoing education and ensure all health and care professionals who are likely to provide care to PwMS are aware of MS bladder dysfunction and its management strategies</p>	<p>Ongoing education on the bladder should be available to HCPs managing PwMS</p> <p>Assessment and management of LUT dysfunction in PwMS should be in line with the cascading ownership of LUT dysfunction described in the Excellence in Continence Care guidelines (NHS England, 2018)</p> <p>Ensure there is continence/urology workforce engagement in local MS networks. This could facilitate virtual discussions and educational opportunities</p> <p>For PwMS practising CISC, provide ongoing support and education, including on no-touch technique, to reduce the risk of UTI</p>	<p>Education providers</p> <p>Health Education England; MS Trust; MS Society; MS Academy; Royal Colleges; BAUN; RCN Continence Care Forum; Association for Continence Advice</p>	<p>9 months</p>

<p><b>UTI management</b></p> <p>UTIs are a frequent cause of admission in MS</p>	<p>Ensure PwMS receive educational materials on the potential problems that can arise</p> <p>Provide PwMS assessed as at risk of UTI with a self-help testing kit</p> <p>If the dipstick test result and the patient's clinical signs are indicative of infection, urine bacterial culture and antibiotic sensitivity tests should be performed before starting antibiotic treatment. Treatment need not be delayed, but may be adapted when the results are available (NICE, 2012a)</p> <p>Be aware that the urine of people who use a catheter will be colonised with bacteria, and thus urine dipstick testing and bacterial culture might be unreliable for diagnosing active infection (NICE, 2012a)</p> <p>Refer PwMS for urgent investigation if they have red flag' signs and symptoms such as, haematuria and recurrent UTI (for example, three or more infections in the past 6 months)</p> <p>Clear, easy-to-follow guidance should be available for HCPs on the UTI management of PwMS. Link with Public Health England and Royal College of Pathologists when developing guidance and empiric antibiotic management of UTI</p> <p>NHS trusts should track and highlight recurrent admissions of PwMS with UTI/sepsis, either as part of their safety thermometer for UTI or a national database of recurrent UTI or CAUTI</p>	<p>Local bladder and bowel services and MS services</p>	<p>Within 12 months</p>
<p><b>Data collection</b></p>	<p>Consider developing a data dashboard with routinely collected data. This will enable monitoring of key metrics and thus support ongoing quality improvement</p> <p>Each ICS should be aware of the number of emergency admissions of PwMS, the associated costs and, in particular, the incidence of UTI in this group</p> <p>NHS trusts should track and highlight recurrent admissions of PwMS with UTI/sepsis, either for their UTI safety thermometer or in a national database of recurrent UTI or CAUTI</p> <p>A&amp;E attendance by or hospital admission of a PwMS should trigger a MS nurse-led clinic follow-up review (NHS England, 2018) to address the reason for attendance/ admissions and determine the management required to avoid further admission (Metcalf and Owen, 2021)</p>	<p>Local bladder and bowel services and MS services</p>	<p>Within 12 months</p>
<p><b>Ongoing care</b></p>	<p>Ensure PwMS undergo a bladder assessment as part of their annual MS review</p> <p>Audit number of patients having a bladder assessment as part of annual review</p>	<p>MS services</p>	<p>Within 12 months</p>

<b>Continence and urology services</b>	<p>All integrated care systems should have explicit links to bladder and bowel services and urology services, so that MS teams are aware of specialist advice and referral routes</p> <p>Joint MS, bladder and bowel clinics and urology clinics should be available, where possible</p> <p>MS networks should be available to facilitate virtual discussions and educational opportunities</p> <p>A UK map of bladder and bowel services and urology services would help streamline referral pathways</p>	Bladder and Bowel Foundation	6 months
--	--	------------------------------	----------

CAUTI – catheter-associated urinary tract infection; CISC – clean intermittent self-catheterisation; HCP – healthcare professional; ICS: integrated care systems; LUT – lower urinary tract; MS – multiple sclerosis; MSU – midstream urine culture; NNAG – National Neuroscience Advisory Group; PVR – post-residual volume; PwMS – patients with multiple sclerosis; UTI – urinary tract infection

## References

- Abo Youssef N, Schneider MP, Mordasini L et al. Cannabinoids for treating neurogenic lower urinary tract dysfunction in patients with multiple sclerosis: a systematic review and meta-analysis. *BJU Int.* 2017; 119(4):515–21. <https://doi.org/10.1111/bju.13759>
- Abrams P, Cardozo L, Wagg A, Wein A (eds). *Incontinence* (6th edn). 6th International Consultation on Incontinence, Tokyo, Japan. 2016. <https://tinyurl.com/ydzkhevq> (accessed 14 January 2022)
- Akakpo W, Chartier-Kastler E, Jousain C et al. Outcomes of ileal conduit urinary diversion in patients with multiple sclerosis. *NeuroUrol Urodyn.* 2020; 39(2): 771–7. <https://doi.org/10.1002/nau.24279>
- Al Dandan HB, Coote S, McClurg D. Prevalence of lower urinary tract symptoms in people with multiple sclerosis: a systematic review and meta-analysis. *Int J MS Care.* 2020a; 22(2):91–9. <https://doi.org/10.7224/1537-2073.2019-030>
- Al Dandan HB, Galvin R, McClurg D et al. Management strategies for neurogenic lower urinary tract dysfunction: a qualitative study of the experiences of people with multiple sclerosis and healthcare professionals. *Disabil Rehabil.* 2021;1–11. <https://doi.org/10.1080/09638288.2021.1887378>
- Avery K, Donovan J, Peters TJ, Shaw C, Gotoh M, Abrams P. ICIQ: a brief and robust measure for evaluating the symptoms and impact of urinary incontinence. *NeuroUrol Urodyn.* 2004; 23(4): 322–30. <https://doi.org/10.1002/nau.20041>
- Avery M, Prieto J, Okamoto I et al. Reuse of intermittent catheters: a qualitative study of IC users' perspectives. *BMJ Open.* 2018; 8(8):e021554. <https://doi.org/10.1136/bmjopen-2018-021554>
- Balhi S, Khalil Mrabet M. Teaching patients clean intermittent self-catheterisation: key points. *Br J Comm Nurs.* 2020. 25(12): 586–93. <https://doi.org.10.12968/bjcn.2020.25.12.586>
- Baroness Cumberlege. First do no harm. Report of the independent medicines and medical devices safety review. 2020. <https://tinyurl.com/54kderyb> (accessed 14 January 2022)
- Batura D, Warden R, Hashemzahi T, Figaszewska MJ. Intravesical sodium hyaluronate reduces severity, frequency and improves quality of life in recurrent UTI. *Int Urol Nephrol.* 2020; 52(3): 495. <https://doi.org/10.1007/s11255-019-02337-5>
- Bhide AA, Tailor V, Fernando R, Khullar V, Digesu GA. Posterior tibial nerve stimulation for overactive bladder: techniques and efficacy. *Int Urogynecol J.* 2020; 31(5):865–70. <https://doi.org/10.1007/s00192-019-04186-3>
- Biontinesi R, Gandi C, Bassi P. Managing urological disorders in multiple sclerosis patients: a review of available and emerging therapies. *Int NeuroUrol J.* 2020; 24(2):118–26. <https://doi.org/10.5213/inj.2040028.014>
- Bombieri L, Freeman RM. Surgery for stress urinary incontinence. *Current Obstetrics Gynaecology.* 2003; 13(5):287–93. [https://doi.org/10.1016/S0957-5847\(03\)00047-7](https://doi.org/10.1016/S0957-5847(03)00047-7)
- Bonkat G, Bartoletti R, Bruyère T et al. EAU guidelines on urological infections. 2021. <https://uroweb.org/guideline/urological-infections/> (accessed 15 November 2021)
- Booth L, Evans S, Fraser S, et al. How to engage and educate patients, healthcare professionals and the public about Pelvic floor disorders and their treatment. The Pelvic Floor Society 2021. <https://tinyurl.com/eyt2vvtj> (accessed 12 November 2021)
- Browne C, Salmon N, Kehoe M. Bladder dysfunction and quality of life for people with multiple sclerosis. *Disabil Rehabil.* 2015; 37(25):2350–8. <https://doi.org/10.3109/09638288.2015.1027007>
- Brucker BM, Nitti VW, Kalra S et al. Barriers experienced by patients with multiple sclerosis in seeking care for lower urinary tract symptoms. *NeuroUrology and Urodynamics.* 2017; 36(4):1208–13. <https://doi.org/10.1002/nau.23101>
- Cabreira V, Abreu P, Maia C et al. Trends in hospital readmissions in Multiple Sclerosis patients between 2009 and 2015. *Mult Scler Relat Disord.* 2020; 45:102396. <https://doi.org/10.1016/j.msard.2020.102396>
- Carr S. Catheter valves: retraining the bladder to avoid prolonged

- catheter use. *J Comm Nurs*. 2019; 33(3):46–51
- Cartwright A. Reducing catheter-associated urinary tract infections: standardising practice. *Br J Nurs*. 2018; 27(1):7–12. <https://doi.org/10.12968/bjon.2018.27.1.7>
- Castel-Lacanal E, Gamé X, De Boissezon X et al. Impact of intermittent catheterization on the quality of life of multiple sclerosis patients. *World J Urol*. 2013; 31(6):1445–50. <https://doi.org/10.1007/s00345-012-1017-8>
- Celius EG, Thompson H, Pontaga M et al. Disease progression in multiple sclerosis: a literature review exploring patient perspectives. *Patient Prefer Adherence*. 2021; 15:15–27. <https://doi.org/10.2147/PPA.S268829>
- Collie M, Mackay G, Randall J, Sahai A, Thiruchelvam N, Knowles C. How we can ensure that patients consistently receive appropriate and expert care. In: seizing the opportunity to improve patient care: pelvic floor services in 2021 and beyond. *Pelvic Floor Society*. 2021. <https://tinyurl.com/4jepd2na> (accessed 12 November 2021)
- Continence Care Steering Group. Minimum Standards for continence care in the United Kingdom. 2014. <https://tinyurl.com/35bpk5kf> (accessed 12 November 2021)
- Cruz F, Herschorn S, Aliotta P et al. Efficacy and safety of onabotulinumtoxinA in patients with urinary incontinence due to neurogenic detrusor overactivity: a randomised, double-blind, placebo-controlled trial. *Eur Urol*. 2011; 60(4):742–50. <https://doi.org/10.1016/j.eururo.2011.07.002>
- De Lott LB, Zerafa S, Shedden K et al. Multiple sclerosis relapse risk in the postoperative period: Effects of invasive surgery and anesthesia. *Mult Scler Relat Disord*. 2020; 26(11):1437–40. <https://doi.org/10.1177/1352458519860304>
- Dobson R, Dassin P, Roberts M et al. UK consensus on pregnancy in multiple sclerosis: 'Association of British Neurologists' guidelines. *Pract Neurol*. 2019; 19(2):106–14. <https://doi.org/10.1136/practneurol-2018-002060>
- Domurath B, Kurze I, Kirschner-Hermanns R et al. Neurourological assessment in people with multiple sclerosis (MS): a new evaluated algorithm. *Mult Scler Relat Disord*. 2020; 44:102248. <https://doi.org/10.1016/j.msard.2020.102248>
- Eckford SB, Kohler-Ockmore J, Feneley RC. Long-term follow-up of transvaginal urethral closure and suprapubic cystostomy for urinary incontinence in women with multiple sclerosis. *Br J Urol*. 1994; 74(3):319–21. <https://doi.org/10.1111/j.1464-410x.1994.tb16619.x>
- Elstad EA, Taubenberger SP, Botelho EM, Tennstedt SL. Beyond incontinence: the stigma of other urinary symptoms. *J Adv Nurs*. 2010; 66(11):2460–70. <https://doi.org/10.1111/j.1365-2648.2010.05422.x>
- European Association of Urology (EAU). EAU Guidelines on Neuro-urology. 2016. <https://uroweb.org/guideline/neuro-urology> (accessed 12 November 2021)
- European Network for Safer Healthcare. Increasing adherence to CAUTI guidelines: recommendations from existing evidence. 2021. <https://tinyurl.com/yuxct966> (accessed 12 November 2021)
- Fernández Ó, Costa-Frossard L, Martínez-Ginés M et al. The broad concept of 'Spasticity-plus syndrome' in multiple sclerosis: a possible new concept in the management of multiple sclerosis symptoms. *Front Neurol*. 2020; 11:152. <https://doi.org/10.3389/fneur.2020.00152>
- Flores SA, Hall CA. *Atrophic vaginitis*. StatsPearls Publishing, 2021
- Fowler CJ, Panicker JN, Drake M et al. A UK consensus on the management of the bladder in multiple sclerosis. *J Neurol Neurosurg Psychiatry*. 2009; 80(5):470–7. <https://doi.org/10.1136/jnnp.2008.159178>
- Fowler S, Godfrey H, Fader M et al. Living with a long-term, indwelling urinary catheter: catheter users' experience. *J Wound Ostomy Continence Nurs*. 2014; 41(6):597–603. <https://doi.org/10.1097/WON.000000000000069>
- Fuller G. Neurology. Grift Programme National Specialty Report. GRIFT, 2021. <https://tinyurl.com/mr2caayd> (accessed 7 December 2021)
- Gelfand JM. Multiple sclerosis: diagnosis, differential diagnosis, and clinical presentation. *Handb Clin Neurol*. 2014; 122:269–90. <https://doi.org/10.1016/B978-0-444-52001-2.00011-X>
- Geng V, Cobussen-Boekhorst H, Farrell J et al. Catheterisation, indwelling catheters in adults, urethral and suprapubic: evidence-based guidelines for best practice in urological health care. 2012. <https://tinyurl.com/5vak4pdx> (accessed 12 November 2021)
- Ginsberg D, Gousse A, Keppenne V et al. Phase 3 efficacy and tolerability study of onabotulinumtoxinA for urinary incontinence from neurogenic detrusor overactivity. *J Urol*. 2012; 187(6):2131–9. <https://doi.org/10.1016/j.juro.2012.01.125>
- Ginsberg D. The epidemiology and pathophysiology of neurogenic bladder. *Am J Manag Care*. 2013; 19(10 Suppl):s191–196
- Ginsberg DA, Drake MJ, Kaufmann A et al. Long-term treatment with onabotulinumtoxinA results in consistent, durable improvements in health related quality of life in patients with overactive bladder. *J Urol*. 2017; 198(4):897–904. <https://doi.org/10.1016/j.juro.2017.05.068>
- Giovannoni G, Butzkueven H, Dhib-Jalbut S et al. Brain health: time matters in multiple sclerosis. *Mult Scler Relat Disord*. 2016; 9 Suppl 1:S5–48. <https://doi.org/10.1016/j.msard.2016.07.003>
- Gratzke C, van Maanen R, Chapple C et al. Long-term safety and efficacy of mirabegron and solifenacin in combination compared with monotherapy in patients with overactive bladder: a randomised, multicentre phase 3 study (SYNERGY II). *Eur Urol*. 2018; 74(4):501–9. <https://doi.org/10.1016/j.eururo.2018.05.005>
- Guillotreau J, Panicker JN, Castel-Lacanal E et al. Prospective evaluation of laparoscopic assisted cystectomy and ileal conduit in advanced multiple sclerosis. *Urology*. 2012; 80(4):852–7. <https://doi.org/10.1016/j.urology.2012.06.039>
- Haddad R, Turmel N, Chesnel C et al. Functional independence measure predicts the outcome of clean intermittent catheterization training in patients with multiple sclerosis. *Ann Phys Rehabil Med*. 65(2): 101539. <https://doi.org/10.1016/j.rehab.2021.101539>
- Hall JS, Harrison S, Harding C, Reid S, Parkison R. British Association of Urological Surgeons suprapubic catheter practice guidelines: revised. *BJU Int*. 2020; 126(4): 416–22. <https://doi.org/10.1111/bju.15123>
- Harrison SCW, Lawrence WT, Morley R et al. British Association of Urological Surgeons' suprapubic catheter practice guidelines. *BJU Int*. 2011; 107(1):77–85. <https://doi.org/10.1111/j.1464-410X.2010.09762.x>
- Hentzen C, Haddad R, Ismael SS et al. Intermittent self-catheterization in older adults: predictors of success for technique learning. *Int Neurourol J*. 2018; 22(1):65–71. <https://doi.org/10.5213/inj.1835008.504>
- Herschorn S, Stothers L, Carlson K et al. Tolerability of 5 mg solifenacin once daily versus 5 mg oxybutynin immediate release 3 times daily: results of the VECTOR trial. *J Urol*. 2010; 183(5):1892–8. <https://doi.org/10.1016/j.juro.2010.01.012>
- Holroyd S. Trial without catheter: what



- is best practice? *Urology Continence Care Today* 2021. <https://tinyurl.com/fydhmz6n> (accessed 12 November 2021)
- Imamura M, Williams K, Wells M, McGrother C. Lifestyle interventions for the treatment of urinary incontinence in adults. *Cochrane Database Syst Rev*. 2015(12):CD003505. <https://doi.org/10.1002/14651858.CD003505.pub5>
- Kalkan S, Jaffe WI, Simma-Chiang V, Li ES, Blaivas JG. Long term results of augmentation cystoplasty and urinary diversion in multiple sclerosis. *Can J Urol*. 2019; 26(3):9974–80.
- Karademir K, Baykal K, Sen B et al. A peripheric neuromodulation technique for curing detrusor overactivity: Stoller afferent neurostimulation. *Scand J Urol Nephrol*. 2005; 39(3):230–3. <https://doi.org/10.1080/00365590510031147>
- Khavari R, Elias SN, Pande R et al. Higher neural correlates in patients with multiple sclerosis and neurogenic overactive bladder following treatment with intradetrusor injection of onabotulinumtoxin A. *J Urol*. 2019; 201(1):135–40. <https://doi.org/10.1016/j.juro.2018.07.066>
- Krhut J, Borovicka V, Bílková K et al. Efficacy and safety of mirabegron for the treatment of neurogenic detrusor overactivity: prospective, randomized, double-blind, placebo-controlled study. *Neurourol Urodyn*. 2018; 37(7):2226–33. <https://doi.org/10.1002/nau.23566>
- Lakin L, Davis BE, Binns CC et al. Comprehensive approach to management of multiple sclerosis: addressing invisible symptoms—a narrative review. *Neurol Ther*. 2021; 10(1):75–98. <https://doi.org/10.1007/s40120-021-00239-2>
- Lawrenson R, Wyndaele JJ, Vlachonikolis I, Farmer C, Glickman S. Renal failure in patients with neurogenic lower urinary tract dysfunction. *Neuroepidemiology*. 2001; 20(2):138–43. <https://doi.org/10.1159/000054774>
- Lee BS, Bhuta T, Simpson JM, Craig JC. Methenamine hippurate for preventing urinary tract infections. *Cochrane Database Syst Rev*. 2012; 17(10): CD003265. <https://doi.org/10.1002/14651858.CD003265.pub3>
- Li V, Barker N, Curtis C et al. The prevention and management of hospital admissions for urinary tract infection in patients with multiple sclerosis. *Mult Scler Relat Disord*. 2020a; 45:102432. <https://doi.org/10.1016/j.msard.2020.102432>
- Li V, Panicker JN, Haslam C, Chataway J. Use of a symptom-based questionnaire to screen for the presence of significant voiding dysfunction in patients with multiple sclerosis and lower urinary tract symptoms: a pilot study. *J Neurol*. 2020b; 267(12):3683–8. <https://doi.org/10.1007/s00415-020-10068-2>
- Lin SD, Butler JE, Boswell-Ruys CL et al. The frequency of bowel and bladder problems in multiple sclerosis and its relation to fatigue: a single centre experience. *PLoS One*. 2019; 14(9):e0222731. <https://doi.org/10.1371/journal.pone.0222731>
- Lipp A, Shaw C, Glavind K. Mechanical devices for urinary incontinence in women. *Cochrane Database Syst Rev*. 2014(12):CD001756. <https://doi.org/10.1002/14651858.CD001756.pub6>
- Lisibach A, Benelli V, Ceppi MG et al. Quality of anticholinergic burden scales and their impact on clinical outcomes: a systematic review. *Eur J Clin Pharmacol*. 2021; 77(2):147–62. <https://doi.org/10.1007/s00228-020-02994-x>
- Logan K. An exploration of men's experiences of learning intermittent self-catheterisation with a silicone catheter. *Br J Nurs*. 2020; 29(2):84–90. <https://doi.org/10.12968/bjon.2020.29.2.84>
- McClurg D, Bugge C, Elders A et al. Factors affecting continuation of clean intermittent catheterisation in people with multiple sclerosis: Results of the COSMOS mixed-methods study. *Mult Scler*. 2019; 25(5):727–39. <https://doi.org/10.1177/1352458518768722>
- McGowan S, Campbell P, Dolan L. The use of urethral bulking agents in the treatment of stress urinary incontinence. *Obstet Gynaecologist*. 2020; 22(2):137–46. <https://doi.org/10.1111/tog.12647>
- Madersbacher H, van Ophoven A, van Kerrebroeck PE. GAG layer replenishment therapy for chornic forms of cystitis with intravesical glycosaminoglycans: a review. *Neurourol Urodyn*. 2013; 32(1):9–18. <https://doi.org/10.1002/nau.22256>
- Mahajan ST, James R, Frasure H. Pelvic floor disorders and multiple sclerosis. *Int J MS Care*. 2014; 16(1):20–5. <https://doi.org/10.7224/1537-2073.2012-052>
- Marin CE, Kfoury PP, Callegaro D et al. Patients and neurologists have different perceptions of multiple sclerosis symptoms, care and challenges. *Mult Scler Relat Disord*. 2021; 50: 102806. <https://doi.org/10.1016/j.msard.2021.102806>
- Marziniak M, Bricchetto G, Feys P et al. The use of digital and remote communication technologies as a tool for multiple sclerosis management: narrative review. *JMIR Rehabil Assist Technol*. 2018; 5(1):e5. <https://doi.org/10.2196/rehab.7805>
- Mackenzie IS, Morant SV, Bloomfield TM, MacDonald TM, O'Riordan J. Incidence and prevalence of multiple sclerosis in the UK 1990–2010: a descriptive study in the General Practice Research Database. *J Neurol Neurosurg Psychiatry*. 2014; 85(1):76–84. <https://doi.org/10.1136/jnnp-2013-305450>
- Metcalfe G, Owen A. Can multiple sclerosis nurses help reduce non-elective admissions? An analysis of a service delivery audit. *Br J Neurosci Nurs*. 2021; 17(Sup3):S28–31. <https://doi.org/10.12968/bjnn.2021.17.Sup3.S28>
- Motavasseli D, Chesnel C, Charlanes A et al. Adherence to anticholinergic therapy and clean intermittent self-catheterization in patients with multiple sclerosis. *Int Neurourol J*. 2018; 22(2):133–41. <https://doi.org/10.5213/inj.1836054.027>
- Mountford K. Smart devices in the management of multiple sclerosis. *Touch Neurology* 2018. <https://tinyurl.com/yb5zrhny> (accessed 12 November 2021)
- MS Trust. MS Trust launches new campaign highlighting the vital need for more MS specialist nurses. MS Trust November 2019. <https://tinyurl.com/3bwzzykw> (accessed 12 November 2021)
- Mueller ER, van Maanen R, Chapple C et al. Long-term treatment of older patients with overactive bladder using a combination of mirabegron and solifenacin: a prespecified analysis from the randomized, phase III SYNERGY II study. *Neurourol Urodyn*. 2019; 38(2):779–92. <https://doi.org/10.1002/nau.23919>
- Multiple Sclerosis Academy. Multiple sclerosis: raising the bar. 2020. <https://tinyurl.com/2fxb2b5c> (accessed 14 January 2022)
- Multiple Sclerosis and Management of Urinary Tract Infection Clinical Practice Guideline. 2013. <https://tinyurl.com/2p98kb6s> (accessed 14 January 2022)
- National Neurology Advisory Group (NNAG). Optimum clinical pathway: multiple sclerosis. The Neurological Alliance 2019. <https://tinyurl.com/d4wba8d5> (accessed 12 November 2021)
- National Clinical Guideline Centre UK. Urinary incontinence in neurological disease: management of lower urinary tract dysfunction in neurological disease. London: Royal



- College of Physicians 2012. <https://tinyurl.com/yxaem3h8> (accessed 12 November 2021)
- National Institute for Health and Care Excellence. Urinary incontinence in neurological disease: assessment and management. NICE 2012a. <https://tinyurl.com/nn6af6mw> (accessed 12 November 2021)
- National Institute for Health and Care Experience UK. Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. NICE 2012b. <https://tinyurl.com/kc3wy7c7> (accessed 12 November 2021)
- National Institute for Health and Care Experience UK. Multiple sclerosis in adults: management. NICE 2014. <https://tinyurl.com/5bnuw25f> (accessed 12 November 2021)
- National Institute for Health and Care Excellence. Urinary tract infection (recurrent): antimicrobial prescribing. Guideline NG112. 2018. <https://tinyurl.com/2p9hf2us> (accessed 11 January 2022)
- National Institute for Health and Care Excellence UK. Urinary incontinence and pelvic organ prolapse in women. NICE 2019. <https://tinyurl.com/9ew8kfvv> (accessed 12 November 2021)
- National Institute for Health and Care Excellence. Urological cancers: recognition and referral. 2021a. <https://tinyurl.com/24nhav93> (accessed 15 November 2021)
- National Institute for Health and Care Excellence. Lower urinary tract symptoms in men overview. 2021b. <https://tinyurl.com/yckv9zm6> (accessed 13 January 2022)
- Nazari F, Shaygannejad V, Mohammadi Sichani M et al. The prevalence of lower urinary tract symptoms based on individual and clinical parameters in patients with multiple sclerosis. *BMC Neurology*. 2020; 20(1):24. <https://doi.org/10.1186/s12883-019-1582-1>
- NHS England. Excellence in continence care: practical guidance for commissioners and leaders in health and social care. NHS 2018. <https://tinyurl.com/2sn2naju> (accessed 12 November 2021)
- NHS Supply Chain. National bladder and bowel health project. NHS 2019. <https://tinyurl.com/3culhpsc> (accessed 12 November 2021)
- NHS. The NHS Long Term Plan. 2019. <https://tinyurl.com/mw9t8schu> (accessed 7 December 2021)
- O'Kane DB, Dave SK, Gore N et al. Urinary alkalisation for symptomatic uncomplicated urinary tract infection in women. *Cochrane Database Syst Rev* 2016; (4): CD010745. <https://doi.org/10.1002/14651858.CD010745.pub2>
- Orrell A, McKee K, Dahlberg L et al. Improving continence services for older people from the service-providers' perspective: a qualitative interview study. *BMJ Open*. 2013; 3(7):e002926. <https://doi.org/10.1136/bmjopen-2013-002926>
- Osman NI, Chapple CR. Are there pharmacotherapeutic options for underactive bladder? *Eur Urol Focus*. 2018; 4(1):6–7. <https://doi.org/10.1016/j.euf.2018.03.012>
- Panicker JN, Fowler CJ. Lower urinary tract dysfunction in patients with multiple sclerosis. *Handb Clin Neurol*. 2015a; 130:371–81. <https://doi.org/10.1016/B978-0-444-63247-0.00021-3>
- Panicker JN, Fowler CJ, Kessler TM. Lower urinary tract dysfunction in the neurological patient: clinical assessment and management. *Lancet Neurol*. 2015b; 14(7):720–32. [https://doi.org/10.1016/S1474-4422\(15\)00070-8](https://doi.org/10.1016/S1474-4422(15)00070-8)
- Panicker JN. Neurogenic bladder: epidemiology, diagnosis, and management. *Semin Neurol*. 2020; 40(5):569–79. <https://doi.org/10.1055/s-0040-1713876>
- Pelvic Floor Society. Seizing the opportunity to improve patient care: pelvic floor services in 2021 and beyond. 2021. <https://tinyurl.com/4w83u3nm> (accessed 12 November 2021)
- Peters KM, Carrico DJ, Perez-Marrero RA et al. Randomized trial of percutaneous tibial nerve stimulation versus sham efficacy in the treatment of overactive bladder syndrome: results from the SUmT trial. *J Urol*. 2010; 183(4):1438–43. <https://doi.org/10.1016/j.juro.2009.12.036>
- Phé V, Chartier-Kastler E, Panicker JN. Management of neurogenic bladder in patients with multiple sclerosis. *Nat Rev Urol*. 2016a; 13(5):275–88. <https://doi.org/10.1038/nrurol.2016.53>
- Phé V, Pakzad M, Curtis C et al. Urinary tract infections in multiple sclerosis. *Mult Scler*. 2016b; 22(7):855–61. <https://doi.org/10.1177/1352458516633903>
- Phé V, Schneider MP, Peryronnet B et al. Intravesical vanilloids for treating neurogenic lower urinary tract dysfunction in patients with multiple sclerosis: a systematic review and meta-analysis. a report from the Neuro-Urology Promotion Committee of the International Continence Society (ICS). *Neurourol Urodyn*. 2018. 37(1):67–82. <https://doi.org/10.1002/nau.23314>
- Prasad RS, Smith SJ, Wright H. Lower abdominal pressure versus external bladder stimulation to aid bladder emptying in multiple sclerosis: a randomized controlled study. *Clin Rehabil*. 2003; 17(1):42–7. <https://doi.org/10.1191/0269215503cr5830a>
- Prieto J, Wilson J, Bak A et al. A prevalence survey of patients with indwelling urinary catheters on district nursing caseloads in the United Kingdom: The Community Urinary Catheter Management (CCaMa) Study. *J Infection Prevention & Control*; 21(4):129–35. <https://doi.org/10.1177/1757177420901550>
- Public Health England. Multiple sclerosis: prevalence, incidence and smoking status: data briefing. 2020. <https://tinyurl.com/u6ahue9b> (accessed 12 November 2021)
- Rahnema'i MS. Neuromodulation for functional bladder disorders in patients with multiple sclerosis. *Mult Scler*. 2020; 26(11):1274–1280. <https://doi.org/10.1177/1352458519894714>
- Reid S, Brocksom J, Hamid R et al. British Association of Urological Surgeons (BAUS) and Nurses (BAUN) consensus document: management of the complications of long-term indwelling catheters. *BJU Int*. 2021; 128(6):667–77. <https://doi.org/10.1111/bju.15406>
- Sabbuba NA, Stickler DJ, Long MJ, Dong Z, Short TD, Feneley RJC. Does the valve regulated release of urine from the bladder decrease encrustation and blockage of indwelling catheters by crystalline proteus mirabilis biofilms? *J Urol*. 2005; 173(1):262–6. <https://doi.org/10.1111/bju.15406>
- Sancaktar M, Ceyhan ST, Akyol I et al. The outcome of adding peripheral neuromodulation (Stoller afferent neuro-stimulation) to anti-muscarinic therapy in women with severe overactive bladder. *Gynecol Endocrinol*. 2010; 26(10):729–32. <https://doi.org/10.3109/09513591003649815>
- Schurch B, de Sèze M, Denys P et al. Botulinum toxin type a is a safe and effective treatment for neurogenic urinary incontinence: results of a single treatment, randomized, placebo controlled 6-month study. *J Urol*. 2005; 174(1):196–200. <https://doi.org/10.1097/01.ju.0000162035.73977.1c>
- Schwartz CE, Stark RB, Rapkin BD. Capturing patient experience: does quality-of-life appraisal entail a new class of measurement? *J Patient-Rep Outcomes*. 2020; 4(1):85. <https://doi.org/10.1186/s41687-020-00254-1>
- Shift.ms. Learn about multiple sclerosis and connect with other MSers. Shift

2021. <https://tinyurl.com/a9c8dzcf> (accessed 12 November 2021)
- Simpson P. Long-term urethral catheterisation: guidelines for community nurses. *Br J Nurs* 2017; 26(9): S22–6. <https://doi.org/10.12968/bjon.2017.26.9.S22>
- Southall K, Tuazon JR, Djokhdem AH et al. Assessing the stigma content of urinary incontinence intervention outcome measures. *J Rehab Assistive Technologies Engineering*. 2017; 4:2055668317738943. <https://doi.org/10.1177/2055668317738943>
- Strober LB. Fatigue in multiple sclerosis: a look at the role of poor sleep. *Front Neurol*. 2015; 6:21. <https://doi.org/10.3389/fneur.2015.00021>
- Stys PK, Tsutsui S. Recent advances in understanding multiple sclerosis. *F1000Res*. 2019; 8:F1000 Faculty Rev-2100. <https://doi.org/10.12688/f1000research.20906.1>
- Tam J, Gross MD, Cheung A et al. Fluid intake and urinary symptoms in patients with multiple sclerosis. *J Urol*. 2020; 204(6):1284–9. <https://doi.org/10.1097/JU.0000000000001309>
- Tepavcevic D, Pekmezovic T, Dujmovic Basuroski I et al. Bladder dysfunction in multiple sclerosis: a 6-year follow-up study. *Acta Neurol Belg*. 2017; 117(1):83–90. <https://doi.org/10.1007/s13760-016-0741-z>
- Thomas S, Giovannoni G, Lawton A. NHS reset and reform. A new direction for health and care in multiple sclerosis. 2021a <https://tinyurl.com/4p3zk7wf> (accessed 12 November 2021)
- Thomas S, Thomas S, Mehta S. The forgotten many: a 2020 vision for secondary progressive multiple sclerosis. 2020. *Wilmington Healthcare*. <https://tinyurl.com/4m9um7bc> (accessed 12 November 2021)
- Thomas S. Integrating services: translating data into practice. *British Journal of Neuroscience Nursing*. 2021b; 17(3):114–7. <https://doi.org/10.12968/bjnn.2021.17.3.114>
- Thomas S, Stross R. Translating data into service change: bladder & bowel management for MS. 2020. <https://tinyurl.com/5n96b7ay> (accessed 14 January 2022)
- Thomson A, Dobson R, Baker D, Giovannoni G. Digesting science: Developing educational activities about multiple sclerosis, prevention and treatment to increase the confidence of affected families. *Multiple Sclerosis and Related Disorders*. 2021; 47. <https://doi.org/10.1016/j.msard.2020.102624>
- TiMS National Working Group. Guidance for use of the TiMS MS self-reported assessment tool. MST June 2021. <https://tinyurl.com/3ecjxh53> (accessed 12 November 2021)
- Tornic J, Panicker JN. The management of lower urinary tract dysfunction in multiple sclerosis. *Curr Neurol Neurosci Rep*. 2018; 18(8):54. <https://doi.org/10.1007/s11910-018-0857-z>
- Tornic J, Sartori AM, Gajewski JB et al. Catheterization for treating neurogenic lower urinary tract dysfunction in patients with multiple sclerosis: A systematic review. A report from the Neuro-Urology Promotion Committee of the International Continence Society (ICS). *NeuroUrol Urodyn*. 2018; 37(8):2315–22. <https://doi.org/10.1002/nau.23733>
- Tudor KI, Bošnjak Pašić M, Nad Škegro S et al. Lower urinary tract symptoms and depression in patients with multiple sclerosis. *Psychiatr Danub*. 2020; 32(Suppl 4):511–9
- Vahr S, Cobussen-Boekhorst H, Eikenboom J. Catheterisation urethral intermittent in adults. Dilatation, urethral intermittent in adults—evidence-based guidelines for best practice in urological health care. *European Association of Urology Nurses* 2013. <https://tinyurl.com/wruvazuu> (accessed 12 November 2021)
- Vecchioli-Scaldazza C, Morosetti C. Effectiveness and durability of solifenacin versus percutaneous tibial nerve stimulation versus their combination for the treatment of women with overactive bladder syndrome: a randomized controlled study with a follow-up of ten months. *Int Braz J Urol*. 2018; 44(1):102–8. <https://doi.org/10.1590/S1677-5538.IBJU.2016.0611>
- Vedanayagam M, Brewin J, Briggs K. The role of hyaluronic acid in the management of uncomplicated recurrent female urinary tract infections: literature review and practical experience. *J Clin Urol*. 2013; 6(4): 243–8. <https://doi.org/10.1177/2051415813481027>
- Vermersch P, Shanahan J, Langdon D et al. Knowledge is power, but is ignorance bliss? Optimising conversations about disease progression in multiple sclerosis. *Neurol Ther*. 2020; 9(1):1–10. <https://doi.org/10.1007/s40120-019-00170-7>
- Wang G, Marrie RA, Fox RJ et al. Treatment satisfaction and bothersome bladder, bowel, sexual symptoms in multiple sclerosis. *Mult Scler Relat Disord*. 2018; 20:16–21. <https://doi.org/10.1016/j.msard.2017.12.006>
- Wileman A, Holroyd S, Carroll A. Catheter care. RCN guidance for health care professionals. Royal College of Nursing 2021. <https://tinyurl.com/ew8mvsve> (accessed 12 November 2021)
- Yates A. Intermittent catheterisation: why it should be taught within a community setting. *Br J Community Nurs*. 2016a; 21(9):442–5. <https://doi.org/10.12968/bjcn.2016.21.9.442>
- Yates A. Nocturia in older people living in residential care. *Nurs Residential Care*. 2017; 19(11):616–8. <https://doi.org/10.12968/nrec.2017.19.11.616>
- Yates A. The risks and benefits of suprapubic catheters. *Nurs Time*. 2016b; 112: 6/7, 19–22. <https://tinyurl.com/mxsyr24d> (accessed 12 November 2021)
- Yates A. Teaching intermittent catheterisation: barriers. *Nursing Times* 2013; 109(44), 22–25. <https://tinyurl.com/nzs2x7st> (accessed 12 November 2021)
- Ye D, Chen Y, Jian Z et al. Catheters for intermittent catheterization: a systematic review and network meta-analysis. *Spinal Cord*. 2021; 59(6):587–95. <https://doi.org/10.1038/s41393-021-00620-w>
- Zachariou A, Filiponi M, Baltogiannis D et al. Effective treatment of neurogenic detrusor overactivity in multiple sclerosis patients using desmopressin and mirabegron. *Can J Urol*. 2017; 24(6):9107–13
- Zachariou A, Filiponi M, Dimitriadis F et al. 433 – Adherence to clean intermittent catheterization in patients with multiple sclerosis. *European Urology Open Science*. 2020; 19:e692. [https://doi.org/10.1016/S2666-1683\(20\)33039-1](https://doi.org/10.1016/S2666-1683(20)33039-1)
- Zecca C, Riccitelli GC, Disanto G et al. Urinary incontinence in multiple sclerosis: prevalence, severity and impact on patients' quality of life. *Eur J Neurol*. 2016; 23(7):1228–34. <https://doi.org/10.1111/ene.13010>
- Zéphir H. Progress in understanding the pathophysiology of multiple sclerosis. *Rev Neurol (Paris)*. 2018; 174(6):358–63. <https://doi.org/10.1016/j.neurol.2018.03.006>



**MA Healthcare**

Part of

**Mark Allen**