Bladder pathway:

Bladder management for people with multiple sclerosis

BE BLADDER AWARE IN MS

A team approach

September 2022, version 1

About this pathway

This integrated care pathway has been created as a collaborative effort – our special thanks to the multiple sclerosis (MS) and bladder and bowel professionals representing a range of specialist services who contributed to this project. We hope the pathway will be a useful resource for both healthcare professionals and providers to ensure best practice in the management of the MS bladder. We are particularly keen to share this resource and receive comments in order to ensure the pathway is as comprehensive as possible.

Currently awareness of the bladder and bowel problems people with MS (PwMS) face and access to appropriate services is variable. Bladder problems may arise even before a diagnosis of MS, PwMS can be young and at the onset of the disease or have more complex progressive forms of MS but one in ten people will report bladder symptoms at the time of diagnosis (Panicker 2020). Ten years into the disease almost all people will be experiencing some bladder problems (Tornic & Panicker 2018).

As a result many PwMS may wait too long for a referral and diagnosis which can have major ramifications for their symptom management and quality of life. It is essential that the complexity of bladder management is understood and we hope this integrated care pathway will help aid improvements and streamlining the care delivered.

This integrated care pathway is easy to navigate by clicking on the menu tabs and icons to view further details.

The pathway is designed to be viewed electronically. Some links redirect to resources that will open in your internet browser – these will require an internet connection.

This pathway was developed by:

- **Joan Bradley** Lead nurse in MS & Rehabilitation, The Hillingdon Hospitals NHS Foundation Trust
- **Georgina Cole** Team Leader, Mersey Care NHS Foundation Trust
- **Marie Girvan** Advanced Specialist Nurse, Bladder and Bowel Service, Mersey Care NHS Foundation
- **Gale Metcalfe** MS Nurse Specialist, CHS Team Leader Leeds Teaching Hospitals NHS Foundation Trust
- **Audrey Owen** MS Nurse Specialist, Calderdale and Huddersfield NHS Trust
- **Margaret Solomons** Clinical Nurse Specialist for Multiple Sclerosis, Central London Community Healthcare NHS Trust
- **Ruth Stross** MS Nurse Specialist Neuro Rehabilitation Team, Surrey Downs Health & Care, Epsom and St Helier University Hospitals NHS Trust
- **Ann Yates** Director of Continence Services, Cardiff and Vale University Health Board, South Wales
- **Mark Webb** Disability and diversity campaigner; Head of Communications, Shift.MS
- **Sarah White** Lead MS Clinical Nurse Specialist, Atkinson Morley Regional Neurosciences Centre, St George's University Hospitals
- **Jane Young** Nurse Consultant, Bladder and Bowel Service, Central and North West London NHS Foundation Trust

Chair: **Sue Thomas** Independent Healthcare Consultant
Medical writer: **Sarah Mehta**

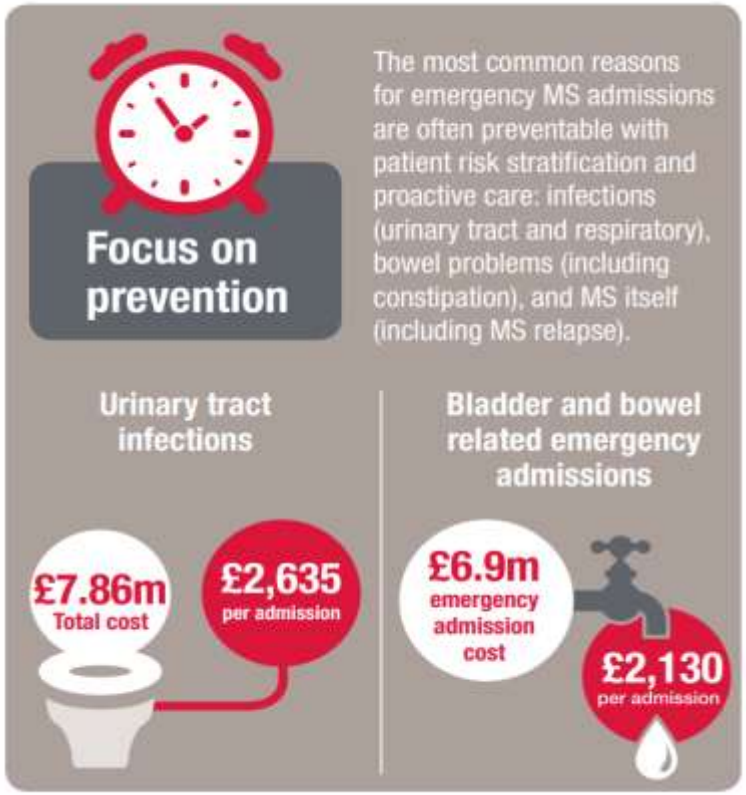
Why bladder matters

Bladder symptoms have a profound impact on PwMS but healthcare professionals may not always realise the impact these are having on their patients or the impact on local health services. The National Neurology Advisory Group (NNAG) developed an Optimum clinical pathway for MS (2019) with a group of specialist MS health and care professionals, MS patient groups and PwMS. It covers referral to diagnosis, diagnosis to specialist assessment, drug treatment, symptom management, advanced MS and specialised components of care and although bladder management is mentioned it does not look in detail at this. Hence the development of this pathway and resources. Read the fictitious but realistic stories of Esther and Rachel about how bladder problems have impacted their lives.

Healthcare professionals may not always be aware of the numbers of their local population affected with bladder problems but it is important to identify these and look at how the Expert opinion consensus document (2022) for MS bladder can be implemented. The COVID-19 pandemic may have shifted the prioritisation of bladder and bowel care but the MS Academy's 2021 report NHS Reset and Reform: A new direction for health and care in multiple sclerosis has highlighted to need to refocus on this to both improve quality of life and reduce NHS costs.

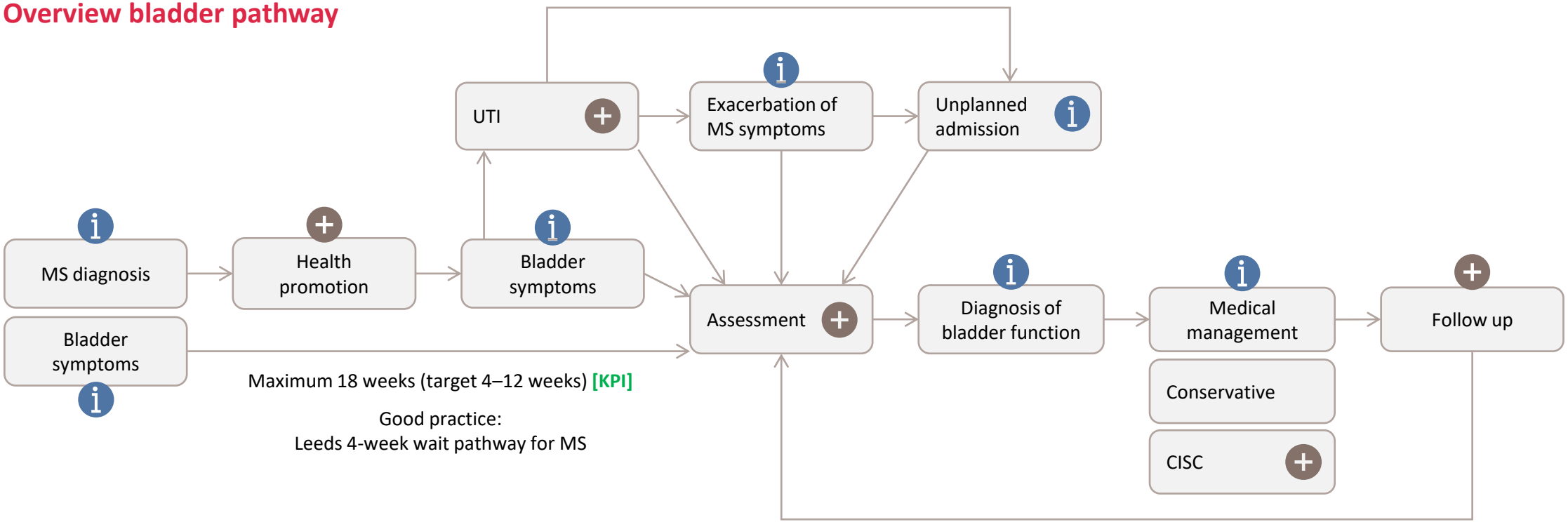
> *"As two people living with MS who experience bladder symptoms to varying degrees, we know first-hand how this can lead to distress and isolation, and can impact one's work, personal and social life. We recall the initial confusion and embarrassment. Yet, today, we still hear examples of patients being met with bewildering terminology as they try to come to terms with this challenge."*
>
> **Mark Webb and Trishna Bharadia**
> (Thomas et al 2022)

Hospital admissions for PwMS, 2020/21 (source: NHS Digital data)



Thomas S et al (2022) Developing a consensus bladder & bowel management pathway for Multiple Sclerosis: process and application British Journal Neuroscience Nursing https://www.magonlinelibrary.com/doi/abs/10.12968/bjnn.2022.18.Sup3.S6

Overview bladder pathway



Healthcare professionals involved:

- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

*Ensure patient consent before performing procedures

CISC, clean intermittent self-catheterisation; HCP, healthcare professional;
KPI, key performance indicator; MSSN, MS specialist nurse; UTI, urinary tract infection.

Diagnosis of MS

- Bladder symptoms may present before (neurological) diagnosis of MS (see McDonald MS diagnostic criteria and NICE guideline NG220).
- The MS Trust and MS Society have information on bladder symptoms to give to patients.
- Hollister e-Learning resource for MS: 2 modules
- Shift.ms has an online bladder chat facility.
- Post-diagnosis an integrated pathway approach is suggested.
- At diagnosis of MS provide a self-help pack which contains details about lifestyle / healthy eating and drinking information.
- Patient education is essential so that patients are aware of what is 'normal' and potential issues that can arise.
- Consider bladder management information is included in early self-help packs and conversations.
- EDSS measurement could indicate likelihood of bladder problems.
  - ≤6 non-complex, ≥6 complex
  - Online EDSS assessment tool

Unplanned admission

Diagnosis of bladder function

Medical management

- Conservative
- CISC

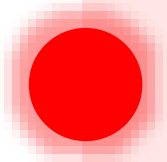
Follow up

Healthcare professionals involved:

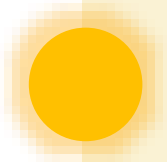
- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

Bladder symptoms in MS

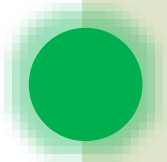
- Bladder symptoms may present before diagnosis of MS.
- Bladder issues can be embarrassing for patients, making them reluctant to seek help. Overcoming these barriers requires that bladder issues are addressed early by professionals, with care, sensitivity and empathy.
- Bladder symptoms:
  - Frequency
  - Urgency
  - Nocturia and/or nocturnal enuresis
  - Urge incontinence
  - Passive incontinence
  - Stress incontinence
  - Mixed incontinence
  - Functional incontinence
  - Overflow
  - Obstructive voiding (chronic or acute retention)
  - Hesitancy
  - Suprapubic pain and discomfort
  - UTI.
- **Red flags** for urgent assessment:
  - Recurrent or unresolved UTI
  - Acute retention (urgent urological assessment)
  - Haematuria in the absence of UTI (urgent urological assessment).
- Information about healthcare professional education on bladder in MS.



Red zone
- Change in neurological function (often first sign in MS).
- Immediate frequency and urgency.
- New incontinence.
- Pyrexia.
- Loin pain.
- Change in normal voiding pattern, i.e frequency.
- Haematuria.
- Pain.
- Intermittent stream.
- Reduced voiding.
- Hesitancy.
- Dysuria.
- Signs of sepsis.



Amber zone
- Change from normal patients function.
- Change in neurological function.
- Dark in colour / pale urine.
- Prolonged frequency and urgency.
- New of increased incontinence.



Green zone
- Normal colour urine.
- Non-malodourus.
- Normal volume of bladder capacity 300–600 mls per void.
- Normal frequency 4–8 voids in 24 hours.
- No bladder symptoms i.e. pain, frequency, haematuria.
- Good flow.

Diagnosis of bladder function

- **Physiology of voiding a normal healthy bladder**
- Overactive bladder
- Underactive bladder / detrusor sphincter dyssynergia
- Stress incontinence
- UTI

Physiology of voiding a normal healthy bladder

Diagnosis of bladder function

- Physiology of voiding a normal healthy bladder
- **Overactive bladder**
- Underactive bladder / detrusor sphincter dyssynergia
- Stress incontinence
- UTI

Overactive bladder symptoms (including frequency, nocturia and urge incontinence)

Conservative measures: – e.g. caffeine avoidance, pelvic floor exercises, bladder retraining.

First-line treatments:

- **Antimuscarinic drugs (anticholinergics)**
  Newer antimuscarinics, such as solifenacin, tolterodine and fesotoderine, have a lower side effect profile, and thus are preferable to older antimuscarinics like oxybutynin (Herschorn et al 2010; Tornic & Panicker 2018). Darifenacin and trospium chloride are particularly suitable for patients with advanced disease (Phé et al 2016; Tornic & Panicker 2018).
- Anticholinergic burden score (>3 straight to mirabegron). See Expert opinion consensus for MS bladder (2022).

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 hyponatremia. Caution not to be used in over 65 year olds for nocturia (Nocdurna licenced for over 65s).

Other treatments:

- **Botulinum toxin type-A**
  Effective second-line treatment for PwMS who are unresponsive to or cannot tolerate antimuscarinics (NICE 2012).
- **Cannabinoids**
  Currently these are an unlicensed product in the UK but evidence suggests they may be effective for treating LUT with a favourable safety profile (Tornic & Panicker 2018; Youssef et al 2017).

Diagnosis of bladder function

- Physiology of voiding a normal healthy bladder
- Overactive bladder
- **Underactive bladder / detrusor sphincter dyssynergia**
- Stress incontinence
- UTI

Underactive bladder/detrusor sphincter dyssynergia (DSD)

First-line treatment:

- Clean intermittent self-catheterisation (CISC): view CISC pathway
- Tamsulosin in men (this is currently unlicensed for women).

Second-line treatment:

- Long-term catheterisation (when consider use of catheter valve)
    - Suprapubic or urethral over long term
    - CISC.

Resources for professionals:

- European Association of Urology (2022) EAU guidelines on urological infections
- European Association of Urology (2022) EAU guidelines on neuro-urology
- Royal College of Nursing (2021) Catheter care: guidance for health care professionals

Resources for patients:

- Shift.ms
- MS Society
- MS Trust
- Bladder and Bowel UK
- Local services patient information.

Diagnosis of bladder function

- Physiology of voiding a normal healthy bladder
- Overactive bladder
- Underactive bladder / detrusor sphincter dyssynergia
- **Stress incontinence**
- UTI

Stress incontinence

Stress incontinence is 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.

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 2016) and with bowel problems and sexual dysfunction these are two other disorders that affect the pelvic floor.

Self help:

- Bladder self-management advice, maintaining a healthy bladder resource, Squeezy app.

First-line treatment:

- Pelvic floor exercises.
- Consider referral to a physiotherapist with expertise in bladder dysfunction for:
    - Pelvic floor muscle training (including Kegel exercises)
    - Biofeedback interventions
    - Neuromuscular electrical stimulation
    - Behavioural management (e.g. timed voiding)
    - Stress incontinence issues.

Second-line treatment:

- Bulking agent.

Drug treatment should not be given for neurogenic stress incontinence (EAU 2022). 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).

Diagnosis of bladder function

- Physiology of voiding a normal healthy bladder
- Overactive bladder
- Underactive bladder / detrusor sphincter dyssynergia
- Stress incontinence
- **UTI**

UTI

The presence of UTIs in the MS population is closely related to the difficulty of these patients in having their bladder completely empty. Risk factors for this occurrence are the use of an indwelling urinary catheter, the existence of a residual volume of more than 300mL and high bladder pressures (although the residual volume may be different for individual patients. See: Expert opinion consensus for MS bladder (2022).

Despite the UTI, MS patients do not necessarily have the symptoms reported by the general population, such as fever, suprapubic or flank pain in cases of pyelonephritis, or urgency, increased frequency, incontinence, and haematuria in cases of acute cystitis. This often makes it difficult to diagnose UTIs in these patients.

Urgency, frequency and incontinence may also be present in these patients without having an infection, due to the MS dysfunction. Additionally, MS patients can present signs and symptoms suggestive of a UTI with high sensitivity (77–95%) despite low specificity (<50%) (Massa et al 2009; Phé et al 2016).

These symptoms are abdominal or back discomfort, neurological status deterioration, reduced appetite or lethargy, leakage between CISC, catheter blockage, or cloudy urine with increased odour

Foul-smelling urine is also a potential predictor of UTI in PwMS with the incidence more common in females.

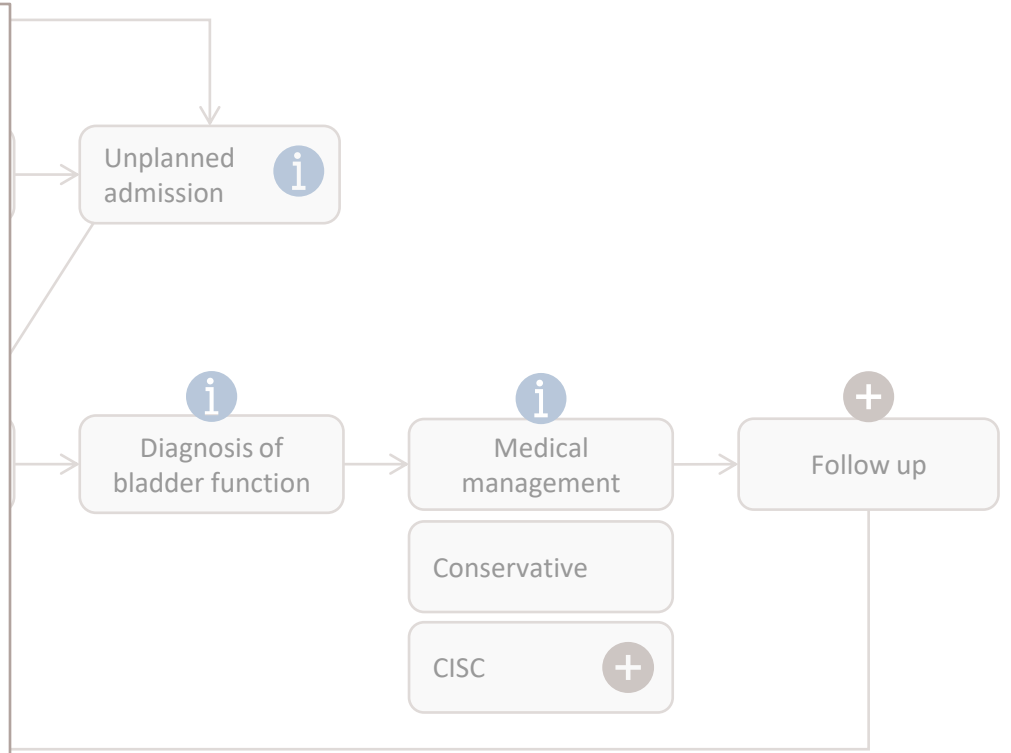
- View UTI pathway

Conservative treatment

Conservative measures, such as bladder retraining, pelvic floor exercises and fluid adjustment, may be helpful for some PwMS with lower urinary tract symptoms (Phé et al 2016; Bientinesi et al 2020). NICE recommends behavioural management programmes, such as bladder retraining, but notes that evidence for such interventions is slim (NICE 2012).

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 lower urinary tract symptoms. Likewise, drinking caffeinated drinks has a minimal effect on symptoms. The authors concluded that modifying fluid intake may not contribute greatly to reducing lower urinary tract symptoms (Tam et al 2020).

The expert panel considered pelvic floor muscle training as first-line treatment for lower urinary tract dysfunction including stress urinary incontinence, in line with NICE guidelines (NICE 2012; NICE 2012b; NICE 2019). Instruction 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).



Healthcare professionals involved:

- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

Healthcare professional education

Education is vital at all levels to ensure that all health and care workers dealing with people who have MS are aware of the potential bladder problems that might exist and are competent to make a referral for support or provide appropriate interventions or management. Education will be at varying levels and delivered in differing formats, for example formal lectures, self-learning modules, webinars etc. Excellence in Continence Care outlines where education is needed; for PwMS this will include, for example, education about bladder and bowel management and for bladder and bowel nurse specialists familiarisation with MS as a condition and education about the particular problems PwMS will encounter. We need to be considering differing levels of education:

- Urology nurse specialists/bladder and bowel nurse specialist education to increase understanding of MS and the bladder and bowel problems that may occur.
- MS specialist nurses to undertake bladder assessments for PwMS.
- Fundamental bladder and bowel care education for healthcare professionals such as care assistants working with PwMS at home and in hospitals.
- Continuous professional development for postgraduates if they care for PwMS with bladder needs or if they are in a position to identify people with problems.
- Healthcare professionals to recognise the bladder problems that may arise and need for referral.
- It is important for nurses to have knowledge on catheters (ISC and indwelling, to ensure patients are using the right type of catheter.
- Education at differing levels, i.e. urology nurse specialist, MS specialist nurse, GPs, district and community nurses, social workers, care assistants as well as neurologists
- Staff directory so we know who can deal with patients.
- Competencies for specialist in bladder and bowel care.

Case study: good practice
Wales has a catheter passport system and e-learning which includes Houdini and set competencies for all settings, which means all professionals are doing the same training and documentation.

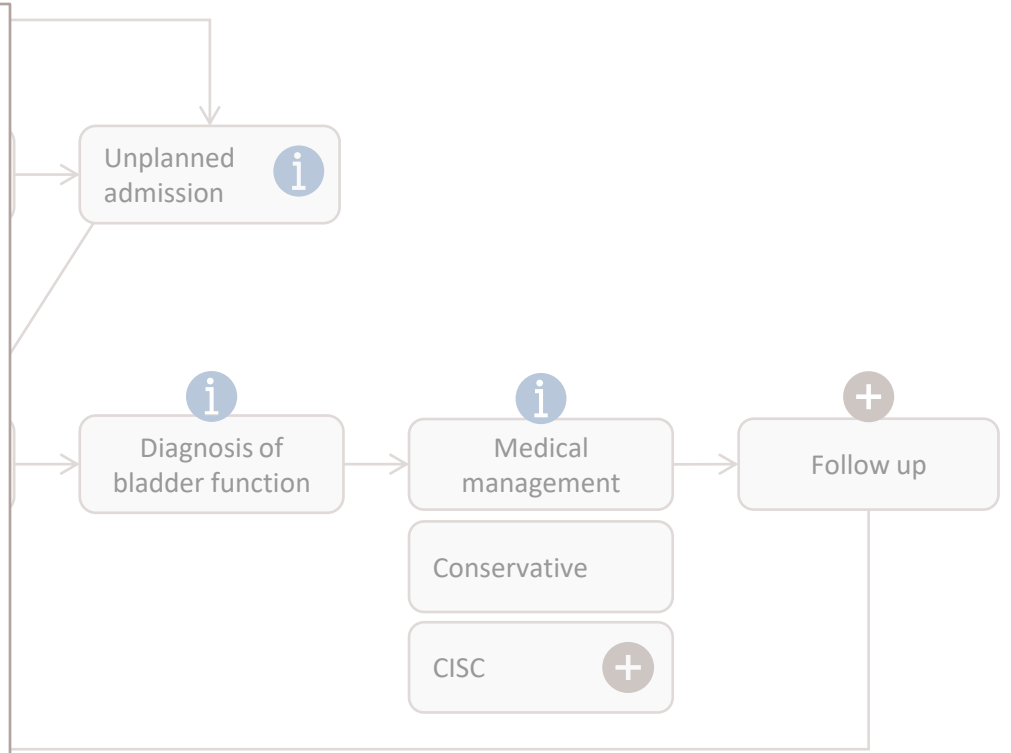
Visit the Hollister e-Learning resource for MS: 2 modules

Exacerbation of MS symptoms

Infection can cause exacerbation of MS symptoms which needs to be treated quickly as PwMS can become seriously unwell very quickly.

Unlike a relapse, pseudo-relapse is a temporary worsening of MS symptoms that have occurred before. The episode usually results from triggers such as an infection, stress or fatigue. In a pseudo-relapse there is no new inflammation or disease activity in the central nervous system and it does not require treatment with corticosteroids. If infection is identified, it should be treated.

It is important for both patients and GPs to be aware of the need for a fast response when MS symptoms worsen. A traffic light system may be helpful for healthcare professionals.

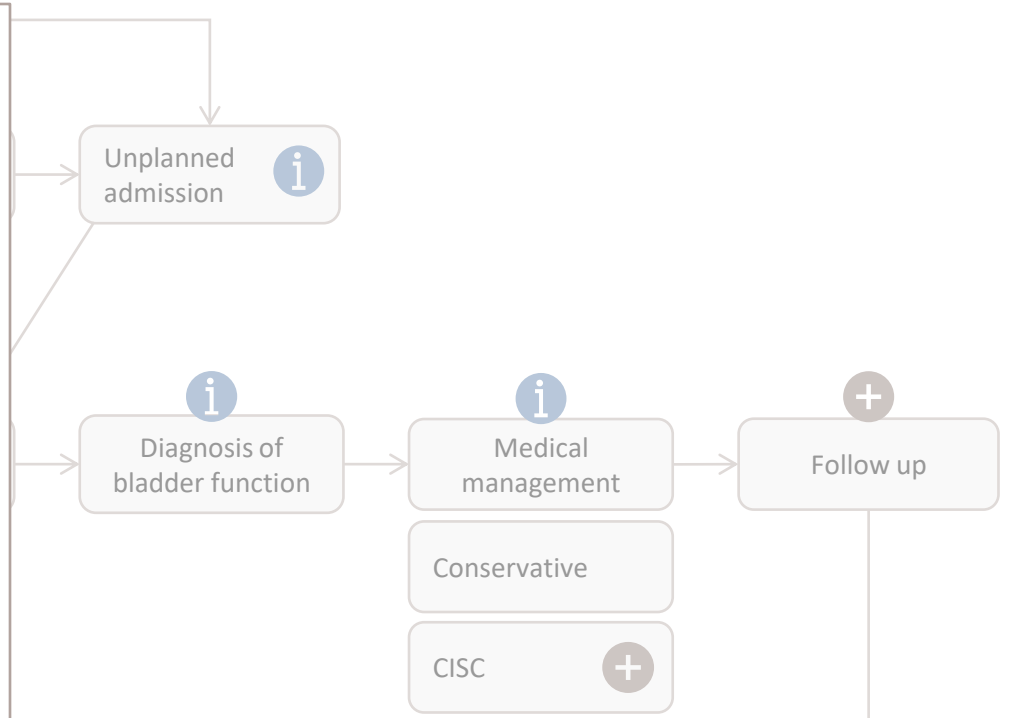


Healthcare professionals involved:

- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

Unplanned admissions for PwMS

- Unplanned admissions have a major impact on patients.
- Empower patients to take control, follow up yourself with GP.
- Flagging systems are needed to ensure that teams are notified of unplanned admissions for PwMS:
  - Clear feedback system with A&E, NHS111.
  - DATIX incident forms: useful way of collecting evidence.
  - One panellist's service operates a 72-hour review, to work out whether true catheter-associated UTI (CAUTI), and whether the case is classified as red, green or amber.
  - Assist with discharge, rehab and catheter removal.
- Optimising catheter care in unplanned admissions:
  - Red flag system important to help prevent unnecessary long-term catheters.
  - Catheter passports.
  - Channel Islands has a new scheme for all patients (not just PwMS) whereby staff teach patients ISC in A&E which ensures that indwelling catheters are avoided. This is a brilliant model and would be really good for MS patients.
  - National Bladder and Bowel Directory is a useful resource on catheter care.
- See: Porter B et al. Urinary tract infection in multiple sclerosis: closing an audit loop by co-design and innovation. Br J Neurosci Nurs. 2019;15(1):20-27.



Healthcare professionals involved:

- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

MS specialist nurse role

MS specialist nurses (MSSNs) are usually the first and main point of contact for PwMS from diagnosis to end of life. As well as offering information, direct support and clinical advice, a nurse can refer PwMS and their carers to other health and social care professionals as appropriate. The MSSN will manage a caseload of PwMS via an annual review or as required.

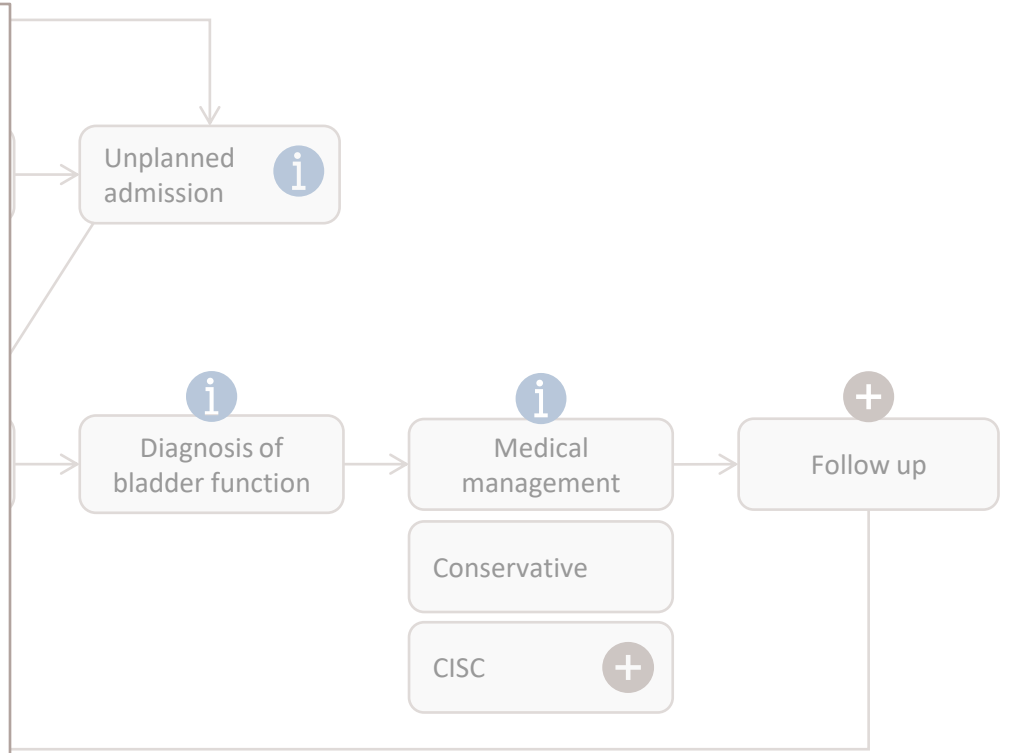
The MSSN will manage medicines, relapse and symptom management and work within a multi-disciplinary team to jointly decide on a disease-modifying therapy (DMT) dependant on the type of MS and eligibility for treatment. The MSSN will monitor the DMT, escalate, de-escalate, switch and stop treatment as agreed within the MS MDT team and manage complex symptoms in progressive disease, so they remain the key point of contact throughout the disease trajectory.

The MSSN is responsible for the development and delivery of specialist care for PwMS. They provide expert clinical care to PwMS; signposting and support for their families; education and support to colleagues and liaise closely with external agencies to develop and improve services.

MSSNs will often have a specialist qualification in neurology and/or MS.

Further information on this role can be found at:

- MS Trust (2021) MS specialist nurses
- MS Society (2017) Being an MS nurse is a truly specialist role
- MS Trust (2012) Defining the value of MS specialist nurses
- The Multiple Sclerosis Specialist Nurse Association
- MS nurse competencies



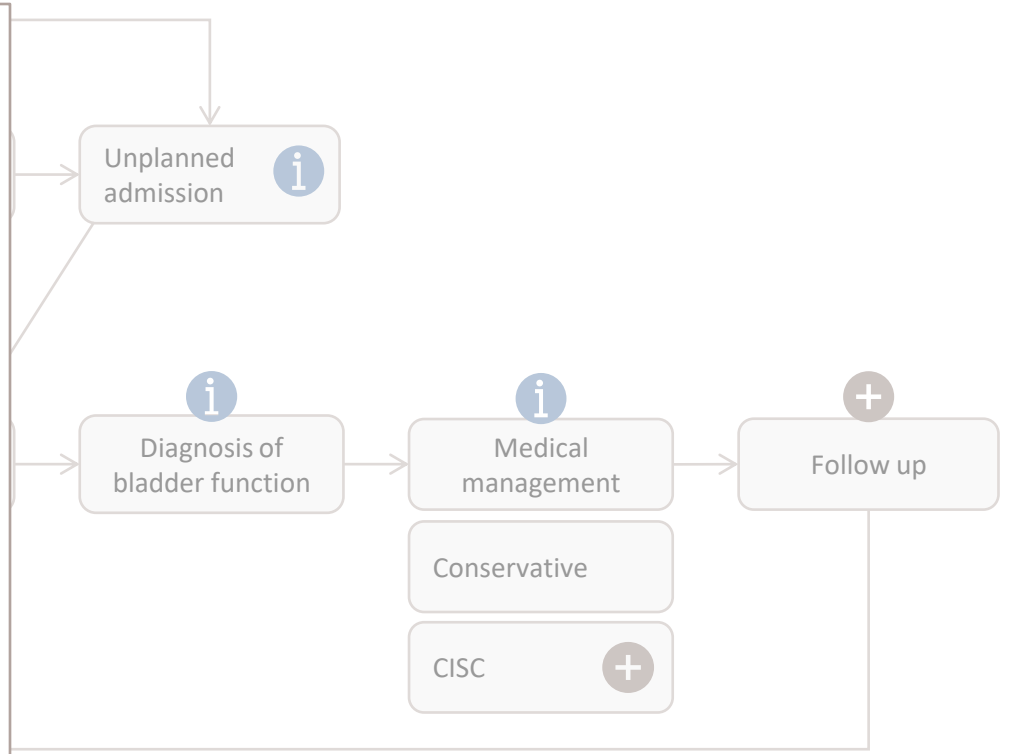
Healthcare professionals involved:

- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

Bladder and bowel nurse role

The bladder and bowel nurse role involves knowledge of the anatomy and pathophysiology in relation to continence status, bowel symptoms and their effect on urinary symptoms, and red flags signs and symptoms.

- Awareness of medication that can affect urinary symptoms.
- Undertaking full bladder and bowel assessment.
- Understanding the implication of urine testing.
- Understanding the use and interpretation of bladder diaries.
- Understanding the use and interpretation of bladder scanners and post void residual urine.
- Undertaking vaginal/rectal examination to assess pelvic floor dysfunction.
- Initiating lifestyle modifications including toileting regimes, fluid advice, caffeine reduction, smoking cessation and weight reduction.
- Initiating bladder retraining programmes.
- Undertaking pelvic floor rehabilitation.
- Knowledge of CISC and use of long-term urinary catheters.
- Knowledge of bowel treatments that can affect urinary status.
- Knowledge of equipment available to manage urinary incontinence.
- Knowledge of when to refer onwards.



Healthcare professionals involved:

- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

Physiotherapist role

In the area of bladder and bowel dysfunction, specialist physiotherapists are frequently involved in supporting individuals with neurogenic dysfunction. The professional expertise of the specialist physiotherapist can help maximise opportunities for improvement of function and quality of life in PwMS and other neurogenic bladder and bowel issues.

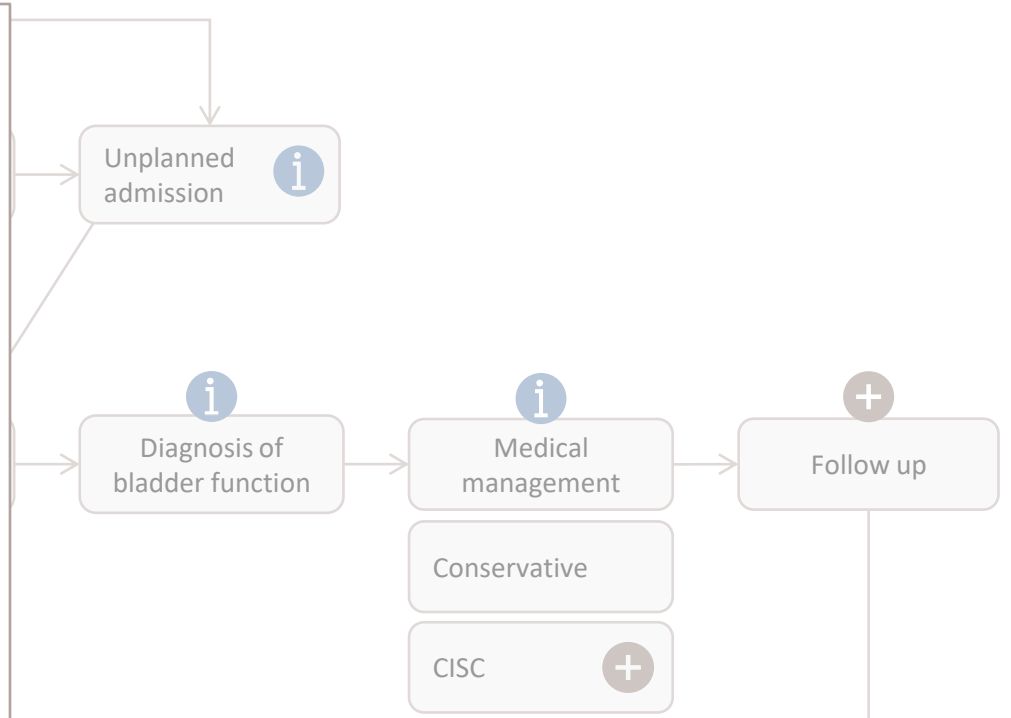
Specialist physiotherapists are highly skilled in the assessment, management and treatment of the pelvic floor dysfunction of women with pelvic organ prolapse or bladder and bowel incontinence, and may also be involved with the assessment, management and treatment of male pelvic floor dysfunction which may include bladder and bowel incontinence.

Specialist physiotherapists in bladder and bowel management are generally part of Pelvic Obstetric and Gynaecological Physiotherapy (POGP), a UK-based professional network affiliated to the Chartered Society of Physiotherapy. Members specialise in the conservative treatment of bladder and bowel incontinence for men and women, and in some cases children, and may also be specialists in the treatment of sexual dysfunction in relation to pelvic floor muscle problems for men and women.

Physiotherapy treatments include:

- Pelvic floor exercises
- Electrical stimulation
- Biofeedback
- Ultrasound
- Pelvic floor muscle exercisers.

- Further information about the role of the specialist physiotherapist in bladder management
- POGP (2017) Promoting continence with physiotherapy



Healthcare professionals involved:

- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

Role of district nurses and other healthcare professionals

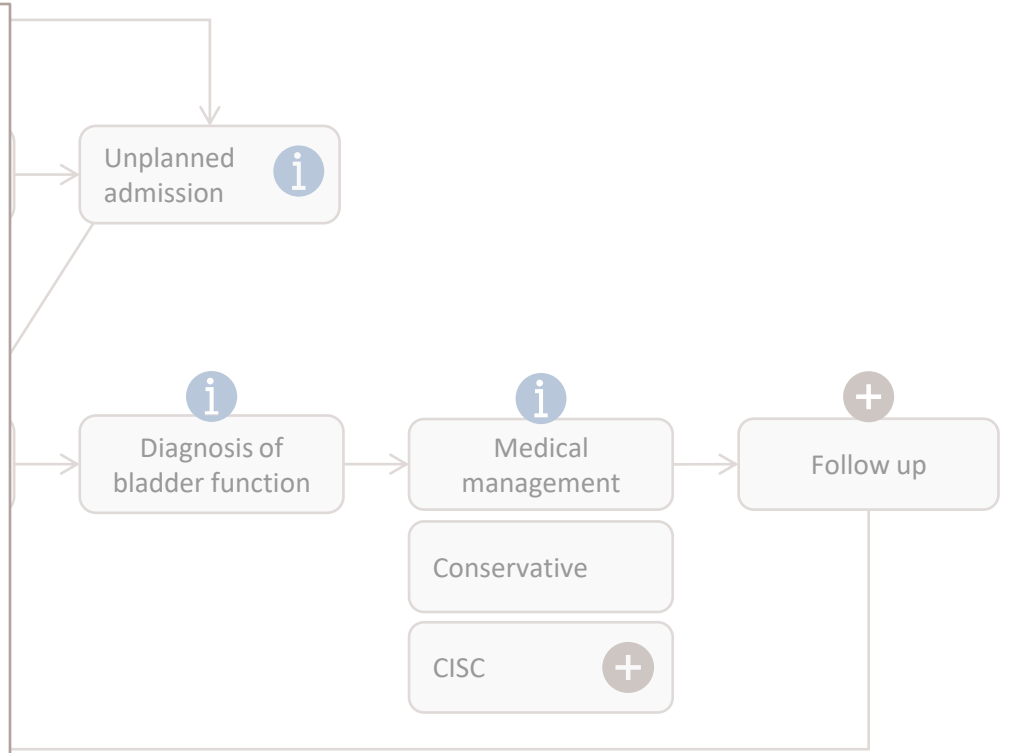
District nurses lead teams of community nurses and support workers, frequently seeing individuals with conditions such as multiple sclerosis and other neurodegenerative conditions. They will visit house-bound patients to provide advice and care such as continence care and catheter management as well as medication support. District nurses are able to prescribe medication to patients in a similar way to GPs, as Community Practitioner Nurse Prescribers under the Nurse Prescribers' Formulary for Community Practitioners (Part XVIIB(i) of the Drug Tariff), depending on individual qualifications.

They may be trained to assess patients' needs for equipment provision such as mobility and independent living aids as well as guidance in applying for grants and welfare benefits. Their work involves both follow-up care for recently discharged hospital inpatients and longer-term care for chronically ill patients who may be referred by other services, as well as working collaboratively with other nurse specialists, for example MS, bladder and bowel, or urology nurse specialists.

District nurses assess people to see how to provide nursing care that allows them to remain in their own homes, maintain their independence, or have additional support after discharge from hospital. A district nurse will manage a team of nurses which may provide training to carers if individuals cannot manage themselves (e.g. catheter care). As well as treatment, a district nurse can offer advice and support with health concerns and refer on to other organisations.

They may be trained to assess patient's needs, for example undertake bladder scanning and support as well as working collaboratively with other healthcare professionals in preventing unnecessary or avoidable hospital admissions.

See: The Queen's Nursing Institute: District nurses



Healthcare professionals involved:

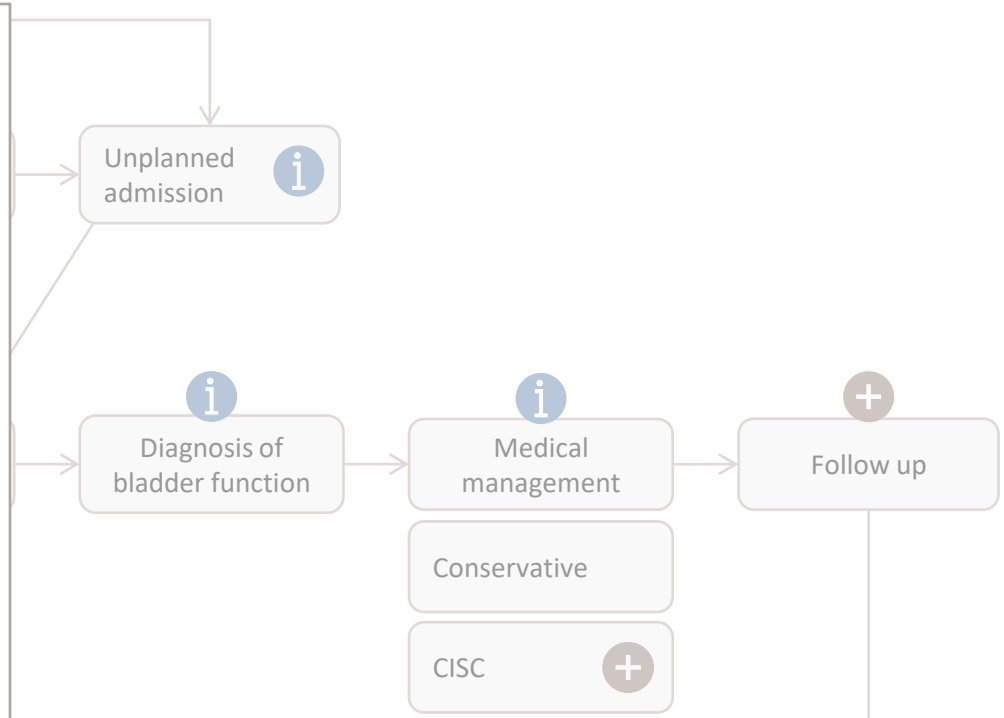
- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

Bowel management

Good bowel management is an important aspect of ensuring the bladder is working well and consideration should be given to:

- Diet and fluids.
- Correct position of sitting on toilet.
- Correct wiping techniques to avoid UTIs.
- Use of gastro-colic reflex.
- Information on how bowels affect bladder.
- Information on how certain medications can affect bowel.
- Details of who to contact if situation changes.

If the PwMS presents with urinary symptoms a full continence assessment should be considered to rule out constipation. This might be managed with medication, suppositories, enemas, or transanal irrigation.



Healthcare professionals involved:

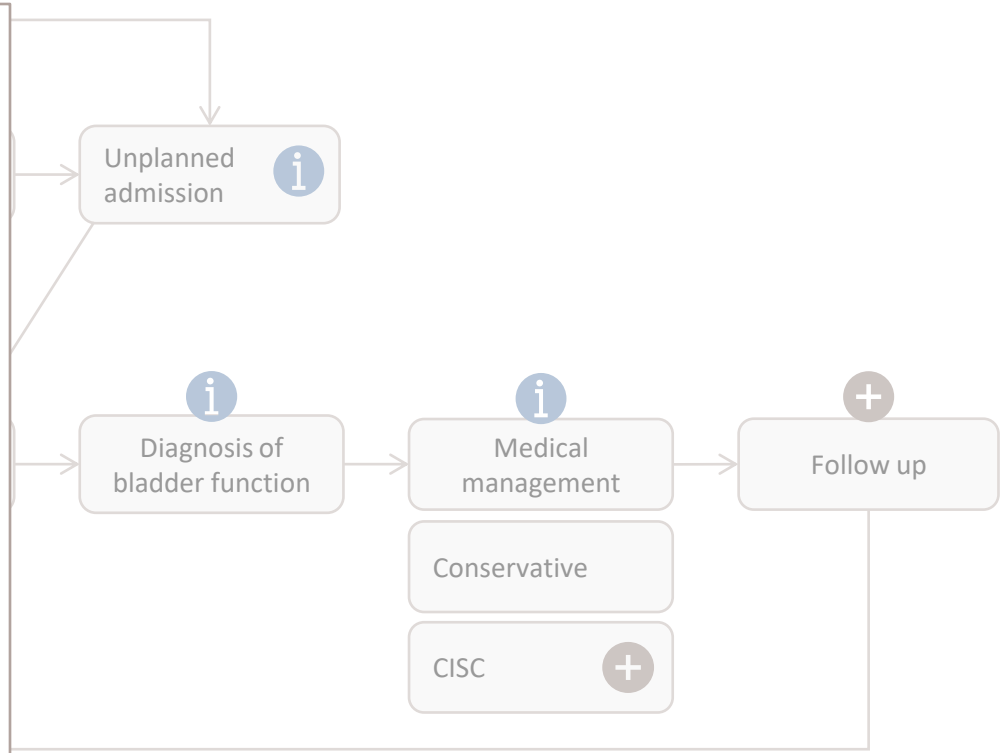
- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

Referral to urologist/urogynaecologist

Criteria for patient referral to urology:

- Presence of haematuria.
- Symptomatic of significant incomplete bladder emptying (referring for urodynamics).
- 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.

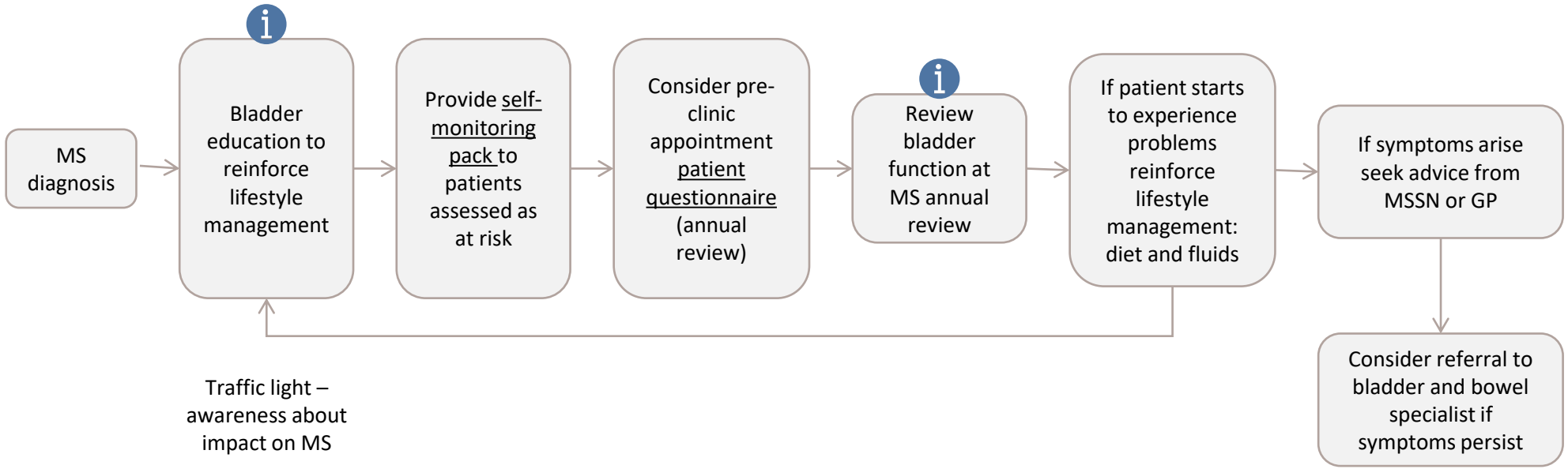
See: NICE (2012) Urinary incontinence in neurological disease: assessment and management. Clinical Guideline [CG148]



Healthcare professionals involved:

- MSSN
- Bladder & bowel nurse
- Physiotherapist
- Well bowel management
- Urologist
- Other HCPs

Promotion of bladder health



Bladder education to reinforce lifestyle management

PwMS should have a six week follow up following diagnosis where initial information of bladder self help could be provided. Individual assessment will indicate if bladder and bowel education is needed:

- How to avoid and manage UTIs and constipation
- Trigger factors
- Lifestyle changes
- Self-monitoring via app.

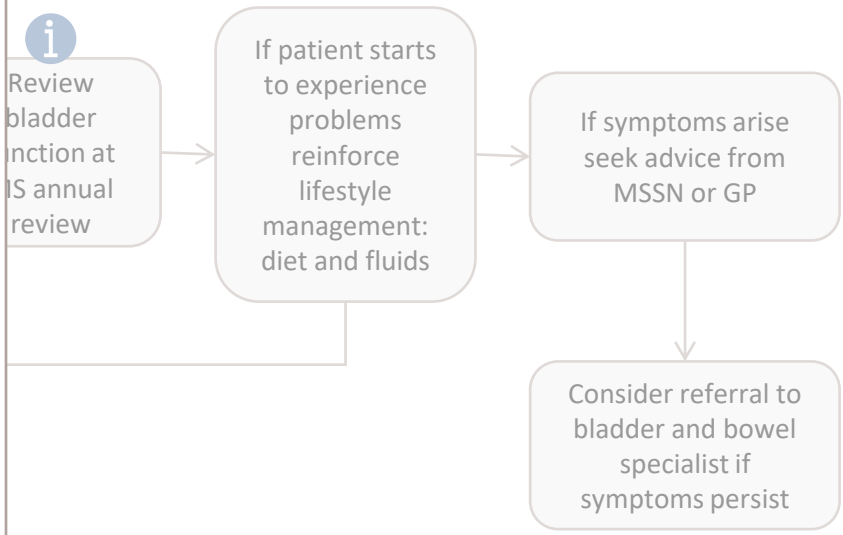
PwMS need bladder guidance on what's normal so that they are able to highlight any bladder issues.

Consider provision of patient information pack:

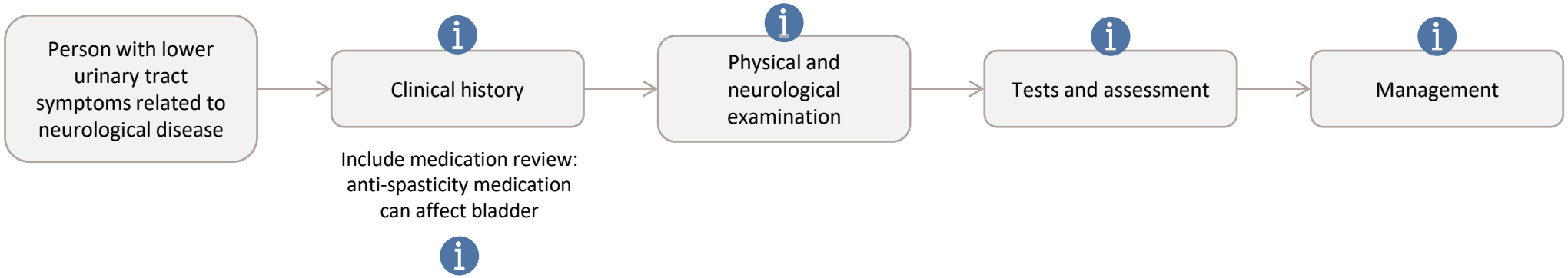
- Local contact phone numbers
- Basic information
- Trigger factors/exacerbation
- Patient leaflet
- Bladder symptoms
- Single point of contact.

Bladder issues can be embarrassing, making PwMS reluctant to seek help. Consider providing information and support for patients, carers and home carers/social care, such as resources from:

- Shift.ms
- MS Society
- MS Trust
- Bladder and Bowel UK
- UK MS Specialist Nurse Association (for healthcare professionals)



Assessment


Person with lower urinary tract symptoms related to neurological disease
Clinical history
Include medication review: anti-spasticity medication can affect bladder
Physical and neurological examination
Tests and assessment
Management

Overview: assessing a person with lower urinary tract symptoms

- Bladder review could be done on the MS annual review although a separate appointment may be necessary if the patient is having symptoms (see NICE guideline CG148).
- It is important to include assessment of prolapse and menopause (see NICE guideline NG23 and guideline NG123).
- Assessment – determine if stress/urge/mixed incontinence, failure to store or failure to empty. Utilise an assessment form.
- Dipstick urinalysis.
- Pre- and post-void bladder scanning.
- Frequency volume charts – volume and type of fluid drunk and voided volumes.
- Bladder booklet – self help.
- Identify reversible factors that may be contributing to incontinence.
- Identify those individuals who may need more specialist diagnostic evaluations, e.g. urodynamics.
- Develop the most appropriate individual treatment or management plan.

Clinical history

- Comorbidities, age, gender, pregnancy.
- Bladder diary.
- Medication review (note: spasticity medication can affect bladder).
- Bowel function.
- Consider prolapse and menopause (see NICE guideline NG23 and guideline NG123).
- Prostate: consider International Prostate Symptom Scores (IPSS) Digital rectal examination with GP.
- ICIQ Short form + examination.

Examination

Examinations (vaginal/rectal/abdominal/neurological), if required, by a competent professional.

Functional problems

Patients should be referred to a neurological physiotherapist (ideally one with expertise in MS) for assessment and management of:

- Reduced mobility which makes accessing the toilet difficult or impossible.
- Increased tone in the lower limbs, especially hip adductors, which can make voiding, wiping etc difficult or impossible.
- Poor hand dexterity.

Case study: Cardiff's dedicated bladder and bowel nurse

For the last 15 years Cardiff and Vale University Health Board has employed a dedicated bladder and bowel nurse for PwMS. This nurse has direct contact with both the MS team and established bladder & bowel team and is a communication link between both services. They are responsible for continence assessment, treatments and subsequent management and continued support for PwMS with regards to bladder and bowel health.

Tests and assessment

A basic continence assessment should comprise:

- Complete medical, surgical and obstetric history, with details of allergies, mental health, mobility, dexterity, and cognitive, body mass index (BMI) or social issues.
- Information about the duration of the problem, symptoms/presentation, effect on quality of life and current management.
- Details of all medication, including over-the-counter medication, herbal remedies and recreational drug use (note: spasticity medication can affect bladder).
- A completed diary (three days for bladder problems and one week for bowel problems), or an observational chart completed by carers/professionals if an individual is unable to complete a diary independently.
- Details of fluid consumption (including amount and type of fluid) and dietary input.
- Dipstick urinalysis — which is used as a screening test rather than a diagnostic test (to rule out dehydration and other medical issues), especially if there are new continence issues (including renal problems, diabetes and potential UTIs).
- Examinations (vaginal/rectal/abdominal/neurological), if required, by a competent professional.
- Bladder scans — if presenting with recurrent UTIs, to check for signs of incomplete emptying or underlying neuropathy.
- Environmental factors that may affect continence, e.g. access to toilets, room sharing, chair/bed heights, toilet height, space to accommodate equipment (e.g. walking aids/wheelchairs), floor surfaces, and unclear signage.

Questionnaires and MS impact scales can be utilised to assess patients and better address their needs:

- Bladder/bowel symptoms/outcome form
- ICIQ incontinence questionnaire
- Female incontinence questionnaire
- Pre-clinic questionnaire
- EDSS
- MS nurse initial appointment
- Fluid intake chart

Spasticity

- Spasticity is a common symptom of MS and many PwMS are taking anti-spasticity medication to manage this; however, this can cause problems with bladder and bowel control.
- Medication should be reviewed by a neurophysiotherapist or competent professional.
- Side effects of anti-spasticity medication can exacerbate other symptoms of MS and mimic disease progression.
- Prescribers often fail to monitor or review the effectiveness of anti-spasticity medication in PwMS.
- Neurological nurses and physiotherapists need to take an active role in monitoring the effects of anti-spasticity medication at assessment and in relation to their own therapeutic interventions.

Case study: Angela

Angela was diagnosed with MS 30 years ago. She lives with her husband and uses an electric wheelchair. She was prescribed gabapentin 12 years ago for spasms interfering with her leg movements. Initially, it worked well. Five years ago she became doubly incontinent. An MS specialist physiotherapist found her legs were very weak, with loss of posture and no use of her arms. In discussion with her GP, she gradually reduced gabapentin.

"I regained some use in my right arm and could feed myself and control my wheelchair. My voice became louder; I was less fatigued, and my personality returned. My posture was better, and I began using a frame to stand upright again. The spasms didn't return."

Ruth Stross, 2022

Tests and assessment → Management

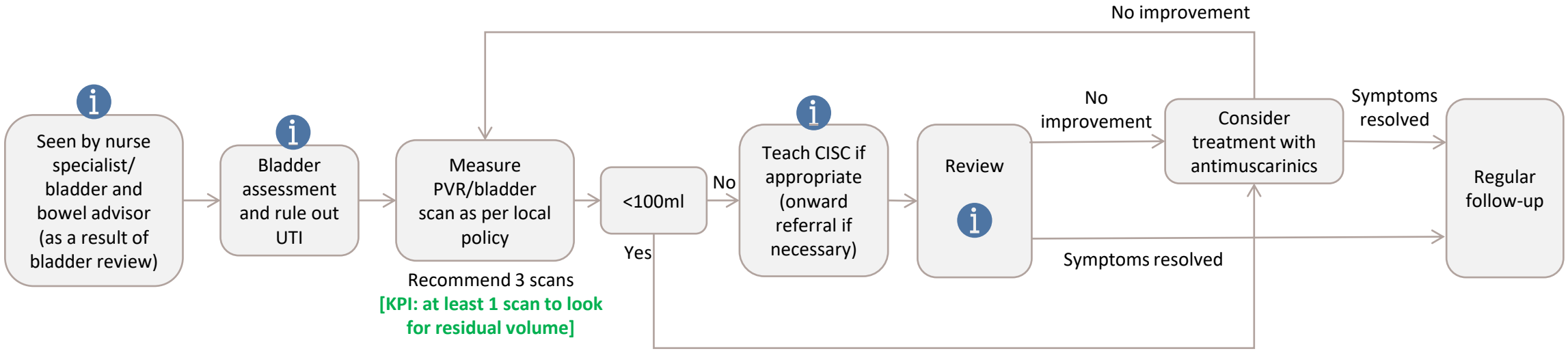
Management

A list of options in bladder management:

- Clean intermittent self-catheterisation (CISC)
- Indwelling catheter
- Anti-muscarinics /tamsulosin/desmopressin
- Urinary sheath
- Bed urinals
- Containment products
- Funnel urinals
- Refer for cystoscopy
- Urodynamics
- Ultrasound of kidneys, ureters and bladder.

When to refer for urgent or specialist investigation.

Clean intermittent self-catheterisation (CISC)



Teaching CISC

- The healthcare professionals should have the skills and competencies to undertake CISC training for PwMS.
- CISC needs to be the choice of the PwMS after education on bladder management options.
- Preference would be to learn CISC at home taught by a competent healthcare professional.
- If patient doesn't have dexterity for CISC consider referral to physiotherapy.
- Strategies for improving adherence to CISC are very important and outlined in the 2022 Expert opinion consensus for MS bladder management, as below:
    - 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 CISC, 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.
- Consider the availability of industry partnerships to support patients on CISC.

Dexterity issues

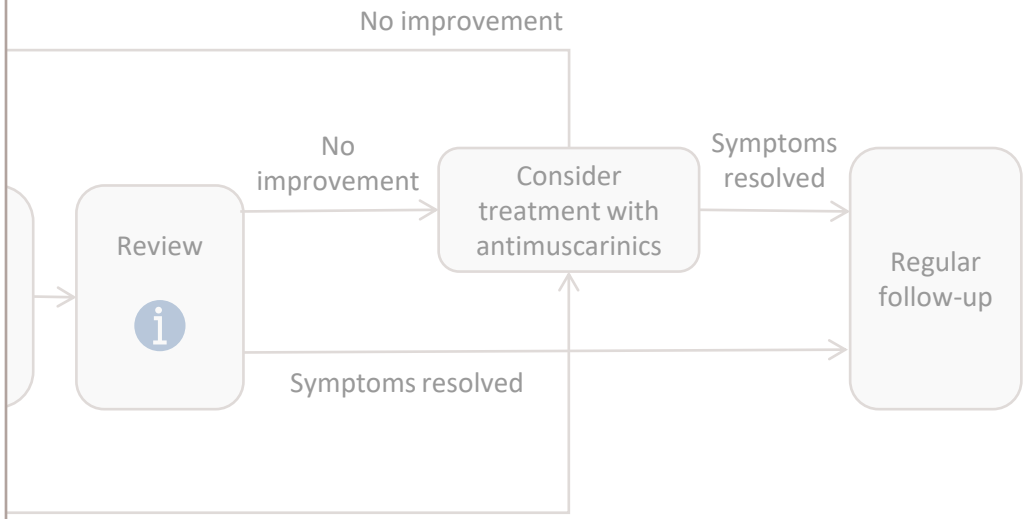
There are many interventions that can help if the PwMS has dexterity issues which referral to a physiotherapist might help:

- Stiffer catheters that are easier to insert
- Catheters with aiding device
- Pressure garments on the arms, weighted wrist cuffs
- Using peripheral vision to perform a task
- Improving postural control when sitting on the toilet or commode.

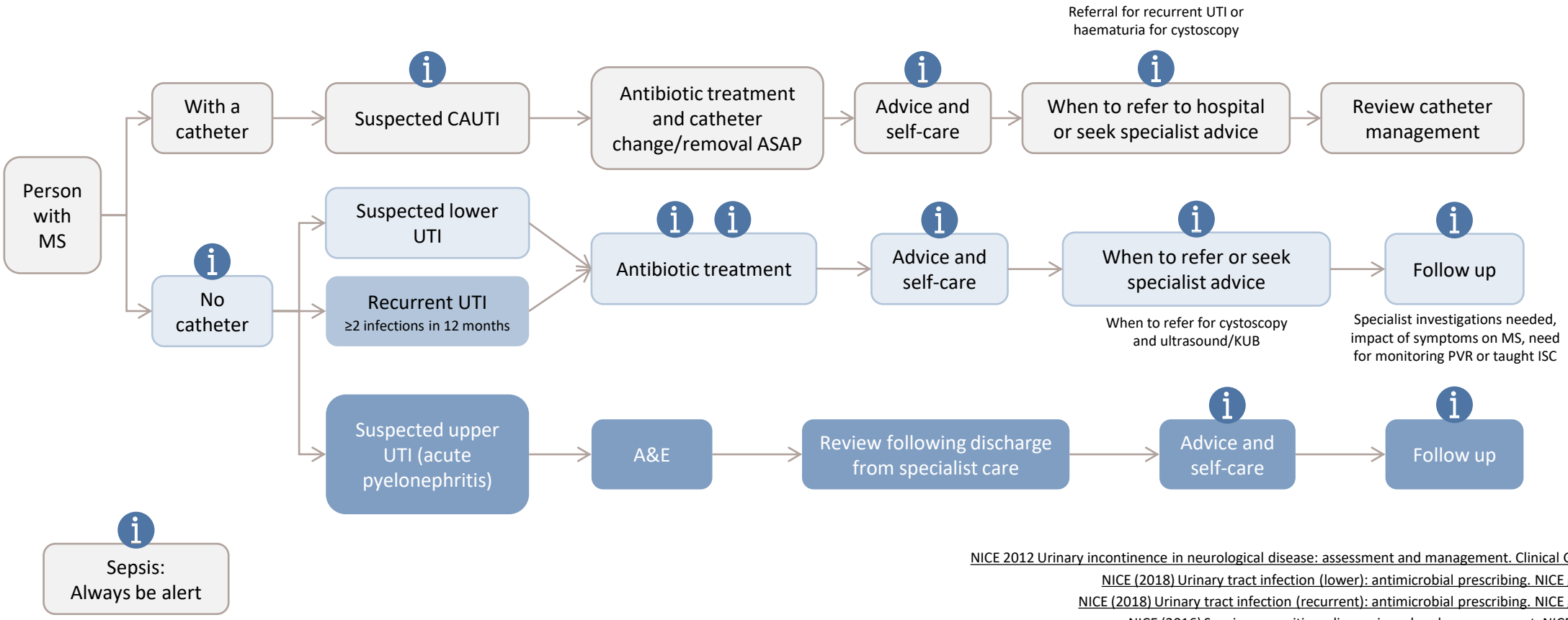
Review [KPI]

CISC review is vitally important for PwMS as part of the annual review or more frequently if problems arise or post UTI or interventions:

- Bladder diary review
- Assess competency with CISC (technique, positioning etc)
- Any UTIs?
- Assess frequency of CISC
- Discuss personal experience
- Suitability and access of equipment
- Refer to manufacturer's guidelines.



Treatment for UTI and intractable major UTI problems



NICE 2012 Urinary incontinence in neurological disease: assessment and management. Clinical Guideline [CG 148]
NICE (2018) Urinary tract infection (lower): antimicrobial prescribing. NICE guideline [NG109]
NICE (2018) Urinary tract infection (recurrent): antimicrobial prescribing. NICE guideline [NG112]
NICE (2016) Sepsis: recognition, diagnosis and early management. NICE guideline [NG51]
NICE (2018) Urinary tract infection (catheter-associated): antimicrobial prescribing. NICE guideline [NG113]

UTI pack

A UTI pack incudes guidance on managing UTI in MS symptoms:

- How to keep a bladder diary
- How to take a MSU pack, using a UTI pack if indicated
- How to self-monitor
- Lifestyle management: diet and fluids
- Some areas may use antibiotic rescue packs and recurrent UTI bladder scan.
- Antibiotic prophylaxis (and topical oestrogen for post-menopausal women, see NICE guideline NG23)
- Guidance on patient-initiated follow up (PIFU) and who to contact.

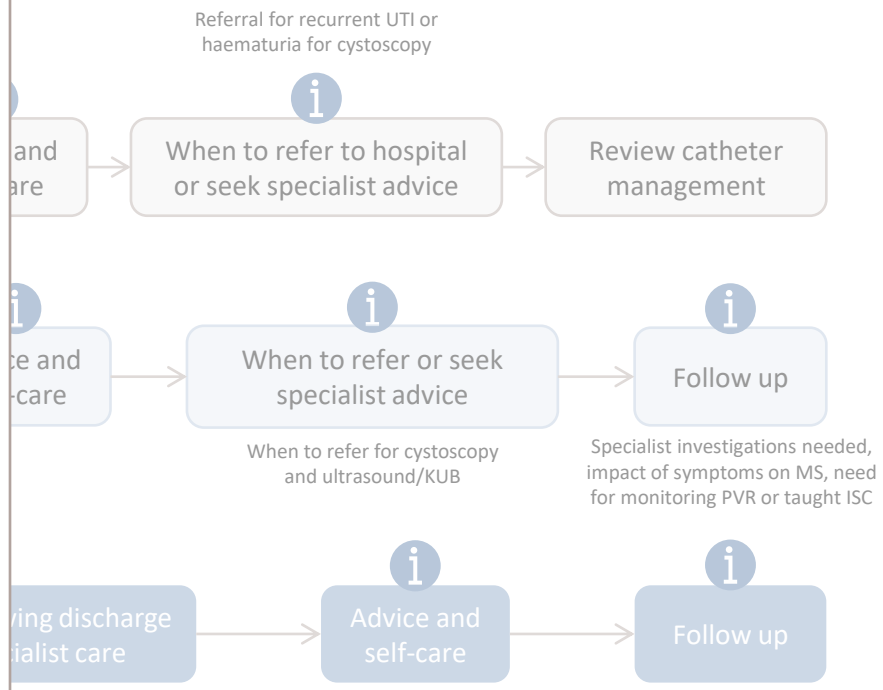
See: Thomas S et al (2022) Expert opinion consensus document. Management of bladder dysfunction in people with multiple sclerosis

Case study: UTI home testing kit

Concerned that COVID-19 would bring an increase in hospital admissions for PwMS with a UTI, Ruth Stross MSSN at Surrey Downs Health and Care service developed a simple home urine test kit for patients with a suspected UTI. The results are sent to the clinical team by email and patients with abnormal results are asked to take a sample to their GP for further testing. The kit has been peer reviewed by local MSSNs and MS practitioners, and has been endorsed by the MS Trust and MS Academy.

"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." (Thomas et al 2022)



NICE 2012 Urinary incontinence in neurological disease: assessment and management. Clinical Guideline [CG 148]
NICE (2018) Urinary tract infection (lower): antimicrobial prescribing. NICE guideline [NG109]
NICE (2018) Urinary tract infection (recurrent): antimicrobial prescribing. NICE guideline [NG112]
NICE (2016) Sepsis: recognition, diagnosis and early management. NICE guideline [NG51]
NICE (2018) Urinary tract infection (catheter-associated): antimicrobial prescribing. NICE guideline [NG113]

Suspected Catheter Acquired Urinary Tract Infection (CAUTI)

Symptoms of CAUTI:

- Exacerbation of MS symptoms, plus UTI symptoms (suprapubic pain, malodorous urine, fever, haematuria, tenderness, cloudy discoloured urine, pus, urethral discomfort.
- Dysuria, frequency, urgency, incontinence, potential pain in groin, testicles or perineum.

In the case of suspected CAUTI:

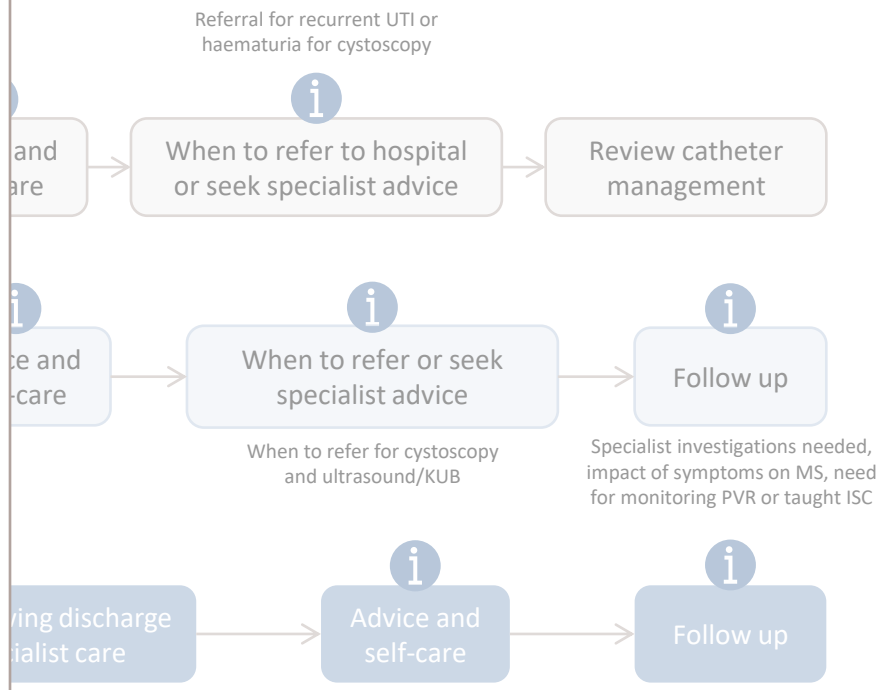
- Advise patient to contact the relevant person GP and community nurse.
- Catheter specimen urine (CSU) from sampling port sent for culture.
- Do not delay starting antibiotics before CSU results or catheter change performed.
- Clinician follow up on results within 48 hours to check prescription correct.
- Repeat CSU if patient still symptomatic.
- State patient has MS, which antibiotic just completed, consider discussion with microbiology team.

See: NICE (2018) Urinary tract infection (catheter-associated): antimicrobial prescribing. NICE guideline [NG113]

Case study: Catheter e-learning module in Wales

To standardise professional education in Wales, an e-learning module has been developed on indwelling catheter insertion, ongoing management and care. The training is available to all, including care home staff and students. The 'All Wales Catheter Passport' has been developed as an education tool for patients with an indwelling catheter, outlining catheter care and management, how to obtain supplies, contact details of relevant professionals and who is responsible for catheter changes.

(Yates 2022)



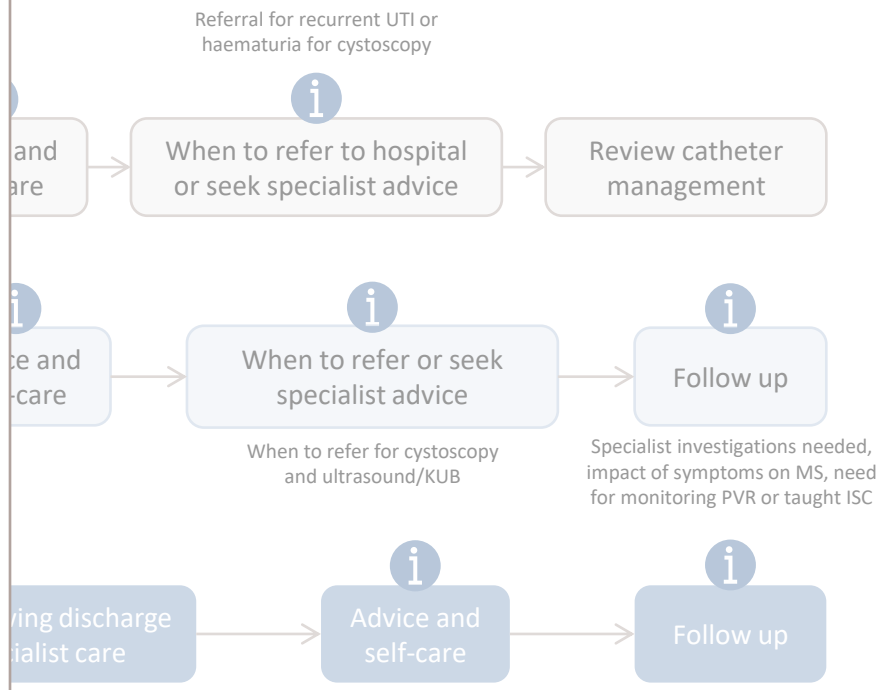
NICE 2012 Urinary incontinence in neurological disease: assessment and management. Clinical Guideline [CG 148]
NICE (2018) Urinary tract infection (lower): antimicrobial prescribing. NICE guideline [NG109]
NICE (2018) Urinary tract infection (recurrent): antimicrobial prescribing. NICE guideline [NG112]
NICE (2016) Sepsis: recognition, diagnosis and early management. NICE guideline [NG51]
NICE (2018) Urinary tract infection (catheter-associated): antimicrobial prescribing. NICE guideline [NG113]

Antibiotic treatment for UTI

- Contact GP, provide MSU, GP dipstick (exclude abnormalities e.g. glycosuria, proteinuria, haematuria, pH, specific gravity), send for culture, treat with antibiotics.
- Ensure patient not being treated with antibiotics previously found to be ineffective.

Guidelines

- NICE (2018) Urinary tract infection (lower): antimicrobial prescribing. NICE guideline [NG109]
- NICE (2018) Urinary tract infection (recurrent): antimicrobial prescribing. NICE guideline [NG112]
- NICE (2018) Urinary tract infection (catheter-associated): antimicrobial prescribing. NICE guideline [NG113]



NICE 2012 Urinary incontinence in neurological disease: assessment and management. Clinical Guideline [CG 148]
NICE (2018) Urinary tract infection (lower): antimicrobial prescribing. NICE guideline [NG109]
NICE (2018) Urinary tract infection (recurrent): antimicrobial prescribing. NICE guideline [NG112]
NICE (2016) Sepsis: recognition, diagnosis and early management. NICE guideline [NG51]
NICE (2018) Urinary tract infection (catheter-associated): antimicrobial prescribing. NICE guideline [NG113]

NICE guideline [NG109], Urinary tract infection (lower): antimicrobial prescribing

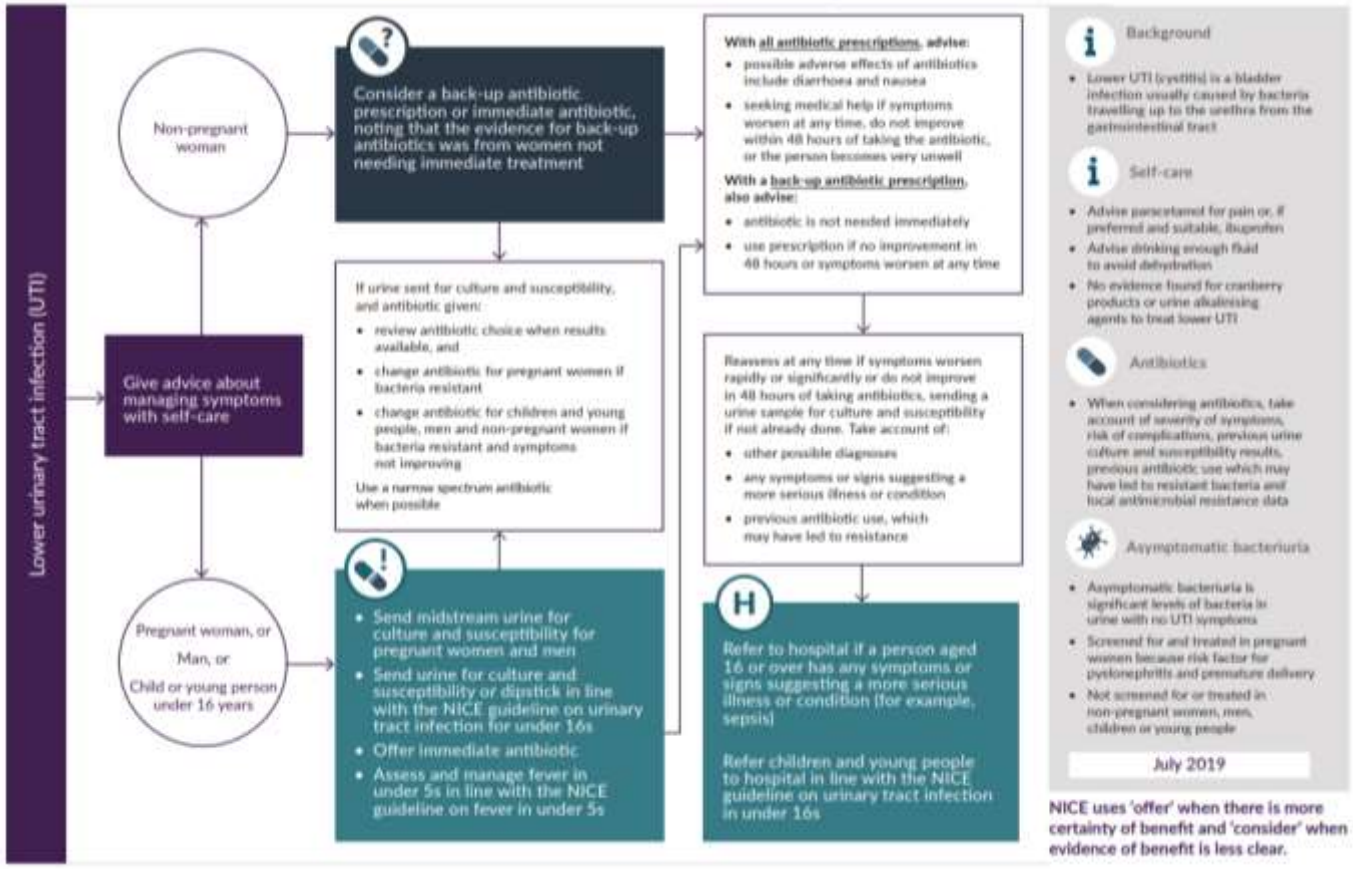


Image shows summary flowchart based on:

NICE (2018) Urinary tract infection (lower): antimicrobial prescribing. NICE guideline [NG109]

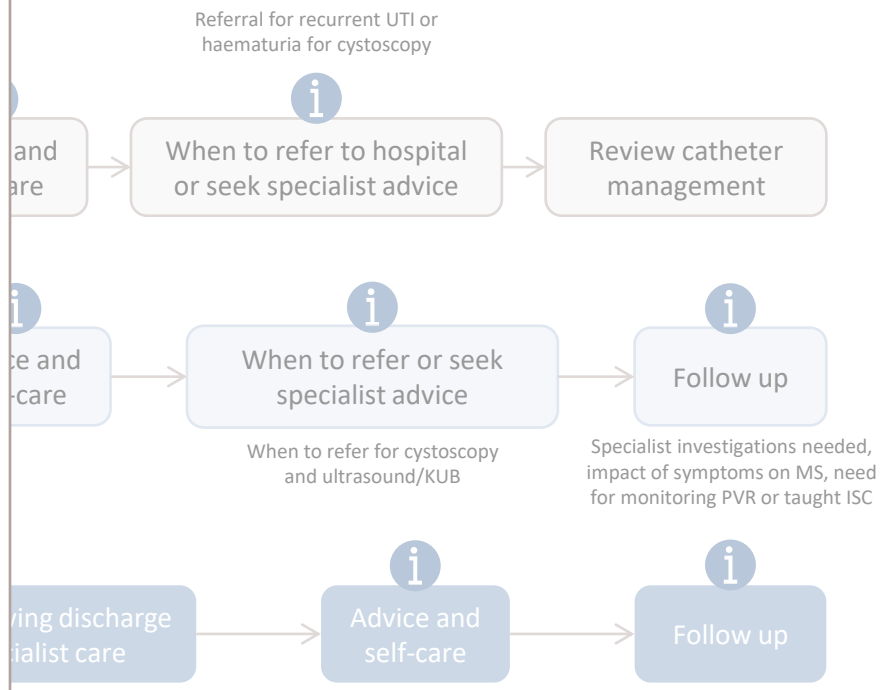
Sepsis

- Sepsis awareness in CAUTI guideline, risk level.
- Signs and symptoms in a catheterised patient.
- NHS RightCare (2018) Scenario: Sepsis identification and care.
- Sepsis awareness detection (see NICE (2016) Sepsis: recognition, diagnosis and early management. NICE guideline [NG51]).

Sepsis can be life threatening to patients and is costly to the NHS in the sub optimal analysis below there is a 38% variation in costs when the patient gets sepsis. Source NHS Rightcare.

Analysis by cost category	Suboptimal	Optimal	Optimal %
Primary care management	£238	£451	190%
Urgent and emergency care	£247	£247	100%
Secondary care management	£7,518	£2,318	31%
Total	£8,003	£3,018	38%

Source: NHS RightCare (2018) Scenario: Sepsis identification and care.



NICE 2012 Urinary incontinence in neurological disease: assessment and management. Clinical Guideline [CG 148]
NICE (2018) Urinary tract infection (lower): antimicrobial prescribing. NICE guideline [NG109]
NICE (2018) Urinary tract infection (recurrent): antimicrobial prescribing. NICE guideline [NG112]
NICE (2016) Sepsis: recognition, diagnosis and early management. NICE guideline [NG51]
NICE (2018) Urinary tract infection (catheter-associated): antimicrobial prescribing. NICE guideline [NG113]

Follow up

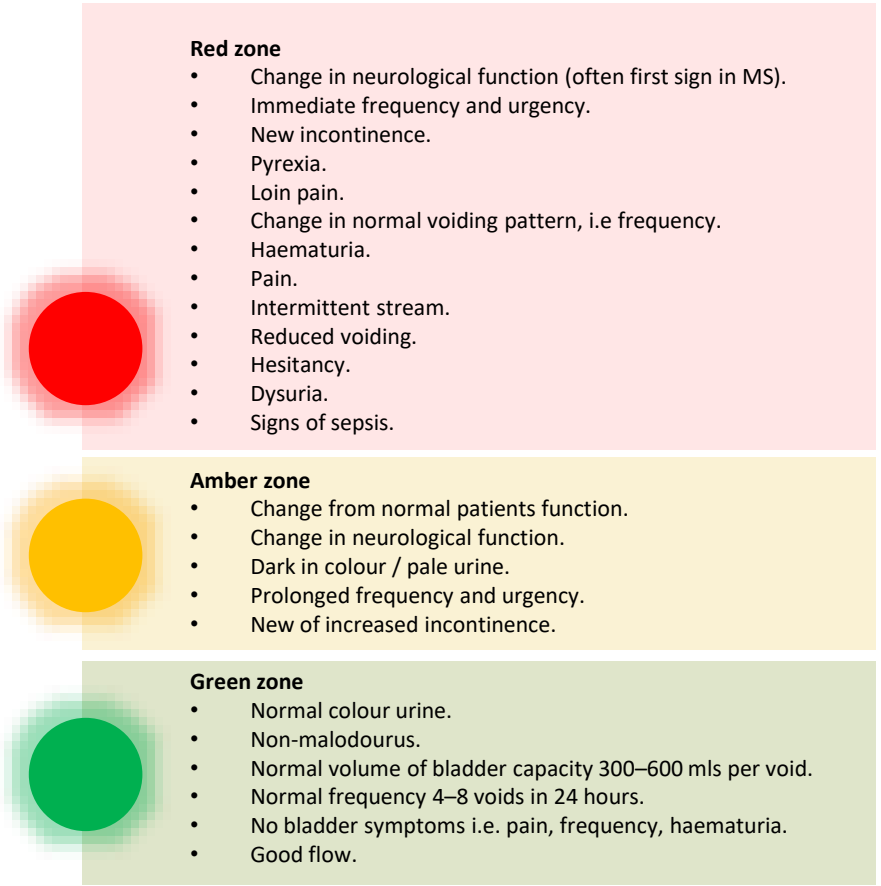
At the MS annual review – ensure a bladder review is undertaken. This should include talking about bladder, including: frequency, urgency, nocturia and any recent history of UTI. These questions will highlight any bladder dysfunction to lead to further investigation.

Consider provision of self-management strategies.

PIFU might run alongside the annual 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 2021). 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 or improving bladder and bowel services and patient outcomes (Metcalfe & Owen 2021).

European Association of Neurology guidelines recommend regular close surveillance of bladder dysfunction in PwMS throughout each patient's lifetime (EAU 2022).

NICE guidelines for MS management (2022) recommend that these patients should undergo a comprehensive review (including bladder function) at least once a year.



References & resources

- Royal College of Nursing (2021) Catheter Care Guidence for Healthcare professionals
- Thomas S, Bradley J, Cole et al. A consensus bladder and bowel management pathway for multiple sclerosis: process and application. BJNN 2022; 18(Sup3):S6-S13
- Thomas S, Bradley J, Bharadia T, et al. Expert opinion consensus document. Management of bladder dysfunction in people with multiple sclerosis. BJNN 2022; 31 (3 Suppl 3), S1–32
- National Neurology Advisory Group (2019) Optimal clinical pathway: Multiple sclerosis
- Hollister e-Learning resource for MS: 2 modules
- Integrated pathway approach
- “Esther’s story”: MS Academy (2021) MS Unite's first steps from vision to reality
- “Rachel’s story”: Wilmington Healthcare (2020) Wilmington Healthcare Improvement Scenario: Relapsing Remitting MS
- Thomas S et al. (2020) The Forgotten Many: A 2020 Vision for Secondary Progressive Multiple Sclerosis
- MS Academy (2021) NHS Reset and Reform: A new direction for health and care in multiple sclerosis

Assessment criteria and scales

- McDonald MS diagnostic criteria
- Online EDSS assessment tool

Healthcare professional education

- NHS England (2018) Excellence in Continence Care: Practical guidance for commissioners, and leaders in health and social care

Patient education

- www.confidencecollege.org/ms/know-your-bladder
- Maintaining a healthy bladder resource
- Managing your bladder

NICE guidelines

- NICE (2022) Urinary tract infection in under 16s: diagnosis and management. NICE guideline [NG224]
- NICE (2022) Multiple sclerosis in adults: management. NICE guideline [NG220]
- NICE (2019) Urinary incontinence and pelvic organ prolapse in women: management. NICE guideline [NG123]
- NICE (2018) Urinary tract infection (catheter-associated): antimicrobial prescribing. NICE guideline [NG113]
- NICE (2018) Urinary tract infection (recurrent): antimicrobial prescribing. NICE guideline [NG112]
- NICE (2018) Urinary tract infection (lower): antimicrobial prescribing. NICE guideline [NG109]
- NICE (2016) Sepsis: recognition, diagnosis and early management. NICE guideline [NG51]
- NICE (2016) Menopause: diagnosis and management. NICE guideline [NG23]
- NICE (2014) Infection prevention and control. Quality standard [QS61]
- NICE (2012) Urinary incontinence in neurological disease: assessment and management. Clinical Guideline [CG148]

Suggested Key Performance Indicators (KPIs) when undertaking service audit

- Each MS service is aware of the numbers of patients who may have bladder symptoms.
- Each MS service is aware of the numbers of patients receiving active treatment for bladder symptoms.
- A patient completed bladder assessment is completed as part of the annual review and is discussed at the review meeting.
- PwMS experiencing bladder symptoms have a dipstix urinalysis, bladder scan and assessment of bladder symptoms undertaken by a competent healthcare professional.
- An integrated bladder pathway is in place between MS and bladder and bowel/urology services.

KPIs:

- Annual review includes bladder screening.
- If problem detected, waiting time for a continence review are 4–12 weeks, maximum of 18 weeks.
- At least 1 scan to look for residual volume.
- UTI follow up after treatment.
- CISC daily follow up following initiation until competent.

- Audit of current situation and pathway implementation then.
- Audit of what's happening/changes.
- What staffing capacity do we need to see patients?
- Timelines.
- Waiting times for different elements.
- Annual review bladder symptoms.

Abbreviations

AHP	Allied healthcare professional
CAUTI	Catheter associated urinary tract infection
CISC	Clean intermittent self-catheterisation
CSU	Catheter specimen urine
DMT	Disease-modifying therapy
DSD	Detrusor sphincter dyssynergia
EDSS	Expanded Disability Status Scale
GIRFT	Getting It Right First Time
HCP	Healthcare professional
HES	Hospital episode statistics
MDT	Multidisciplinary team
MS	Multiple sclerosis
MSSN	MS specialist nurse
MSU	Midstream specimen of urine
MUI	Mixed urinary incontinence
NICE	National Institute for Health and Care Excellence
NNAG	National Neurology Advisory Group
OT	Occupational therapist
PIFU	Patient-initiated follow-up
PVR	Post-void residual
PwMS	People with MS
SALT	Speech and language therapy
UTI	Urinary tract infection

Appendices

- **Bladder/bowel symptoms/outcome form**
- ICIQ incontinence questionnaire
- Female incontinence questionnaire
- Pre-clinic questionnaire
- EDSS
- MS nurse initial appointment
  - Page 1
  - Page 2
  - Page 3
- Fluid intake chart

NHS No

Date:- Day Month Year

Patient Bladder / Bowel Symptoms / Outcome Form

Many people experience bladder and / or bowel problems. We are interested in finding out your individual experiences of these symptoms, how much it bothers you and affects your life. We would be grateful if you could answer all of the following questions, thinking about how you have been over the **PAST THREE MONTHS**. These answers will assist the professional in assessing and treating your condition and establishing how effective treatments are for outcome measures.

1. Please write in your age ☐

2. Please specify your gender ☐

3. In 24 hours how often do you (please tick appropriate)

Pass Urine		**Open your Bowels**	
1-4 times	☐	1-3 times daily	☐
5-8 times	☐	More than 3 times a day	☐
More than 9 times	☐	Less than every 3 days	☐
Are you woken up at night	☐	Less than once weekly	☐
(If Yes how many times)	☐		

4. Please specify consistency / type of stool according to Bristol Stool Chart (see below) ☐

BRISTOL STOOL CHART

Type 1	Separate hard lumps	SEVERE CONSTIPATION
Type 2	Lumpy and sausage like	MILD CONSTIPATION
Type 3	A sausage shape with cracks in the surface	NORMAL
Type 4	Like a smooth, soft sausage or snake	NORMAL
Type 5	Soft blobs with clear-cut edges	LACKING FIBRE
Type 6	Mushy consistency with ragged edges	MILD DIARRHEA
Type 7	Liquid consistency with no solid pieces	SEVERE DIARRHEA

5. Do you experience any of the following:- (Please tick all that apply)

Urine		**Bowel**	
Hesitancy	☐	Pain	☐
Straining to empty bladder	☐	Bleeding	☐
Poor / Prolonged flow	☐	Incomplete emptying	☐
Incomplete emptying	☐	Straining to empty bowel	☐
Urgency	☐	Urgency	☐
Burning / pain	☐	Passing involuntary flatus / wind	☐

If during voiding and/or defecating you experience pain please specify where _____and how would you describe it on the scale below (Please circle a number between 1 (mild) and 5 (a great deal))

Adapted from ICIQ-UI short form & ICIQ-B
Ann Yates Director of Continence Services Cardiff & Vale UHB
Final Version October 2018 – Review 2020

1 2 3 4 5
mild a great deal

6. Do you ever leak (tick the appropriate box(es))

Urine		**Faeces**	
Never	☐	Never	☐
2-3 times a week	☐	2-3 times a week	☐
Several times a day	☐	Several times a day	☐
All the time	☐	All the time	☐

If Never to both please go to Question 9

7. Can you express the amount of leakage of each incontinent episode (please tick appropriate box(es))

Urine		**Faeces**	
None	☐	None	☐
A small amount	☐	A small amount	☐
Moderate amount	☐	Moderate amount	☐
Large amount	☐	Large amount	☐

8. When do you leak (Please tick ALL that apply)

Urine		**Faeces**	
Never		Never	☐
Before you get to toilet	☐	Before you get to toilet	☐
When you cough/sneeze	☐	When you cough/sneeze	☐
When you are asleep	☐	When you are asleep	☐
Physically active	☐	Physically active	☐
No obvious reason	☐	No obvious reason	☐
Leaks all the time	☐	Unpredictable	☐
Sexual intercourse	☐	Sexual intercourse	☐
When you think you have finished	☐	Leaks all the time	☐

If you use a pad product or any device for protection please specify type and number in 24 hours ☐

9. Overall in your day to day life how much do these symptoms bother you (Please circle a number between 0 (not at all) and 5 (a great deal))

0 1 2 3 4 5
Not at all a great deal

Thank you for completing the questions
Please hand completed form to relevant Health Professional.

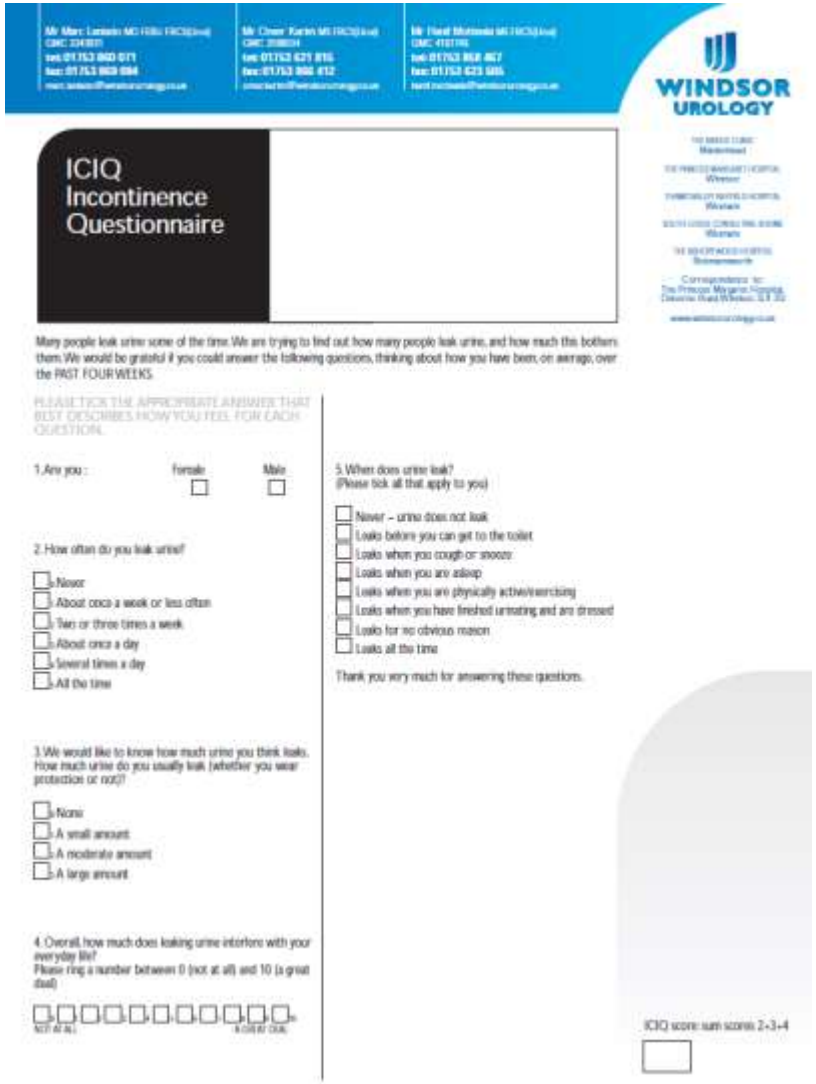
For Assessing Professional

If individual has identified relevant bothersome factors and is appropriate and relevant for further assessments please discuss referral to specialist continence service with individuals consent.

Adapted from ICIQ-UI short form & ICIQ-B
Ann Yates Director of Continence Services Cardiff & Vale UHB
Final Version October 2018 – Review 2020

Appendices

- Bladder/bowel symptoms/outcome form
- **ICIQ incontinence questionnaire**
- Female incontinence questionnaire
- Pre-clinic questionnaire
- EDSS
- MS nurse initial appointment
  - Page 1
  - Page 2
  - Page 3
- Fluid intake chart



WINDSOR UROLOGY

ICIQ Incontinence Questionnaire

Many people leak urine some of the time. We are trying to find out how many people leak urine, and how much this bothers them. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the PAST FOUR WEEKS.

PLEASE TICK THE APPROPRIATE ANSWER THAT BEST DESCRIBES HOW YOU FEEL FOR EACH QUESTION.

1. Are you : Female ☐ Male ☐

2. How often do you leak urine?
- ☐ Never
- ☐ About once a week or less often
- ☐ Two or three times a week
- ☐ About once a day
- ☐ Several times a day
- ☐ All the time

3. We would like to know how much urine you think leaks. How much urine do you usually leak (whether you wear protection or not)?
- ☐ None
- ☐ A small amount
- ☐ A moderate amount
- ☐ A large amount

4. Overall, how much does leaking urine interfere with your everyday life?
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 10
NOT AT ALL — A GREAT DEAL

5. When does urine leak?
(Please tick all that apply to you)
- ☐ Never – urine does not leak
- ☐ Leaks before you can get to the toilet
- ☐ Leaks when you cough or sneeze
- ☐ Leaks when you are asleep
- ☐ Leaks when you are physically active/exercising
- ☐ Leaks when you have finished urinating and are dressed
- ☐ Leaks for no obvious reason
- ☐ Leaks all the time

Thank you very much for answering these questions.

ICIQ score: sum scores 2+3+4 ☐

Appendices

- Bladder/bowel symptoms/outcome form
- ICIQ incontinence questionnaire
- **Female incontinence questionnaire**
- Pre-clinic questionnaire
- EDSS
- MS nurse initial appointment
  - Page 1
  - Page 2
  - Page 3
- Fluid intake chart

Central and North West London NHS
NHS Foundation Trust

FEMALE INCONTINENCE SYMPTOM QUESTIONNAIRE

Name:..... Date of Birth: .....

Today's Date: ..... ICIQ score: **1 + 2= + 3 .....**

Please complete this questionnaire to help us find out more about any urinary problems you might have. We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the **PAST FOUR WEEKS**.

1. How often do you leak urine? (please tick one box below)

		SCORE
Never		0
Once a week or less often		1
2-3 times per week		2
Once a day		3
Several times a day		4
All the time		5

2. How much urine do you think usually leak (please tick one box below)?

AMOUNT	PLEASE TICK	SCORE
None		0
Small amount		2
Moderate amount		4
Large amount		6

3. Overall, how much does leaking urine interfere with your everyday life? Please ring a number between 0 (not at all) and 10 (a great deal):

0 1 2 3 4 5 6 7 8 9 10

4. When does urine leak (tick all that applies to you)?

	PLEASE TICK
Never – urine does not leak	
Leaks before you can get to the toilet	
Leaks when you cough or sneeze	
Leaks when you're asleep	
Leaks when you are physically active/exercising	
Leaks when you have finished urinating and are dressed	
Leaks for no obvious reason	
Leaks all the time	

Please remember to bring this sheet with you when you come for your appointment.

BLADDER DIARY

Central and North West London NHS
NHS Foundation Trust

Name:

Please record any fluids that you drink and use a jug to measure the amount of urine that you pass. Enter the amount in the box at the appropriate time. If you are unable to measure the volume (e.g. if you are at work) then put a tick in the box instead. However, please try and perform the measurements on a typical day, and on a day when you are able to measure every time you pass urine.

Here is an example:

	Day 1		Day 2		Day 3	
Time	Fluid intake Volume	Urine Output Volume	Fluid intake Volume	Urine Output Volume	Fluid intake Volume	Urine Output Volume
6am	100mls	600mls		450mls	150mls	500mls
7am			200mls	100mls	100mls	
8am	150mls				200mls	200mls

Please complete this chart for 3 days.

	Day 1		Day 2		Day 3	
Time	Fluid intake Volume	Urine Output Volume	Fluid intake Volume	Urine Output Volume	Fluid intake Volume	Urine Output Volume
6am						
7am						
8am						
9am						
10am						
11am						
12 Noon						
1pm						
2pm						
3pm						
4pm						
5pm						
6pm						
7pm						
8pm						
9pm						
10pm						
11pm						
12 Mn						
1am						
2am						
3am						
4am						
5am						

Please remember to bring this sheet with you when you come for your appointment.

Appendices

- Bladder/bowel symptoms/outcome form
- ICIQ incontinence questionnaire
- Female incontinence questionnaire
- **Pre-clinic questionnaire**
- EDSS
- MS nurse initial appointment
  - Page 1
  - Page 2
  - Page 3
- Fluid intake chart

PATIENT NAME……Date Of Birth :……
Date……

PATIENT PRE CLINIC QUESTIONNAIRE

To help plan for your appointment please consider the following and note any changes you would like to discuss. Please put N/A if not applicable to you.

Please select the 3 main areas you would like to discuss. Please bring this to clinic if you appointment is face to face, or email to sdhc.ms@nhs.net if appointment is virtual or over the phone

Current Disease modifying Therapy	Name and date started: Where prescribed:	
Other medication (incl Vit D)	Name, frequency, dose, date started and reason	
Date of last MRI	Brain and spine?	
Date of last blood test & where? Smoke/Alcohol		

	Select to discuss	Your comments	MS Nurse comments
Do you have any pain? If so where is it and how would you describe the pain?			
What is your regular exercise? How often per week do you exercise?			
Do you get breathless at rest or while doing exercise?			
Is your vision affected? Do you wear Glasses?			
Do you drink Caffeinated drinks? Are you on a diet?			
Do you experience Fatigue? (please explain) How do you sleep? (pattern, hours, disrupted? If so by what?)			
Do you have frequency or urgency with your			

PATIENT NAME……Date Of Birth :……
Date……

bladder? (Please explain if Yes)			
Has your bowel routine changed recently?			
How would you describe your mood? Has this changed over the last year?			
How would you describe your memory? Has this changed over the last year?			
Have you had any changes to your libido? Is there anything you would like to discuss with us on this topic?			
Do you have any difficulties completing any day to day activities?			
Have you noticed any changes to the strength in your arms or legs?			
Please mention what hobbies or exercise you include in your leisure time?			

Have you had any of the following:

		Date/Comment
Any Health screens recently?	e.g. mammogram, blood pressure, cholesterol check bone health	
Do you have any appointments booked for the future?	e.g. Consultant, physiotherapy	
COVID19	Have you been vaccinated for COVID19? If so please include date Do you think you have had COVID19? Was this confirmed with a lateral flow or PCR test?	

Please bring this questionnaire, any results, letters, a list of your current medications and any questions you may have with you to your appointment

Thank you for your time with completing this form, we are hoping this will enable us to ensure there is more time available for your questions. If you have any comments on how we can improve this form please email sdhc.msdmt@nhs.net

N:\Long Term Care\Neuro\MS\MSSN\A – Templates\In progress\Patient pre-clinic questionnaire 2021

Appendices

- Bladder/bowel symptoms/outcome form
- ICIQ incontinence questionnaire
- Female incontinence questionnaire
- Pre-clinic questionnaire
- **EDSS**
- MS nurse initial appointment
    - Page 1
    - Page 2
    - Page 3
- Fluid intake chart

Expanded Disability Status Scale (EDSS)

Score	Description
0	Normal neurological exam, no disability in any FS
1.0	No disability, minimal signs in one FS
1.5	No disability, minimal signs in more than one FS
2.0	Minimal disability in one FS
2.5	Mild disability in one FS or minimal disability in two FS
3.0	Moderate disability in one FS, or mild disability in three or four FS. No impairment to walking
3.5	Moderate disability in one FS and more than minimal disability in several others. No impairment to walking
4.0	Significant disability but self-sufficient and up and about some 12 hours a day. Able to walk without aid or rest for 500m
4.5	Significant disability but up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance. Able to walk without aid or rest for 300m
5.0	Disability severe enough to impair full daily activities and ability to work a full day without special provisions. Able to walk without aid or rest for 200m
5.5	Disability severe enough to preclude full daily activities. Able to walk without aid or rest for 100m
6.0	Requires a walking aid – cane, crutch, etc. – to walk about 100m with or without resting
6.5	Requires two walking aids – pair of canes, crutches, etc. – to walk about 20m without resting
7.0	Unable to walk beyond approximately 5m even with aid. Essentially restricted to wheelchair; though wheels self in standard wheelchair and transfers alone. Up and about in wheelchair some 12 hours a day
7.5	Unable to take more than a few steps. Restricted to wheelchair and may need aid in transferring. Can wheel self but cannot carry on in standard wheelchair for a full day and may require a motorised wheelchair
8.0	Essentially restricted to bed or chair or pushed in wheelchair. May be out of bed itself much of the day. Retains many self-care functions. Generally has effective use of arms
8.5	Essentially restricted to bed much of day. Has some effective use of arms retains some self-care functions
9.0	Confined to bed. Can still communicate and eat
9.5	Confined to bed and totally dependent. Unable to communicate effectively or eat/swallow
10.0	Death due to MS

Source: MS Trust (2020) Expanded Disability Status Scale (EDSS)

Appendices

- Bladder/bowel symptoms/outcome form
- ICIQ incontinence questionnaire
- Female incontinence questionnaire
- Pre-clinic questionnaire
- EDSS
- MS nurse initial appointment
  - **Page 1**
  - Page 2
  - Page 3
- Fluid intake chart

CSH

Multiple Sclerosis nurse Initial Appointment

Clinician: Review Date:

Telephone/Domiciliary/Clinic review

PATIENT NAME MOBILE NUMBER: EMAIL ADDRESS: RIO NUMBER	DOB OCCUPATION/PREVIOUS OCCUPATION FULL TIME/PART TIME RETIRED BENEFITS MARITAL STATUS ETHNIC GROUP MALE/FEMALE
REFERRED BY:	DATE OF REFERRAL:
KNOWN ALLERGIES: **NEXT OF KIN:** ADDRESS/PHONE NUMBER: RELATIONSHIP:	PREFFERED GP: PHONE NUMBER: FAX:
CURRENT DIAGNOSIS (WITH DATE IF DIFFERENT TO INITIAL DIAGNOSIS) Benign CIS Relapsing Remitting Secondary Progressive Primary Progressive **DATE OF INITIAL DIAGNOSIS & TYPE OF MS BY WHOM:**	**NEUROLOGIST NAME & ADDRESS** **NEXT APPT DATE**
LAST REVIEW DATE WITHIN CSH SURREY	
LAST RELAPSE DATE:	**TYPE OF RELAPSE:** Length of time to recover: Steroids given: Infection present: Neurologist aware: Escalation of treatment:
INVESTIGATIONS LAST MRI: DATE: BRAIN/SPINE	LUMBAR PUNCTURE: EVOKED POTENTIALS:
CURRENT DISEASE MODIFYING MEDICATION DATE STARTED: NAME OF DMT:	**LAST BLOODS:** DMT managed by whom: Name/Hospital:

CSH

PREVIOUS DMTs – DATE STARTED/STOPPED/ **REASON FOR STOPPING** 1. ..... 2. ..... 3.	**VITAMIN D LEVEL:** LAST TEST DATE:
OTHER MEDICATION **NAME, DOSE, TIMES GIVEN AND FREQUENCY** 1. ..... 2. ..... 3. ..... 4. ..... 5. ..... 6. ..... CONTRACEPTION HRT	REASON FOR STARTING (AS SEEN BY PATIENT).
PAST MEDICAL HISTORY ASTHMA/DIABETES/EPILEPSY/OPERATIONS/OTHER	
MAIN PROBLEMS: 1. ..... 2. ..... 3.	
SOCIAL HISTORY LIVES ALONE: YES/NO FAMILY RESPONSIBILITIES: Dependants/Children Smokes: Alcohol: TYPE OF ACCOMODATION: OWNED/RENTED/SOCIAL HOUSING STAIRS: ADAPTATIONS TO HOME: EMERGENCY BUTTON **CAR DRIVER: Date stopped:** **Notified DVLA:** INTERESTS/HOBBIES	**CARER** Family Member Provate carer Care package Carers allowance Last respite **KNOWN TO:** DN CM Continence advisor Rehab Team- OT Physio SLT Diet Social Worker Home Care Meals on Wheels Day Centre

Multiple Sclerosis nurse Initial assessment form – Version 1, September 2017
Review due October 2019

Appendices

- Bladder/bowel symptoms/outcome form
- ICIQ incontinence questionnaire
- Female incontinence questionnaire
- Pre-clinic questionnaire
- EDSS
- MS nurse initial appointment
  - Page 1
  - **Page 2**
  - Page 3
- Fluid intake chart

CSH

	MEMBER OF LOCAL MS SOCIETY:
LOWER LIMB Fully mobile Distance can walk unaided Distance can walk with aid Wheelchair user Transfers Pressure sores Balance Problems Falls Spasms Spasticity	**UPPER LIMB** Weakness Problems with buttons Zips Wash/Shave/Brush **TREMOR** Rest/Action/Intention Right/Left Limb Involved Writing tremor Affect on ADLs
VISION Unaffected/Impaires Partially sighted Registed blind Diplopia Use of Aids **Last eye test:**	**COGNITIVE** Concentration problems Memory Problems
BLADDER Urgency Frequency Hesitation Nocturia Incontinence Infections- if so date of last one: Catheter (interim/continual) Medication given:	**SPEECH** Unaffected/affected Difficulties experienced ?seen by SLT: if so date: **SWALLOW** Unaffected/affected Difficulties experienced History of Chest infections
BOWEL Constipation Incontinence Medication	**SEXUAL** Libido/Function Last smear Last mammogram Contracetion discussed Medication
MOOD Unaffected/affected Depression/Anxiety Medication **FATIGUE** Unaffected/affected Patient % reported (100%- No Fatigue 0%- Severe Fatigue) Affects ability Prevents all	**SENSATION** Unaffected/affected Numbness Tingling Impaired Pain Sites involved Sensitivity to heat Medication:

Multiple Sclerosis nurse Initial assessment form – Version 1, September 2017
Review due October 2019

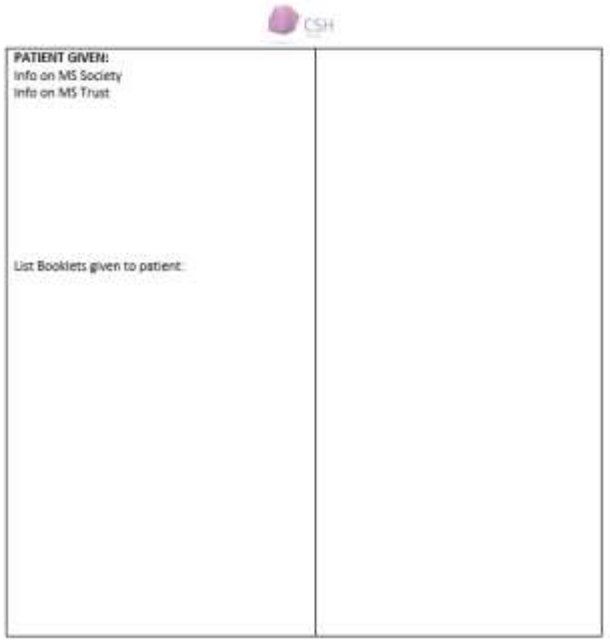
CSH

Medication:	
SLEEP Unaffected/affected Hours of sleep Interruptions- reason for waking? Daytime sleepiness Nocturia	**PAIN** (other than Sensory pain as above) Type Where ? Injury Analgesia Who is this being managed by?
ACTION PLAN AS AGREED WITH THE PATIENT:	RECOMMENDATIONS/REFERRALS/ TO FOLLOW UP/ SUPPORT GROUPS/ MEDICATION CHANGES
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	
FOLLOW UP APPOINTMENT:	
PATIENT INTERESTED IN: Newly Diagnosed course Fatigue Management Symptom Management Upcoming trials for…….. Benefits advice Carer support Counselling Contact with MS Society	

Multiple Sclerosis nurse Initial assessment form – Version 1, September 2017
Review due October 2019

Appendices

- Bladder/bowel symptoms/outcome form
- ICIQ incontinence questionnaire
- Female incontinence questionnaire
- Pre-clinic questionnaire
- EDSS
- MS nurse initial appointment
    - Page 1
    - Page 2
    - **Page 3**
- Fluid intake chart



PATIENT GIVEN:
Info on MS Society
Info on MS Trust

List Booklets given to patient:

Appendices

- Bladder/bowel symptoms/outcome form
- ICIQ incontinence questionnaire
- Female incontinence questionnaire
- Pre-clinic questionnaire
- EDSS
- MS nurse initial appointment
    - Page 1
    - Page 2
    - Page 3
- **Fluid intake chart**

Frequency volume chart

Time	Date:		Date:		Date:	
	Day 1		Day 2		Day 3	
	Fluid out	Wet	Fluid out	Wet	Fluid out	Wet
1am						
2am						
3am						
4am						
5am						
6am						
7am						
8am						
9am						
10am						
11am						
12pm						
1pm						
2pm						
3pm						
4pm						
5pm						
6pm						
7pm						
8pm						
9pm						
10pm						
11pm						
12am						