Urinary Continence Promotion and Care

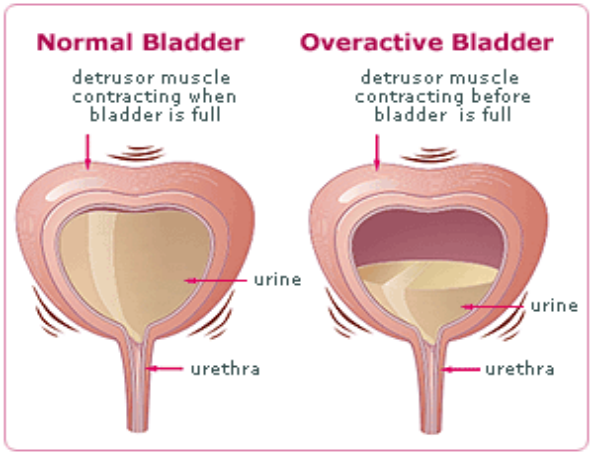
HELP SHEET

MJD FOUNDATION

This Help Sheet provides general information about urinary incontinence that may be encountered by people living with Machado Joseph Disease (MJD). It is important to remember that each person with MJD needs to be assessed and supported according to individual need.

Background

Neurogenic bladder is a common feature of MJD and describes the condition when the nerve pathways that control bladder function are impaired. This can cause issues related to overactive bladder (OAB) like urinary incontinence (UI) and retention. Unmanaged UI in people living with MJD can result in catastrophic complications, including renal impairment and the increased risk of falls with secondary fractures.



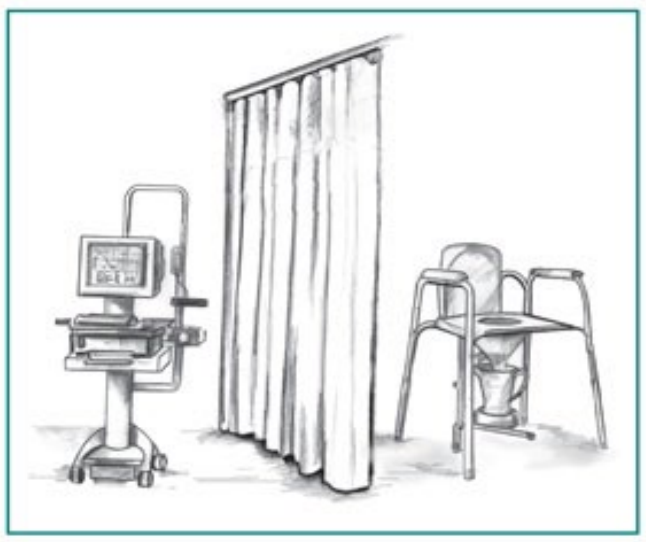
OAB has a significant impact on the quality of life of individuals living with MJD, and management presents challenges for clients, carers and healthcare professionals. These challenges include the limited evidence available to assist with the development of satisfactory urinary continence management plans for clients.

Assessment

Gender sensitivity should be taken into account when assessing a person who has MJD for urinary continence issues. Given the complexity of MJD symptoms, a collaborative approach to continence management is highly recommended.

Prior to any interventional therapy, a full diagnostic work-up is recommended including: Past medical history, Physical exam, Urinalysis & Renal Function Tests, Bladder diary, Urodynamics (including cystometrogram), and Radiological imaging (including kidney, bladder ultrasound).

Urodynamic Testing Equipment



Management

The most effective management program is based on individualised assessment and a process of trial and error to develop personalised solutions for patients with MJD. Given the complexity of MJD symptoms, a multidisciplinary collaborative approach to urinary continence management is highly recommended.

Conservative approach:

1 Fluid Advice (Caffeine Regulation) - Reduction of caffeine intake to <100mg/day has demonstrated improvement of OAB. Avoid fluid intake prior to bedtime to limit UI overnight. Take caution as excessive fluid restriction causes dehydration, constipation, and kidney issues.

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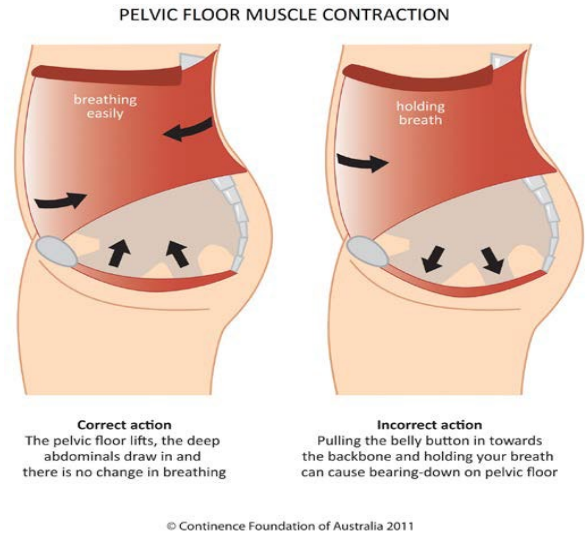
Reduce intake of non-essential fluids (ie sugary drinks) not water.

Fluid reduction not advised for MJD clients who self-restrict fluid or have severe MJD and do not receive enteral nutrition (ie via feeding tube).

2 Management of Constipation – Constipation is associated with MJD and can impact bladder control. A full assessment and bowel management plan is recommended.

3 Smoking Cessation - Smoking irritates the bladder and is linked to bladder cancer. It is recommended that counselling and treatment be offered to those who smoke.

4 Pelvic Floor Muscle Training (PFMT) & Bladder Retraining – Supervised PFMT trial of at least 3 months is recommended. MJD is associated with decreased bladder sensation. These clients should be instructed to perform scheduled toileting with pelvic floor exercises. Urge suppression techniques (distraction, curling of the toes, etc.) can delay frequency and encourage toileting when the bladder is full.



5 Continence Aides – also known as containment. Some people resort to containment as a self-help strategy without proper assessment by a health professional, but it is important people with MJD seek assistance for assessment and treatment of UI.

Medications:

1. Management of Recurrent UTI – Treating asymptomatic bacteriuria alone can lead to antibiotic resistance. Rather than routine testing, it is recommended MJD clients have a urinalysis on initial evaluation and at follow-up of signs/symptoms of infection.

2. Antimuscarinics - First line medication for OAB. Take caution with the elderly and people using other anticholinergics (eg allergy medicine, antidepressants).

3. Beta 3 Agonists - Recommended for OAB due to selectivity and fewer side effects when antimuscarinics are contraindicated.

4. Botox – Recommended by the international guidelines for neurogenic bladder. Requires a qualified practitioner and maintenance doses.

Catheters:

1. Clean Intermittent Self Catheterisation (CISC) – Recommended for MJD clients who have urinary retention. Requires good manual dexterity or a suitable carer to assist.

2. Suprapubic Catheterisation (SPC) - Preferred route for long-term catheterisation when CISC is no longer an option. Can be easier to manage for wheelchair users and is associated with a lower risk of infection.

3. Indwelling Catheterisation (IDC) – Recommended when UI is not well managed by other methods and the client declines surgery. Associated with recurrent UTIs.