

URINARY DYSFUNCTION IN MULTIPLE SCLEROSIS

A behavioural bladder dysfunction management guide for patients
with multiple sclerosis

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Abstract

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<p>Name of Degree</p> <p>Bachelor of Health Care</p>		
<p>Abstract</p> <p>Bladder dysfunction among patients with multiple sclerosis (MS) is common. Bladder problems not only are being physically uncomfortable, but they can disrupt patients' daily life, interfere with work and diminish participation in their social life.</p> <p>The purpose of this thesis was to help MS patients with bladder dysfunction to maintain the quality of life while living with an autoimmune disease.</p> <p>The aim of this thesis was to create a bladder dysfunction patient's guide. This guide provides information about bladder dysfunction symptoms and their behavioural management. Through this guide, the patient can learn to recognize urological problems, encourage an open discussion about them with medical personnel and find useful additional professional support.</p> <p>The function framework thesis was a project that it is composed of a theoretical knowledge part about multiple sclerosis, common bladder symptoms and their management. The data search for the guide was focused on the latest research related to the thesis' topic.</p> <p>In discussion it was emphasized the importance of assessment and management of bladder symptoms in patients with MS as they are complex and multifaceted. As the disease is often progressive the patients will need continuous reassessment and changes to care plans that address bladder symptoms effectively.</p> <p>The guide will be available for the patients and the medical professionals at the urological and neurological polyclinics in the Päijät-Häme's central hospital.</p>		
<p>Keywords</p> <p>Multiple sclerosis, bladder dysfunction, lower urinary tract symptoms, neurogenic bladder, bladder dysfunction management</p>		

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Tiivistelmä <p>Virtsarakon toimintahäiriöt ovat multipeliskeroosi (MS) potilailla yleisiä. Virtsarakon toimintahäiriöt eivät ole vain fyysisesti epämukavia, mutta voivat myös häiritä potilaiden arkea, työelämää sekä heikentää sosiaalista elämää.</p> <p>Tämän opinnäytetyön tarkoituksena oli auttaa virtsarakon toimintahäiriöstä kärsiviä MS-potilaita, jotta he voisivat ylläpitää elämänlaatua autoimmunisairaudestaan huolimatta.</p> <p>Tämän opinnäytetyön tavoitteena oli tuottaa opas virtsarakon toimintahäiriöstä kärsiville MS-potilaille. Oppaasta saa tietoa virtsarakon toimintahäiriöiden oireista sekä niiden käytännöllisen hallinnasta. Oppaan avulla potilaat oppivat tunnistamaan urologisia oireita, rohkaistuu keskustelemaan ongelmista terveydenhuollon ammattilaisen kanssa ja etsimään hyödyllistä ja ammattimaista lisätukea.</p> <p>Opinnäytetyö oli projekti, johon sisältyi teoriaosuus MS-taudista, yleisistä virtsarakon oireista ja niiden hallinnasta. Oppaan tekemistä varten tiedonhaussa keskityttiin opinnäytetyön aiheeseen liittyviin uusimpiin tutkimuksiin.</p> <p>Projektissa oli korostettu virtsarakon monimutkaisten ongelmien arvioinnin ja hallinnan tärkeyttä MS-tautia sairastavilla potilailla. Koska sairaus on usein progressiivinen, potilaat tarvitsevat jatkuvaa uudelleenarviointia ja muutoksia hoitoihin, jotta ne tehoaisivat tehokkaammin virtsarakon oireisiin.</p> <p>Tämä opas tulee potilaiden ja lääketieteen ammattilaisten saataville Päijät-Hämeen keskussairaalan urologian ja neurologian poliklinikoille.</p>		
Asiasanat Multipeliskeroosi, virtsarakon toimintahäiriöt, alempi virtsateiden oireita, neurogeeninen rakko, virtsarakon toimintahäiriöiden hallinta		

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1 INTRODUCTION

Multiple sclerosis (MS) is a long-term, or chronic condition that affects the central nervous system (CNS). According to Atlas of MS (2013), the estimated number of people with MS globally has increased from 2.1 million (2008) to 2.3 million (2013).

The brain, spinal cord and optic nerve make up the CNS. Sclerosis refers to hardening of tissue in the body. In MS, scar tissue forms in the CNS. This makes it hard for messages to travel smoothly between the brain and the rest of the body. (Multiple Sclerosis Trust, 2011.) MS lesions in the spinal cord can impair the transmission of messages that control bladder function (Mccombe et al. 2009, 331).

Not every patient with MS will encounter bladder issues, however, they are common. These symptoms can appear whenever during the illness course and they are not connected with how long the patient has had MS. Bladder issues can be very annoying for individuals with MS. In some cases, the symptoms can be physically awkward, but they can also disturb the patients' everyday life, and decrease their social life activity. Patients that have the fear of involuntary loss of bladder control, tend to avoid interaction with other people. (Broersma et al. 2018, 537; Holland et al. 2016, 1.)

In most cases, patients with MS do not inform their neurologist or their MS-nurse when they have urological dysfunction. As it is a sensitive subject, they feel awkward and embarrassed to start talking about it. There are cases though, where the patients do not have enough information about these symptoms. They do not know that they are common and can be often self-managed at home, or with the help of medical professionals. (Salomaa 2019.)

Our purpose is to help the MS patients with bladder dysfunction to maintain the quality of life while living with an autoimmune disease.

Our aim is to create a bladder dysfunction patient's guide. This guide will provide information about behavioural management solutions for bladder dysfunction symptoms. Through this guide, the patient can learn to self-manage primary urological problems, to encourage an open discussion about them and to find useful additional professional support and resources as the disease progresses.

2 METHODOLOGY

2.1 Data search, review and collection

The data search for this guide is based on the latest research related to the thesis topic between the year 2007-2019, to get up-to-date and reliable information. The relevant keywords to the topic that are used for data searching include:

- Multiple sclerosis
- Bladder dysfunction
- Lower urinary tract symptoms
- Neurogenic bladder
- Bladder dysfunction management

The data collection is based on the databases provided by Lahti University of Applied sciences (LAMK) via the advanced nursing search of Mastofinna such as:

- e-books
- EBSCO
- PubMed
- Sage
- CINAHL
- terveystietti

In addition, reliable information also was collected from search engines and online associations such as google scholar, national multiple sclerosis society and Suomen Neuroliitto.

2.2. Functional framework thesis

The function framework thesis was a project that it is composed of a theoretical knowledge part about MS disease, common bladder symptoms and their management. The aim of the study is to increase awareness about bladder dysfunction which can have a negative effect on the overall quality of life among patients with MS.

It is common that healthcare providers often forget to talk with MS patients about bladder dysfunction management or because it is verbal advices and recommendations, patients may easily forget or misunderstand them. But a patient's guide can be read repeatedly.

Moreover, the effective patient education guide can increase patients' abilities to manage better their own health and illness and improve the outcome of their treatment. (Elsevier clinical solutions 2015, 1-10)

Therefore, the final product of this thesis was a guide giving information about common bladder symptoms and their behavioural management related to the theoretical part of this thesis.

3 MULTIPLE SCLEROSIS (MS)

3.1 Epidemiology and prevalence of multiple sclerosis

Multiple sclerosis (MS) is an autoimmune disease that causes the progressive deterioration of the central nervous system (CNS), the brain and spinal cord. When the CNS becomes impaired and no longer function normally, the patients may experience cognitive problems and a wide range of physical difficulties. (Iezzoni 2010, 1-11.) MS causes inflammation of myelin sheath and insulates substance around surface of nerve cells, which leads to damaging of myelin called demyelination (Rog 2010, 1-14). The damaging of myelin sheaths causes weakened or completely lost nerve signals. Since those signals play important roles in controlling several body functions, thus when the signals are damaged, those body functions may be affected. However, in each patient with MS, those damages may take place in different parts of CNS with different intensity and frequency. Therefore, it makes MS difficult to recognize and predict. (Amor & van Noort 2012, 1-10.)

MS often causes fatigue, muscle weakness and stiffness, spasticity or tremors and loss of bladder control (Amor & Van Noort 2012, 11-22). Around 75% of people with MS experience bladder dysfunction. Moreover, it is also reported that around 70% of those people experienced moderate to severe bladder dysfunction which causes anxiety, affects the daily living and decreases quality of life in people with MS. (Williams 2012, 39-46.)

According to Atlas of MS (2013), the estimated number of people with MS globally has increased from 2.1 million (2008) to 2.3 million (2013). Even though MS is present in all regions globally, but prevalence is being highest in North America and Europe (140 and 108 per 100,000 respectively) and lowest in Sub-Saharan Africa and East Asia (2.1 and 2.2 per 100,000 respectively.) (Figure 1) However, the prevalence also differs considerably within regions found that the highest prevalence in Europe is 189 per 100,000 in Sweden, and the lowest is 22 per 100,000 in Albania. Furthermore, Finland is also the country in high-risk regions which the prevalence of MS is 105 per 100,000 in 2013. (Multiple sclerosis international federal 2013, 8-10.) (Figure 2) MS is a relatively common disease in United State, Canada, New Zealand, some parts of Australia and Europe. On the other hand, it is uncommonly found in tropical and subtropical areas as well as Asia. (Giesser 2011, 15-25.)

Generally, MS symptoms presented between young adult age between 20 and 40 years and women are likely affected more than men as ratio almost 2:1 (Búrca & O'Mahony 2010, 43-56). Likewise, Holmberg et al. studied the incidence of female with MS in Finland

shown that it is particularly increased among females which the total F/M ratio were 2.2 (Holmberg et al. 2013, 1-6).

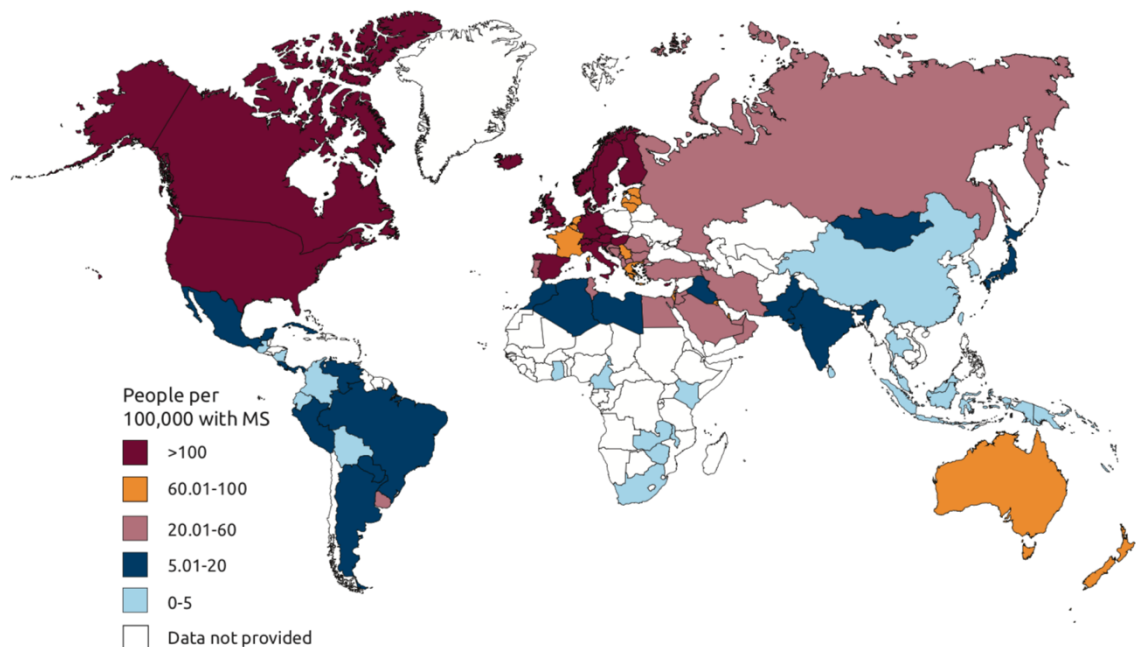


Figure 1 Prevalence of MS by country in 2013 (Multiple sclerosis international federal 2013, 8)

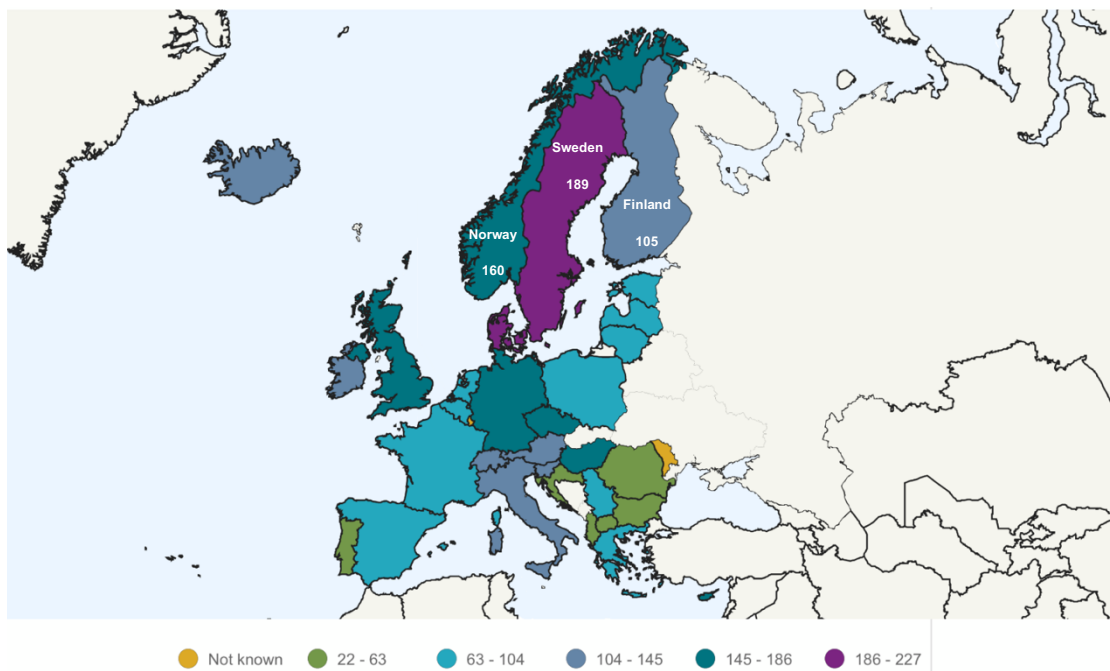


Figure 2 Prevalence of MS in Europe (Multiple sclerosis international federation 2013. retrieved from: <https://www.msif.org/about-us/who-we-are-and-what-we-do/advocacy/atlas/>)

3.2 Causes and risks of multiple sclerosis

After many decades of studies, the cause of multiple sclerosis remains unknown. However, many studies recognized that hypovitaminosis D is one of the MS risk factors. For this reason, populations of mid- and high-latitude countries that often lack vitamin D have a higher risk of developing MS. (Miclea et al 2017, 1-6.) Likewise, Müller & Scholz (2012) has shown that decreased sunlight, vitamin D, smoking, stress, and infections are the most predictors of MS risk (Müller & Scholz 2012, 59-65).

MS may be caused by a genetic component, based on the fact that MS can possibly occur in more than one member of the same family. However, it is not directly inherited, but it is increasingly obvious that genetic factors help to determine who may be susceptible to MS. (Murray, Holland & Saunders 2012, 27-38.)

Race and geography are known to influence the prevalence of MS. The inhabitants of northern Europe have a higher risk than other ethnic groups that are living at the same latitude (Béthoux, Fox & Rae-Grant 2013, 42-54). According to Amor & van Noort (2012) as well, the risk of MS varies between different regions in the global. Most of the people with MS live in moderate climates in Europe, North America, Australia and New Zealand.

3.3 Symptoms of multiple sclerosis

Multiple sclerosis usually causes inflammation in different parts of the brain and spinal cord with varying severity. Therefore, each patient with MS may experience various problems with different severity. (Amor & van Noort 2012, 11-22.) The cumulative result of multiple lesions in the brain and spinal cord often develop a wide range of neurological symptoms including muscle weakness, fatigue, ataxia, bladder and bowel dysfunction, visual problems, cognitive impairment and emotional symptoms. The average age of onset is between 20 and 40. (Müller & Scholz 2012, 59-75.) Due to this wide range of symptoms and severity, it makes MS difficult to distinguish from other neurological diseases (Weiner & Stankiewicz 2012, 77).

Fatigue is the most common symptom of MS that appears in all ages and subtypes of MS and hits around 75% to 95% of patients. Moreover, it is often the main symptom for diagnosis of MS. (Zwibel & Smrtka 2011.) Spasticity in patients with MS results in painful spasms, contractures, fatigue, gait abnormalities and poor mobility. Unfortunately, spasticity and its intensity may lead to several problems including urine retention, bladder and kidney stones, infections, constipation. (Armutlu 2010, 41-48.) Similarly, Zwibel & Smrtka (2011) have shown that spasticity strikes up to 75% of patients with MS and it often

worsens gait problems, bladder and bowel dysfunction, and physical component of quality of life.

Bladder dysfunction is also one common symptom of MS that can lead to changes in personal and social activities, sleep disruption, embarrassment, dependency, and isolation. Around 80% of patients with MS experience significant bladder dysfunction at some point during the MS course. (Halper & Harris 2017, 68-70.) Unfortunately, if these symptoms are left untreated the persons may have difficulties in different aspects for their lives including loss of employment, psychological problems, role reversals, social and vocational problems, relationship troubles, and financial concerns. (Weiner & Stankiewicz 2012, 213-230.)

3.4 Subtypes of multiple sclerosis

The classification of clinical subtypes of MS is crucial for communications among clinicians and patients, prognosis and decision making for treatment. The classification based on the frequency and severity of the neurological symptoms, the ability of the CNS to recover and the progression of the disease. Therefore, MS classification is described into four subtypes: relapsing-remitting multiple sclerosis (RRMS), secondary progressive multiple sclerosis (SPMS), primary progressive multiple sclerosis (PPMS) and progressive-relapsing (PRMS). (Müller & Scholz 2012, 66-68; Lublin et al. 2014, 278-286.)

Relapsing-remitting multiple sclerosis (RRMS) is characterized by unpredictable relapses or attacks followed by complete or partial remission or return to normal within period of months to a year. Approximately 85% of patients with MS represent in this subtype. However, RRMS usually begins with an attack of demyelinating disease but does not meet criteria for MS yet. Therefore, this is called clinically isolated syndrome (CIS) which 30% to 70% of patients with CIS develop MS later. (Müller & Scholz 2012, 66-68; Hurwitz 2009, 226-230; Multiple sclerosis international federal 2013, 11.)

Secondary-progressive multiple sclerosis (SPMS) is a progressive deterioration of neurological function without remission which usually occurs after initiation of RRMS form. Around 50% of patients develop SPMS within the first 10 years after RRMS form is represented. (Müller & Scholz 2012, 66-68; Lublin et al. 2014, 278-286.)

Primary-progressive multiple sclerosis (PPMS) is defined as a gradually progressive deterioration of neurological function without remission. Approximate 10% of patients with MS represent PPMS and the age of onset is around 40 years of age. Moreover, PPMS patients usually develop disability 50% faster than patients with RRMS. (Müller & Scholz 2012, 66-68; Lublin et al. 2014, 278-286.)

Primary-relapsing multiple sclerosis (PRMS) is described as the steady progressive worsening of neurological function from the onset with clear relapses or attacks with or without full recovery. (Müller & Scholz 2012, 66-68; Lublin et al. 2014, 278-286.)

Bladder dysfunction is fairly common in MS. These symptoms may represent at the onset of MS or at any stage throughout the course of the disease. Bladder symptoms can disrupt daily life, social life, sexual activities, interfere with work, and decrease the quality of life. (Uccelli 2014, 4-8.)

4 MULTIPLE SCLEROSIS AND BLADDER DYSFUNCTION

4.1 Normal bladder function

The urinary tract is divided into the upper- and lower urinary tract. The upper urinary tract composes of kidney and ureters, and the lower urinary tract includes bladder and urethra. (Figure 3) The bladder is an elastic sac situated in the pelvic cavity that stores the urine prior to voiding. The bladder function is controlled by the brain, message from the brain is conveyed via the spinal cord to the bladder and urethra. During the storage, urine collects gradually into the bladder, causing expanding of the bladder. The detrusor muscle also remains relaxed to hold the urine and the urethra maintains closed by contracting sphincter muscles to prevent leakage of urine during bladder fills. Once the bladder has collected around four to eight ounces of urine, the pressure receptors on the wall of the bladder send the signals to the brain via the spinal cord that urination is needed. However, the person prepares when and where to do so, thus the brain sends a return signal to the spinal cord that triggers the voiding reflex. The voiding reflex causes two actions simultaneously include, the detrusor muscle contracts to eliminate the urine from the bladder and the external sphincter relaxes and opens to allow the urine to pass into the urethra and out of the body. (Uccelli 2014, 4; Holland 2016, 2.) (Figure 4)

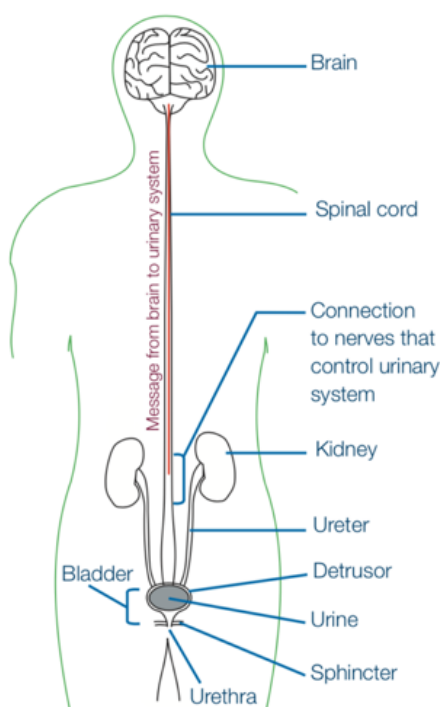


Figure 3 Urinary tract system (Uccelli 2014, 4)

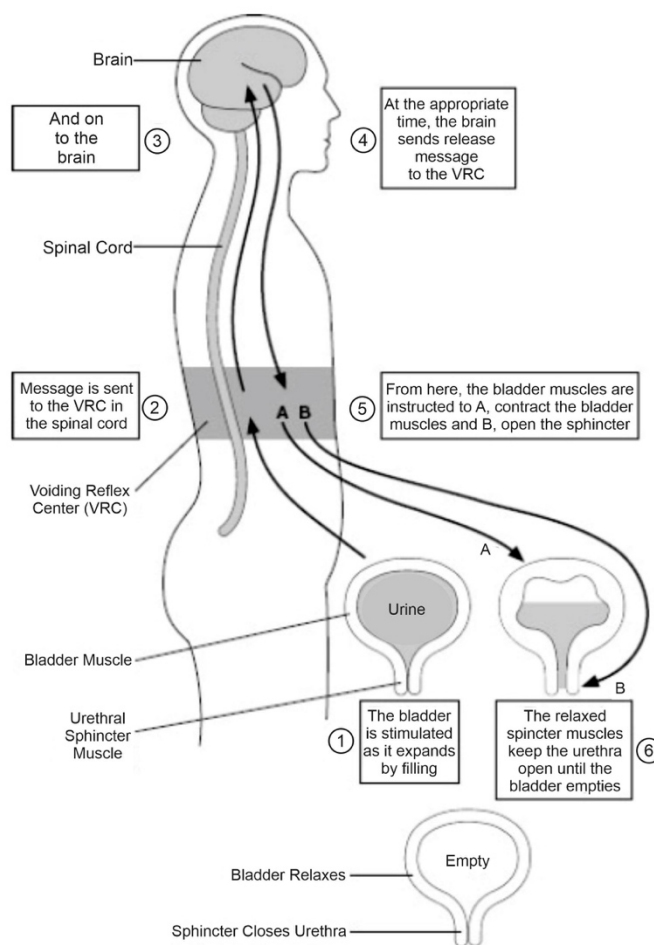


Figure 4 Normal voiding function (Schapiro 2007, 47)

4.2 Most common bladder dysfunctions in multiple sclerosis

Bladder dysfunction is a common consequence of MS. The prevalence and severity of bladder dysfunction increase depending on the severity of MS. Due to the fact that several components of the CNS are associated with regulating urination, thus MS may lead to a wide range of urinary symptoms and urologic complications. (Wintner et al. 2016, 212-218.) However, raising the conversation with patients about bladder dysfunction may be the hardest part of caring for these problems, because many patients often avoid discussing about it. (Béthoux, Fox & Rae-Grant 2013, 201.)

Bladder dysfunction impacts around 75% of patients with MS which is a major disruption of daily life. However, what each MS patient experiences with bladder dysfunction is unique. Therefore, it is important for patients with MS to have knowledge in relation to their own bladder symptoms. In addition, healthcare professionals play an important role in exploring their self-management strategies during the assessment of bladder

symptoms. (Browne, Salmon & Kehoe 2015, 2350-2358.) In neurological patients, MS is a leading cause of lower urinary tract dysfunction which may manifest as storage dysfunction or voiding dysfunction or combined dysfunction (Tornic & Panicker 2018, 1-11). According to Onal et al. (2009), the prevalence of combined dysfunction is higher than storage or voiding dysfunction alone. The bladder dysfunction symptoms tend to occur more frequently usually around 6 to 8 years after the onset of MS. However, in some patients, it may occur earlier and up to 14% of patients with MS complain about acute urinary symptoms at their initial onset of MS. (Béthoux, Fox & Rae-Grant 2013, 201-202.)

Storage dysfunction defines as the bladder failure to store urine which may be caused by an overactive detrusor muscle also known as overactive bladder (OAB). It means the bladder starts to contract as soon as a small amount of urine has accumulated in the bladder. This cause the person to feel urinary urgency. An intense urinary urgency may also cause urge incontinence. Moreover, it can also be correlated with increased urinary frequency during day and night. If urinary frequency occurs at night also called nocturia. (Table 1) (Uccelli 2014, 4; Holland 2016, 2; Zecca et al. 2016, 1228-1229)

MS creates demyelination in the spinal cord area and as result, the spinal cord is unable to send the signal to the brain that voiding is needed or to the external sphincter that needs to relax. These result in failure to empty the bladder or voiding dysfunction. Having hypoactive detrusor muscle during urination can cause incomplete bladder emptying and left post-voiding residual which is a leading cause of urinary tract infections (UTIs). Moreover, lacking voluntary control, the urine continuously fills the bladder making it to expand. Overly relaxed bladder may cause bladder symptoms as urinary urgency, incontinence, uncontrolled leakage of urine (dribbling), delay or difficulty starting urination and the need to urinate (hesitancy). (Table 1)(Uccelli 2014, 6-7; Holland 2016, 3.) UTIs is a secondary problem of MS, mild UTIs can cause urinary frequency and urinary urgency, whereas severe UTIs cause fever and generalized illness. The incidence of UTI is higher in those who have retention bladder due to bacteria grows in retained urine. Moreover, those who need to perform intermittent self-catheterization and those who have an indwelling Foley catheter also have a higher risk of getting UTI because such procedures may provide bacteria with a direct route into the bladder. (Schapiro 2007, 53)

Table 1 Bladder symptoms experienced by patients with MS (Béthoux, Fox & Rae-Grant 2013, 202)

SYMPTOMS	DEFINITION
Urinary urgency	The sudden strong desire to urinate that cannot be delayed
Urinary Frequency	A complaint by the patient that he or she voids too often
Urge incontinence	Involuntary urine leakage followed by an urgent desire to urinate
Nocturia	The complaint of having to wake up many times during the night to urinate
Urinary retention	A painful or non-painful bladder that remains palpable or percussable after the patient has passed urine. It may be associated with incontinence which generally a residual urine volume more than 150 ml.
Hesitancy	Difficulty initiating a urine stream resulting in the delay in onset of voiding
Straining	Requiring additional muscular effort to initiate, maintain, or accelerate the urine stream

According to Phé, Chartier-Kastler & Panicker (2016), the lower urinary tract dysfunction is frequent in patients with MS. It is commonly reported as overactive detrusor which is a major negative impact on the patient quality of life. Similar to the cohort study of Zecca et al. (2016), found that more than one-third of MS patients experience urinary incontinence which half of them feel urinary frequency at least once per week. However, Aharony et al. (2017) surveyed more than 9700 patients with MS in the North American Research Committee on Multiple sclerosis (NARCOMS) and found that the most prevalence signs of bladder dysfunction were nocturia, urinary urgency and urinary frequency respectively, but urinary incontinence and voiding dysfunction were less reported.

4.3 The bladder dysfunction's effect on general health

MS is an autoimmune disease with frequent display of lower urinary tract symptoms (LUTS) whereas upper urinary tract deterioration is rare (Onal et al. 2009, 326-333). LUTS has a significant negative influence on quality of life (QoL) in MS patients and significant burden on national health care services (Tornic & Panicker 2018, 1-11).

According to Khan et al. (2009), bladder dysfunction impacts the QoL in patients with multiple sclerosis including emotional health and the ability to do household chores. Similarly, Zecca et al. (2016), showed that urinary incontinence may reduce the patient's ability to socialize, impair the intimate relationship and decrease the ability to do household tasks. LUTS also reveal distressing and embarrassing symptoms which can cause lower self-

esteem and social stigma. Moreover, urinary incontinence is a significant burden for most patients with MS.

Sometimes patients with MS are unwilling to talk about the bladder dysfunction symptoms due to the sensitive nature of the topic. They may feel embarrassed and uncomfortable to raise these topics and discuss them with the healthcare providers. Or they may lack information about bladder dysfunction, thus they may not realise these problems. (Uccelli 2014, 5.) Even though starting the conversation about bladder symptoms may be the most challenging part of caring for this problem, health providers need to keep in mind that the bladder dysfunction management is an important component of all MS patients' care. (Béthoux, Fox & Rae-Grant 2013, 201.)

Urinary disorders not only reduce quality of life but also lead to complications, the most frequent being recurrent UTIs. Moreover, neurological symptoms can deteriorate acutely when patients develop infections and high fever. (Gallien et al. 2014, 1252-1253.) The risk of bladder cancer is greater in MS than in the general population, especially in patients under chronic catheterisation (De Sèze et al. 2007, 920). Failure of bladder emptying can lead to complications such as hydronephrosis, renal insufficiency and renal failure, which can exist in 15-20% of MS patients (Williams 2012, 45).

5 BLADDER DYSFUNCTION MANAGEMENT IN MULTIPLE SCLEROSIS

The patients should be educated about the effects of the disease on the bladder when MS disease is diagnosed. Assessment of bladder dysfunction should start with an accurate and complete diary of daily bladder function. The assessment tool used should have space for recording fluid intake and voided output, including frequency and type of fluid consumed, together with any episodes of incontinence. (Williams 2012, 41.) Patients should understand how to seek timely health care, how to get more information about their disease and their right for more examinations. These examinations can include urine samples, blood creatinine levels, urinary ultrasound examination and residual urine measurement. (Salomaa 2016.)

Further examinations are carried out in specialized medical care, including a post-void residual volume of urine (PVR). A PVR that exceeds 100mL is regarded as a significant determinant of urinary bladder voiding dysfunction in patients with MS. (Panicker 2010, 583.) Based on the results, each patient gets individual treatment and managing methods. These can be behavioural and dietary management, medication therapy, intermittent self-catheterization, Botox injection (Botulinum), electrical stimulation of the sacral nerve or a combination of them. (Korpela 2019.) Symptoms that may have a major impact on daily living are in many cases effectively treated pharmacologically or with multidisciplinary interventions including physiotherapy (Rønning & Tornes 2017, 531).

Many healthcare providers consider advice on lifestyle factors including fluid intake and diet, toileting habits, the use of absorbent products, pelvic floor muscle training and bio-feedback an important role in their clinical practice. While it may not be always possible where physical disability is advanced or when there is evidence of cognitive impairment some patients might prefer it to taking medicines. (Hay-Smith EJC et al. 2007, 87; Motta & Carvalho 2008, 358; Korpela 2019.)

Neurogenic detrusor overactivity represents the most widely reported chronic urinary symptom in patients with MS (Williams 2012, 40-41). Antimuscarinic drugs, formerly known as anticholinergics, can offer significant improvement in symptoms of urinary urgency, frequency and nocturia (Rigby 2011, 378-380). The mode of action of antimuscarinic medications is to block the neurotransmitter acetylcholine from influencing muscarinic receptors in the bladder, resulting in relaxing the detrusor muscle (Williams 2012, 43-44). These medications' most common side effects are constipation, dizziness, dry mouth and memory problems. For overactive bladder is usually prescribed another medication also, mirabegron. The action of this medication is to relax the smooth muscle around the bladder and in that way to increase the bladder's urine storage capacity. As the rest

medications, this one has also side effects. It can increase the blood pressure, or symptoms of common cold and headache can occur. (Holland et al. 2016, 6-7.)

Botulinum neurotoxin type A (BoNT/A) are the next form of medication if the bladder is overactive. This treatment has been used for about ten years, especially in the neurogenic bladder dysfunction. A typical treatment group is MS patients and patients with spinal cord injury. Botox treatment is given by an urologist at urological units in Finland. (Sairanen 2015.) BoNT/A injections block the action of parasympathetic acetylcholine, essential for bladder contraction (Williams 2012, 44). The disadvantage of Botox treatment is creating possible bladder depression and consequent need for catheterization. The duration of treatment is 6-9 months and the response is usually good. The treatment can be renewed after nine months. (Sairanen 2015.) The urotherapist should carefully inform the patient about the procedure as much for the benefits as for the side effects too (Korpela 2019).

The best management for failure of voluntary bladder emptying is intermittent self-catheterization (ISC), with the addition of anticholinergic medication if necessary, for the hyper-reflexic bladder (Rantell 2012, 61-62). This relatively simple technique works quickly and effectively to eliminate residual urine. This form of bladder management has significant advantages over indwelling Foley catheters, with reduced risk of catheter-associated urinary tract infection. (Williams 2012, 45.)

There are several requirements for patients to perform the procedure successfully. A reasonable level of cognition and dexterity; good physical ability; motivation; ability to visualize the urethral meatus; capacity to follow verbal and non-verbal instructions and read and understand written instructions; awareness of problems associated with intermittent self-catheterisation; and understanding of how to avoid problems such as urinary tract infections (UTIs). (Winder 2012, 19; Aharony & Corcos 2017.)

A urinary tract infection (UTI) may need to be suspected in the presence of vague non-specific symptoms such as back or abdominal discomfort, reduced appetite or lethargy, deterioration of neurological status, leakage between intermittent self-catheterization (ISC), catheter blockage or the report of a cloudy urine with increased odour. (Motta & Carvalho 2008, 357; Phé et al. 2016, 856.)

For the nurse or urotherapist, it is essential to assess patients on an individual basis and tailor teaching methods to meet their needs. It is important to identify how often they will need to catheterise and whether they will do this at home, or in public or workplace toilets. It is also essential to ascertain whether they spend long periods travelling. The answers to these questions may change many factors, including the position that they are taught to

assume when performing ISC and the type of catheter recommended, as well as the level of follow up and support they may need. (Korpela 2019; Salomaa 2019.)

A promising treatment for bladder dysfunction nowadays is the electrical stimulation of the sacral nerve. Functional electrical stimulation is a recognized management strategy for people with foot-drop secondary to an upper motor neurone disorder, approved as effective by the UK National Institute for Health and Clinical Excellence. (Hare et al. 2018, 1358.) For the bladder dysfunction an electrical stimulation provided by a surgically-implanted stimulator helps the bladder muscle to store and expel urine appropriately. The stimulator delivers electrical impulses that mimic those that would normally be delivered by undamaged nerves. (Holland et al. 2016, 10.) The treatment requires commitment and a long-term treatment relationship.

Another sort of sacral nerve stimulation intervention is percutaneous posterior tibial nerve stimulation (PTNS). In this technique, a needle is placed in the posterior tibial nerve, located on the inner leg at the ankle. An electrical impulse is delivered to the nerve that in turn stimulates the sacral nerves. The typical treatment is 30 minutes once per week for 12 weeks. If the symptoms reappear, extra treatment can be given. (Motta & Carvalho 2008, 358; Gobbi et al. 2011, 1515-1516.)

Nurses can have a key role in the management of bladder dysfunction symptoms by promoting an integrated approach to care. Educating and informing the patients about bladder control can reduce patient's anxiety in everyday life by finding treatments and intervention solutions. (Williams 2012, 39; Korpela 2019.)

6 COOPERATING ORGANIZATION

This thesis is carried out in cooperation with the urological polyclinic of Päijät-Häme's central hospital. The urological polyclinic works as a referral and follow-up clinic which investigates and treats bladder dysfunction that is caused by several illnesses including MS. The urotherapist is the main responsible person in counselling and guiding the patients about bladder dysfunction and ways of management. If necessary, the urotherapist also cooperates with other specialists such as the MS nurse or a urologist. (Koskela 2019.)

At neurological polyclinic, an MS nurse works independently at reception work and comprehensive care of the patient by giving the care guide which aims to increase the patient's ability to self-independent living and adaptation to the disease (MS-nurse 2019).

According to both polyclinic nurses' statements, patients have always issues to express any urological problems they have, as it is a sensitive and personal subject to talk about. Our final guide can create an awareness and hopefully become a way for patients to talk more freely and openly about urological problems. (Koskela 2019; MS-nurse 2019.)

7 PURPOSE AND AIM OF THE THESIS

The purpose of this thesis is to help the MS patients with bladder dysfunction to maintain the quality of life while living with an autoimmune disease.

The aim of this thesis is to create a bladder dysfunction patient's guide. This guide will provide information about behavioural management solutions for bladder dysfunction symptoms. Through this guide, the patient can learn to recognize and self-manage primary urological problems, to encourage an open discussion about them with medical professionals and to find useful additional professional support and resources as the disease progresses.

8 CREATING A GOOD WRITTEN PATIENT'S GUIDE

Nowadays patient education guides play an important role in encouraging the patients to actively participate in their own care. It is also shown that the patients who receive the right education seem likely to follow physician's instructions, adhere to medication regimens, and make the necessary lifestyle changes. Therefore, the right materials can significantly enhance patients' abilities to self-manage their own health. These can also help to prevent disease, improve healthcare outcomes, promote healthy behaviours and reduce healthcare costs. The educating guides for the patients are a crucial part of patient care. They must provide critical information that the patients need to know and support patients' own ability to actively engage with their care. They can also encourage the patients to discuss their illness with caregivers. (How to develop and use effective patient/consumer education 2015, 1-9; Developing a Patient Guide for Your Primary Care Practice 2013, 1-12.)

When creating an effective patient education guide, evidence-based, reliable, and up-to-date medical information must be used. Moreover, target audience, key health interest and outcome need to be identified. Getting to know the target audience will help to determine such as the age group, cultural background and reading level which may impact on the content, graphics and writing style of the guide. To grab the readers' attention at first sight, the headline should stand out by using compelling clear language. The structure of the guide should be made logically, include all the most important points and explain why it is important to them. Plain language should be used and avoid using medical terms in order that the patients receive clear information and can easily understand. Using text bullets where appropriate instead of dense blocks of text to make the guide easy to read. (How to write easy-to-read health materials 2017; Simply Put A guide for creating easy-to-understand materials 2009, 1-43.)

To make the text's appearance look great affects readability, the font style and size between 12 and 14 points and the headings at least 2 points larger than the main text size should be considered. Using both upper and lower case and dark letters on a light background also make the guide easier to read. An illustration helps to grab the audience's attention and highlight key components of the guide. Moreover, high-quality visuals, sharp resolution, true colour, contrast and good composition make the guide more credible. (Simply Put A guide for creating easy-to-understand materials 2009, 1-43; Creating material 2010.)

9 BEHAVIOURAL BLADDER DYSFUNCTION MANAGEMENT GUIDE

9.1 Implementing the patient's guide

Following our theoretical findings, we created a medical tri fold guide as our final functional product. The guide is aiming to educate MS patients about bladder dysfunction and how they can self-manage at home any urological symptoms. It can be a way for the MS-nurse to open a conversation with the patients about this sensitive subject, or a tool for the urotherapist to explain the symptoms and suggest solutions.

We have created the guide according to our chapter "Creating a good written patient's guide". The guide was developed at our own cost and we have made it available as a PDF. Permission is granted to print and distribute it as widely as possible, in any setting whereby this information would be useful. All vector images have been purchased from vector bank image online (<https://www.istockphoto.com/fi>) and have been edited with Adobe Photoshop and illustrator to fit the needs of our subject in the guide. The images chosen were the common toilet symbols used worldwide. So, the patient can connect immediately the image with urological problems.

The outline chosen is a simple A4 page, as it is easy for everyone to print and use. The font chosen was Arial Rounded MT Bold for its simplicity and ease of reading. It is freely available to download on the Internet. The colour scheme was kept simple and minimal. The use of yellow colour was deliberately chosen to fit our subject. As though in most cases the guide will be printed in grayscale, we took in consideration that it will not lose its original way of looking even in black and white. The highlights and symbols make the guide easy to read and visually keep the reader's attention.

The language used is deliberately simple as we are intending for this guide to be read by patients and use it as a check-list at home. We have kept the definitions simple yet relevant to medical language used by professionals. The guide's text was firstly written in English, but later translated by us, as our target group is Finnish MS patients.

The guide encompasses and summarizes our aim and purpose for the thesis, which is through behavioural management solutions and interventions to help the patients maintain the quality of life.

9.2 Analyzing and evaluating the patient's guide

Research into how to create an effective educational guide was done. The guide's content was created by using evidence-based materials, easy language, correct paper contrast, readable font, photos or symbols to supplement our text, using the objectives and

outcomes to structure the content and having it proof-read by more than one person (How to write easy-to-read health materials 2017; Simply Put A guide for creating easy-to-understand materials 2009, 1-43; Creating material 2010; Karten 2007, 507).

An evaluating form was created by us based on an article "Health Literacy: A Guide". Where questions concerning the guide's content, structure, design and language and tone were made. This way our evaluators would know what to take in consideration, when giving us their feedback for the guide.

Then the guide and the evaluation form were given to urotherapist Mia Koskela in the urological polyclinic and the MS-nurse in the neurological polyclinic in Päijät-Häme central hospital to be evaluated.

According to Mia Koskela and her working team, the guide includes accurately all the necessary information that it should have. The information is up-to-date, and it is easily readable. The main points are correctly supported by the images and the symptoms are easily understandable.

The language that we used in her opinion is friendly enough but still we managed to keep terms that medical professionals use. The language translation had some problems and we had used some English terms that are not used in Finnish language, but she assisted us to correct it.

The guide has logic order that makes it easy for the reader to understand the sequence of symptoms and actions. The visual design is attractive and in her opinion the guide would immediately catch the readers' attention. She finds the use of the guide useful for patients and nurses in the urological polyclinic and in the neurological polyclinic as well.

According to the MS-nurse and her working team, the guide's look is pleasant, polished and really clear. The chosen pictures complement the text nicely. The sentence structures may not be the most typical used in medical guides but are very clear and understandable. In some sentences the text was ordering patients to take action, so it was advised to avoid that and use suggestion sentences. This way it would become more patient-friendly. It was emphasized to avoid saying to patients to drink cranberry juice or take cranberry tablets, and instead suggest that they can use them. Overall the feedback was positive, and she would like to use our guide in the neurological polyclinic.

10 DISCUSSION

Urinary disturbances may be a presenting sign in up to 14% of newly diagnosed MS patients and is a major problem for over 50% of patients at some point throughout their disease course (Haggiag 2017,1). It is common that bladder problems in patients with MS can be related to other health problems or symptoms. Other diseases that the patients have or medications' side effects that they take. Conditions like diabetes, post- menopause period, prolapsed bladder or uterus, pregnancy, enlarged prostate or arthritis, can create bladder dysfunction. There are also medications that can affect urinary function, like those ones for hypertension. Therefore, in order for bladder management to improve, these kinds of conditions need to be assessed first. (Holland 2016, 11.)

In addition to being uncomfortable and embarrassing, the bladder symptoms of MS can have a significant impact on patients' long-term health. The impact of these symptoms can be limited if patients report urinary symptoms promptly to their healthcare provider. Based on the information the patients give, the medical professionals can do the necessary tests to diagnose the underlying problem and recommend the appropriate medications and management strategies. (Holland 2016, 12; Williams 2012.) The interventions and management solutions described in this thesis patient's guide can be more effective if they are implemented when the patients' symptoms are in an early stage. As faster the symptoms are recognised, the patients can start managing them and prevent any other maybe serious complications. This can offer them a better daily activity routine with more confidence and comfort.

The assessment and management of bladder symptoms in patients with MS are complex and have many different aspects. The disease process is often progressive, and patients will need continuous reassessment and changes to care plans that address bladder symptoms effectively. (Williams 2012.) Treatment remains a challenge for health care providers. However, adopting a treatment algorithm beginning with non-invasive therapy offers a wide spectrum of different treatments targeting different mechanisms for managing bladder dysfunction (Tornic & Panicker 2018, 8). Management of bladder dysfunction in patients with MS can only be effective if an integrated approach is adopted by all those involved in caring for this patient group. (Williams 2012.)

At the moment in Päijät-Häme central hospital, MS patients when going to the MS-nurse, rarely admit having bladder problems or when they do it is already at an advanced stage where only medication or catheterization can help. Therefore, as a future development, the MS-nurse by using our guide can inform the newly diagnosed MS patients about bladder dysfunction and introduce them to the behavioural self-interventions. This way the

patients can benefit by preventing as much as possible bladder dysfunction problems and will recognize them at early stage so the assessment and treatment in the urological polyclinic will be faster and more effective.

This guide can be a tool for patients and medical professionals to communicate among them problems about bladder dysfunction and take faster the appropriate actions to better medical assessments, interventions and treatments.

11 IMPLICATIONS FOR FUTURE STUDIES

During our data research, we had difficulties to find behavioural interventions for the neurogenic bladder dysfunction in MS. Most studies were focusing on the effect of medications or analyzing bladder dysfunction management and few could give solutions for self-interventions.

It is proven that as years pass even more patients refuse to take medications as their first option and want to try any other alternatives before that. Therefore, it would be useful further studies to take place and try to find new ways or combine the behavioural management together with medication and other intervention managements to help MS patients with neurogenic bladder dysfunction.

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APPENDICES

Appendix 1 Patient's guide

VIRTSA TIETULEHDUKSET

Rakon riittämätön tyhjentäminen voi aiheuttaa bakteerien määrän kasvun. Rakkoon jäänyt virtsa lisää virtsatieulehduksen riskiä.



Jatkuva virtamistarve
Kova virtsaamisen tarve, mutta virtsan määrä on vähäinen



Kivulias virtsaaminen
Poltto, kipu, vastuksen tunne virtsatessa



Alavatsan kipu
Aiheutuu virtsarakon supistumisesta



Muuttunut virtsan väri
Virtsa voi olla tummempaa tai hajua voi olla voimakkaampi



Jos tulehdus vaikuttaa muunaissiin tai eturauhaseen, oireet kuten kuume ja selkkipu ovat mahdollisia

Jos sinulla on virtsatieulehduksen oireita, ota viipymättä yhteyttä omaan terveyskeskukseesi.

Ota yhteyttä

Jos huomaat että sinulla on jokin edellä mainituista oireista, ota yhteyttä MS-hoitajaasi.

MS-hoitaja voi tehdä lähetteen urologian poliklinikalle, jossa pystytään suorittamaan tarvittavat tutkimukset terveydentilastasi ja näin parantaa joka päiväistä elämänlaatuaasi.

Kuntoutukseen hakeutuminen

Kela järjestää kuntoutusta kaiken ikäisille ja turvaa toimeentuloa kuntoutuksen aikana. Kuntoutus auttaa elämään sairauden kanssa, jatkamaan toissa tai palaamaan työelämään.

Jos kuntoutus kiinnostaa, ota asia puheeksi MS-hoitajasi kanssa.

MS-Hoitaja
Neurologian poliklinikka
PHKS
puh. 044 719 5524
(takaisinsoittopalvelu)

LISÄTIETOA

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Opas: Pinelopi Polizzi, Rattiiya Kuparinen
Lahden Ammattikorkeakoulu (LAMK)
Opiinayhteisö kevät 2019
Kuvat: <https://www.istockphoto.com/>

MS-tauti

Oireileeko rakkosi?



MS-TAUTI - OIREILEEKO RAKKOSI?

Multipeliskeroosi eli MS-tauti on krooninen sairaus, joka voi aiheuttaa monia fyysisiä ongelmia.

Virtsarakon toimintahäiriöt ovat MS-potilailla yleisiä, jotka saattavat aiheuttaa negatiivisia vaikutuksia elämänlaatuun.

Joskus virtsatieongelmat voivat olla sairauden ensimmäisiä oireita. Potilaalla voi ilmetä esimerkiksi äkillistä voimakasta tai tihentynyttä virtsaamistarvetta, virtsankarkailua, tarpeesta huolimatta ilmeneviä virtsaamisvaikeuksia sekä virtsatieulehduksia.

Tämän vuoksi on tärkeää keskustella lääkärin, MS-hoitajan tai uroterapeutin kanssa kaikista oireista, jotka saattavat liittyä virtsateiden toimintaan ongelmiin.

Oireet

VOIMAKAS VIRTSAAMISTARVE

- usein tarve virtsata (virtsaamistarvetta on yli kahdeksan kertaa vuorokaudessa)
- virtsaat suhteellisen pieniä määriä kerrallaan
- voimakkaan virtsaamistarpeen yhteydessä voi ilmetä myös virtsankarkailua
- Yövirtsaisuus (nokturia) eli virtsapakko herättää useita kertoja yössä
- virtsankarkailu

RAKON TYHJENTÄMISVAIKEUDET

- virtsaamisen aloittaminen voi tuottaa vaikeuksia
- heikko tai katkonainen virtsan suihku
- virtsankarkailu
- tihentynyttä virtsaamistarvetta
- virtsatieulehduksia

Mitä voit tehdä itse

- 1** Juo tarpeeksi vettä ja tarkkaile virtsan väriä.
- 2** Vältä juomia jotka sisältävät alkoholia tai kofeiinia.
- 3** Vältä nesteiden juomista noin kaksi tuntia ennen aktiviteetteja, missä vessassa käynti ei ole mahdollista. Vältä juomista ennen nukkumaan menoa.
- 4** Käytä imukykyisiä suoja virtsankarkailuun. Saatavilla on kattavasti erilaisia tuotteita niin naisille kuin miehille.
- 5** Tee säännöllisesti virtsarakon ja lantiopohjalihasten harjoitteita, jotka vahvistavat lihaksia.
- 6** Yritä käydä vessassa säännöllisesti päivän aikana.
- 7** Rajoita sitrusmehujen käyttöä.
- 8** Voit käyttää karpalo tabletteja tai juo karpalomehua päivittäin.

Huomioikaa jos virtsaamisessa ilmaantuu muutoksia

Jos oireet eivät tänäkään jälkeen helpota, sinulle sopiva ratkaisu voi löytyä katetroinnista, lääkkehoidosta, botoxista tai näiden yhdistelmästä

