

Disability and Incontinence – A Marriage Made in Heaven

Disability and incontinence, a marriage made in heaven. As a person with a spinal cord injury I will try to give you a very personal perspective of the reasons for incontinence in most of the disabilities and I will focus on the impact of the incontinence on your life and the different approaches towards it.

It is interesting to note that a person without a disability have the freedom to say that he/she wants to go for a quick wee-wee, but as a PWD there is different terminology for that. We normally just excuse ourselves and disappear on certain intervals for a “couple of minutes”.

It is also safe to remember that quite a few of the different types of disabilities are unwilling partners in this marriage. There is for every PWD that very special and memorable “first time” in this marriage, when you realise, this is it, this buildings plumbing is not too good! This realisation can be when you first wake up in hospital after a decent accident or it can be as a small child if you grow up with the disability and you realise that your waterworks doesn't function as your sister's. It is interesting that this realisation has quite the same impact on your life as your first kiss; you never forget the smallest of details

Incontinence sets in, after any injury of the spinal cord, after certain injuries of the brain or in disabilities that causes deterioration of the muscles. Disabilities most common to incontinence are spinal cord injuries, multiple sclerosis, spina bifida, certain groups of cerebral palsy and several more disabilities.

Spinal cord injury at any level almost always affects your control over your bladder. This is because the nerves controlling these internal organs are attached to the very base of the spinal cord (levels S2 - 4), and then pass down through the cauda equina, the 'horse's tail' below the cord itself. Although you will not have the *same* control that you were used to before your injury - a whole range of techniques exist to help you to 'manage' your bladder and to reach your personal optimal level of continence.

But first of all, let's have a look at what is urine and where does it come from. The **kidneys** constantly produce urine, by filtering certain waste products from the blood to make urine. The kidneys typically produce 30 – 90 ml of urine each hour. Urine is carried from the kidneys through tubes called **ureters** to the bladder, where it is temporarily stored until urination occurs. Each ureter is about 24-30 cm long. The ureters end in the lower portion of the **bladder** and they are attached to the bladder in a way that helps prevent urine from flowing back up towards the kidneys. The lowest part of the bladder (the neck) is encircled by a muscle (the urinary **sphincter**) that remains contracted to close off the channel that carries urine out of the body (the urethra), so that urine is retained in the bladder until it is full. The **bladder** is a hollow organ with a muscular wall and two primary functions – the storage and emptying of urine.

In a relaxed state, the bladder can hold about 500 ml of urine before you feel a strong urge to urinate. The size and shape of the bladder and the amount of urine stored vary from person to person.

Emptying the bladder (also called voiding or urination) involves coordination of both voluntary and involuntary muscles. When the bladder is emptied, urine leaves the body through a tube called the urethra. The urethra carries urine from the bladder out of the body. It is a muscular tube lined with a mucous membrane. The opening of the urethra is called the meatus.

When the bladder is full, messages travel along nerves from the bladder to the spinal cord. The messages are then relayed to the brain, and the person becomes aware of the urge to urinate. A person who has control of urination can consciously and voluntarily decide whether to release the urine from the bladder or to hold it for a while. When the decision is made to urinate, the sphincter muscle relaxes, allowing urine to flow out through the urethra, and the bladder wall muscles contract to push the urine out. A healthy functioning nervous system and brain are crucial for proper coordination of this complex process. You will now experience that very familiar relaxed feeling.

Type of Urinary Incontinence	Common Symptoms	Common Causes
Stress	Urine loss during activities such as coughing, sneezing, laughing or lifting.	Pregnancy, childbirth, menopause, pelvic radiation, and surgical trauma.
Urge	A sudden need to urinate, occasionally with large volume urine loss. Can also exist without incontinence.	May be associated with pregnancy, childbirth, menopause, pelvic trauma, and neurologic disease such as Parkinson's disease and Multiple Sclerosis.
Mixed	Combination of stress and urge forms.	
Overflow	A frequent dribble of urine as a result of inefficient bladder emptying. Symptoms are similar to stress incontinence.	Many causes such as spinal cord injury, diabetes, neurological damage, Parkinson's disease, Multiple Sclerosis, enlarged prostate.
Functional	Urine loss not associated with any pathology or problem in the urinary system.	Associated with physical or cognitive impairment such as immobility, Alzheimer's disease, or head injury

Urinary incontinence can lead to many complications. For example, incontinence that is not properly managed can contribute to the development of bladder and kidney infections. Particularly among older adults, incontinence can also increase the risk for skin rashes and pressure sores (because urine can irritate the skin), and falls (because an incontinent person may fall when rushing to use the toilet).

After an injury, or with the onset of incontinence, the body's normal system of bladder control no longer works, because messages can no longer pass between the bladder muscles and the brain. If your injury is T12 or above, you usually have what is called a **reflex** (or 'automatic' or 'spastic' bladder). With an injury below the T12 level you will usually have an **acontractile** (or 'flaccid') bladder.

In the onset of trauma related incontinence (like a spinal cord injury) the doctor will approach you very cautiously and begin to explain of the failing of the waterworks.

Reflex bladder: reflex bladder allows automatic involuntary control of the bladder so that when the bladder fills above a certain level it contracts and urine flows out automatically.

Acontractile bladder: with lower lesions, the reflex arc is also damaged; the bladder has no muscle tone and doesn't contract to empty automatically. Instead, it continues to fill and small amounts of urine may eventually dribble out. The bladder can be emptied at regular intervals by intermittent self catheterisation.

The final outcome of how your bladder would behave is not solely related to the level of injury. There may be other factors which will have influence.

Although there have been huge improvements, urinary tract (and hence kidney) complications are still one of the main causes of illness and death in spinal cord injured people. So, correct bladder supervision is literally vital.

In the first few weeks after injury, your bladder will commonly need to be emptied regularly through a fine tube or catheter. This is either inserted every few hours by a nurse through your urethra (the tube through which you void or 'pee') and up into the bladder, and then withdrawn when the bladder is empty; or a small surgical incision is made just above your pubic area, and a 'suprapubic' catheter inserted directly into your bladder and left in place. After a few weeks you will be gradually trained to empty your own bladder. The method used depends on the level of your lesion, your bladder behaviour and whether you are male or female.

As the marriage reaches maturity and you go into rehabilitation the doctors will start playing around with the different types of management for your specific marriage. They will look now at the following permanent options:

- Intermittent Catheterization
- Indwelling Catheter
- Suprapubic Catheter

INTERMITTEND CATHETERIZATION

This is often the method of choice for people with a contractile bladders, and is commonly used by men and women with paraplegia. Patients with reflex bladders that have good capacity can also use this method. Anyone with sufficient hand control can learn to self-catheterise, though dexterity is required to insert the catheter without damaging the urethra. You are less likely to get an infection if you change your own catheter than if someone else does it for you. Both men and women can usually catheterise while in bed, in a wheelchair or on the toilet. The aims of intermittent self-catheterisation are to empty your bladder completely at regular intervals, and to achieve continence without the need to wear an appliance. It is important with all catheters not to use too large a size which can damage your urethra. The main disadvantage is that you need some privacy or access to a toilet or bathroom, and you may not be able to rely on this when travelling or away from home. Care with hygiene is required

Intermittent catheterization is easy to learn. Supplies can be carried discreetly in a pocket or bag, and the procedure can be done fairly quickly. To learn the procedure, you must learn where the catheter is inserted and how to use the product. You must also be able to reach your urethra and manipulate the catheter. You can drain the urine through the catheter and into the toilet, or drain the urine into a disposable bag. Women can't always see their urethra and may learn to do the procedure by touch or by using a mirror.

I might share with you that I hated every second of this phase, as someone has to teach you in the beginning how to operate, and for me it was an absolute horror and I hated this invasion of my privacy.

INDWELLING CATHETERS

If you are unable to insert and remove a catheter to drain your bladder, you may need to use an indwelling catheter. This type of catheter is held in the bladder by an inflatable balloon and it provides continuous drainage. Indwelling urethral catheters need to be changed regularly, every 4-6 weeks. If you have sufficient hand control (and not too much spasm) you should be able to change your own. Otherwise your personal assistant or district nurse will need to do it. Great care needs to be taken to ensure that the catheter itself and everything used in the changing process are sterile. There is a high risk of infection as an indwelling catheter leaves the urinary tract permanently 'open' for bacteria to enter

Complications of indwelling catheters may include urinary tract or kidney infections, blood infections (septicemia), urethral injury, skin breakdown, bladder stones, and/or blood in the urine (hematuria).

Again, with this option, my body responded with a severe marital

squabble and my body decided that regular separation is the way to go.

SUBRAPUBIC CATHETERS

A suprapubic catheter is an alternative for individuals who have difficulty managing intermittent catheterization, such as those with paralysis of the arms and/or legs. A suprapubic catheter is an indwelling catheter that is placed directly into the bladder through the skin above the pubic bone. This catheter must be placed by a urologist during an outpatient surgery or office procedure. The insertion site (opening on the skin), and the tube, must be cleansed daily with soap and water.

Again my bladder didn't like the new marital affair, and I was left all on my own with an out of control incontinence. People, at this stage I really want you all to think of what this does to the person living this experience's self esteem and also your trust in the medical team. I cannot tell you how a person will experience this situation if he is born with this situation, but I can tell you, that

as a person that became incontinent due to trauma, this situation is killing you emotionally. You question yourself, your body and worst of all, you question the poor medical team.

With all the catheter options you are very prone to infections because a foreign body is inserted into your sterile body and the body's normal response is to reject anything foreign. The result: INFECTION!!!! If you have a neurogenic bladder, the body can go as far as to try to get a divorce and push the catheter out.

Urinary tract infections occur when there is an increased amount of bacteria (or other microorganisms) in the bladder, urethra and kidneys, sometimes as a result of residual urine in the bladder. In men, urinary tract infections can also include the genitals such as the prostate or seminal vesicles.

You may experience these symptoms if you have a urinary tract infection:

- More frequent urination than normal
- Leakage of urine between normal voiding or catheterization
- Increased muscle spasms (if you are spinal cord injured)
- Fever
- Back pain
- Milky, cloudy, or darkly coloured urine
- Foul smelling urine

For some people, special tests during urination (urodynamic evaluation) and a cystoscopy may be helpful. Urodynamic tests measure the pressure in the bladder at rest and when filling. A catheter is inserted through the urethra into the bladder and water is passed through the catheter while the pressure within the bladder is recorded. Normally, the pressure increases only when the bladder is relatively full. In some people, pressure builds in sudden spasms or rises too sharply before the bladder is completely filled. The pattern of pressure change helps the doctor determine the type of incontinence and the best treatment. The rate of urine flow can also be

measured. This measurement can help determine whether urine flow is obstructed and whether the bladder muscles can contract strongly enough to expel the urine. Additionally, the function of the urethral sphincter muscle, which helps retain urine in the bladder, can be assessed. A weak urethral sphincter muscle may cause or contribute to incontinence. Cystoscopy involves looking directly into the bladder with a flexible viewing tube (similar to colonoscopy) to identify abnormalities that may be contributing to the incontinence and related symptoms.

Doctors often test urine for evidence of a urinary tract infection and test blood for evidence of impaired kidney function. They may also test for the bladder's ability to empty completely by using an ultrasound or inserting a catheter in the bladder (a test called post-void residual determination).

This whole process will still be accompanied by medicine, where they either try to help you to strengthen the bladder muscles, or the medicine that you will receive is to relax the bladder and to weaken the involuntary muscle spasms of the bladder. On a personal note I can confide in you that the latter situation of bladder spasms is a very abusive and painful marriage.

A neurogenic bladder means that you have some type of bladder malfunction caused by a neurologic disorder or injury. Your bladder may empty too frequently, not frequently enough, or in an uncoordinated way. Your urinary sphincters may also work incorrectly. The way your bladder and sphincters behave depends on the location of the neurologic disorder in your brain, spinal cord, or peripheral nerves, and the extent of your disease or injury.

It usually occurs after acute spinal cord injury above the level of S2-S4. It results in frequent uncontrolled voiding due to bladder spasms and a lack of sensation.

Some neurologic disorders prevent the bladder from emptying properly. Your bladder fills with urine yet you don't feel the need to urinate or you can't make the urine come out. Neurologic disorders or injuries can also cause the urinary sphincters to function improperly. They may not close or open at the right

times; or may not close at all. In a condition called detrusor sphincter dyssynergia, the pelvic floor muscles contract and close the urethra when the bladder contracts; preventing the bladder from emptying. This can cause urine to flow up the ureters toward the kidneys, which can damage the kidneys.

But now, if the catheter and your body don't compliment each other, as in some cases with a neurogenic bladder the doctor will advice you that surgical intervention is the next best option. At this stage a part of the big intestines will be taken to enlarge the bladder to try to lessen the pressure that can build up in the bladder (Ileocystoplasty) and in the very final procedure a little chimney is built for the bladder (an Ileal vent) to try to lessen the pressure in the bladder. **Ileal Conduit** – The ureter is implanted into a segment of bowel which is then opened out on to the surface of the skin to form a stoma. The urine can then drain from the kidney to a collection appliance ("stoma bag") fixed over the stoma. This way the urine does not go into the bladder at all.

Remember, as in every marriage, you go into it with stars in your eyes and you believe that this is the perfect marriage. In very severe cases of a neurogenic bladder the doctor can decide to do a Brickers illeostomy, where the urethras are disconnected form the bladder and connected to a poach made from the colon, which are connected to your chimney.

When the bladder has to be removed or bypassed, and the urine comes out through an opening on the skin, it is called a **urostomy**. The place where the urostomy opens onto your skin is called the **stoma**. Urine will drain from the stoma. Your stoma may also drain mucous, a sticky thick fluid that looks like cloudy material in the urine. The stoma is normally red and moist, bleeds easily, and has no feeling.

Your waterworks are now officially converted to a very special sports model and if you were this lucky, you form part of just 0, 01% of the population in the world.

People please remember, every sport has its own injuries, and every marriage has its own fights. Incontinence is part of your life, manage it, enjoy it and

remember, you have the right to go for a wee-wee, if you don't, you have even bigger problems coming.

And for the rest of the world out there give us our day in court and grant us our time in the loo.

Thank you

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