

# **Scottish Muscle Network**

Patient information leaflet

## **Continence care – bladder issues in neuromuscular disorders**

## **Introduction**

Bladder issues, such as incontinence, can be a common symptom in people with a neuromuscular disorder. There are several reasons why the bladder may be affected.

## **What is bladder incontinence?**

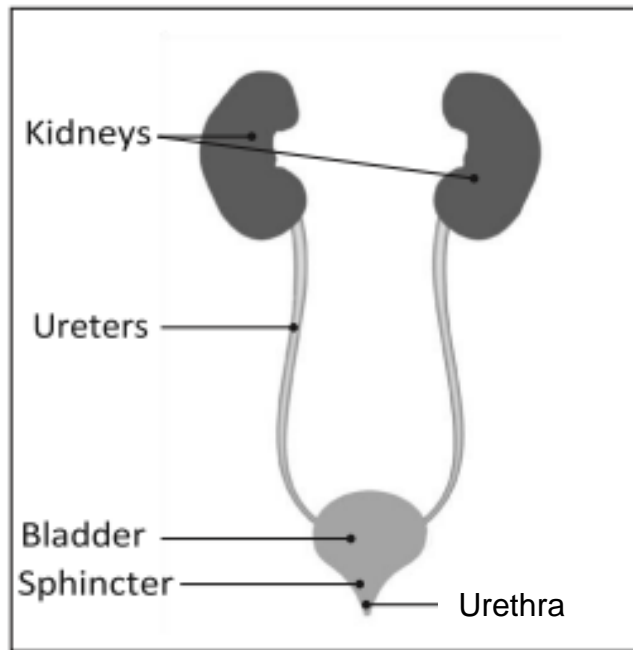
Bladder incontinence is when you pass urine without meaning to. Some people are unaware they have done this whilst others know they are doing it but are unable to stop. Bladder problems can be embarrassing, and some people will avoid going out if they are unsure if there will be suitable toilets available. If they have mobility issues and need help with their personal hygiene or even getting onto the toilet, they will often avoid going to unfamiliar places and events.

There are several reasons why toileting may be difficult for you and this leaflet explores some of the common problems and offers some solutions too. Finding the best way to manage these symptoms can improve your quality of life.

## **How do the bladder and kidneys work?**

The kidneys are always working to make urine and a trickle of urine continuously passes from the kidneys into the bladder. If you drink more or eat foods with high water content such as fruit and vegetables, you will make more urine. If you are exercising or sweating, you will make less. As the urine passes into the bladder, the bladder stores it.

As the bladder is a muscle, it can expand to allow more urine in or contract to empty the urine out. The urethra (or sphincter) is where the urine comes out and this is normally kept closed until you are ready to go to the toilet. The pelvic floor muscles surround the urethra and help to keep this outlet closed. As the bladder starts to fill, stretch receptors in the bladder muscle alert you to the fact you will need to empty your bladder and so when the time is right, your bladder muscle contracts, and the pelvic floor muscles and urethra relax allowing you to empty your bladder.



## What are the common bladder issues?

### 1. Stress incontinence

This is the most common type of incontinence and is usually caused by muscle weakness which is a key feature in neuromuscular disorders. When the bladder starts to fill, the pressure in the bladder may become too great for the weak pelvic floor muscles and these muscles cannot stay closed tightly enough to withstand the pressure from the filling bladder. Urine may then leak out when you cough, sneeze, or laugh. The bladder can also become overfull as the bladder muscle itself is weak and is more easily stretched.

### 2. Urge incontinence

This type of incontinence tends to take people by surprise. It happens when you have an urgent need to go to the toilet and sometimes urine leaks out before you get there. A common example is when you arrive home and suddenly need to go to the toilet and dribble a bit whilst you are approaching the toilet, or your bladder decides it needs to empty before you are ready to let go. This may be caused by the bladder being overactive, being overfull (as the muscle is weak) or the fact that the bladder muscle is sending wrong signals to the brain (neurogenic bladder). This may occur over time as you have frequently held on too long i.e. some children don't like going in school so will hold on as long as possible until they get home, or some people don't like using public toilets so will wait. Whilst this is fine in the short term, repeatedly ignoring the bladder signals can lead to nerve problems in the long term. In some conditions where nerves are affected, which is the primary reason the muscles are weak, a neurogenic bladder may be a pre-existing factor in bladder incontinence and the additional muscle weakness as time goes on, may make a pre-existing bladder problem progress.

### **3. Mixed incontinence**

It is possible to have a combination of stress and urge incontinence.

## **Treating and managing bladder incontinence**

### **1. Weight loss**

If you are overweight, it may help to lose weight. If you are carrying additional weight around your abdomen, this can put extra stress on your bladder and if your bladder muscle is already weak, then this can cause stress incontinence. Sometimes losing a small amount of weight can make a big difference towards helping incontinence.

### **2. Pelvic floor exercise**

Whilst it may not be possible to build muscle in neuromuscular disorders, it is possible to help your muscles work more effectively and efficiently with practice. There are specific exercises you can do to improve muscle function; however, it is important to discuss the issue of neuromuscular muscle fatigue with staff. Ask your GP about a referral to the continence care service as there are several different ways to exercise as well as different methods that can help you to work on the muscles more effectively.

In some cases, surgery can help tighten the pelvic floor muscles and for some people, this could be helpful.

### **3. Toileting**

Getting to the toilet can be one of the most difficult issues in neuromuscular disorders.

- **Males**

If you use a wheelchair, when you are out and about, you may want to carry a bottle with you. This means you can use this in a disabled toilet and empty it out before placing it back on the wheelchair. Some people use a sports shoe bag hooked over the handle of the wheelchair as this is a discreet way of carrying your bottle around. If you are concerned about your bladder function at night, you could keep a bottle at the side of your bed to save you getting up in the middle of the night and in the dark. There are a variety of bottles on the market and some males prefer to use a small portable discreet urinal bag (available on prescription) that expands for use and can be kept in the pocket.

Some men find it difficult to use a bottle as their penis retracts in the sitting position. This is a common problem and a bottle with a longer neck may be required. Your District Nurse, Occupational Therapist or Continence Nurse may be able to suggest a specific bottle. If you can recline your chair, then this opens the hip angle and can make it easier to use the bottle. The type of wheelchair you have may affect your toileting method. You may want to discuss your toileting needs with your wheelchair provider. Some males also carry a blanket that can be placed across their legs, and they can toilet discreetly with a bottle underneath if there are no disabled toilets.

For males who feel that the toileting issue is too challenging for them and their carers, a uri sheath is another option. Uri sheaths are like condoms that go over the penis and are connected to a collection bag that attaches around the leg. Your District Nurse or Continence Nurse can give further advice. This is non-invasive (i.e. does not involve a medical procedure) and means you do not have to be near a toilet. Some young men prefer to use these if they are going out for the day or for extended periods of time i.e. College or University.

- **Females**

Getting to the toilet is more difficult for females. Although there are various types of female bottles, such as the portable female urinal type bottle, female toileting does require a degree of dexterity and loosening clothing within a wheelchair can be challenging. For the most part, this is where Bladder training is more effective.

## **Bladder training**

A member of staff will tell you about Bladder training. This is where you measure the amounts of fluid you drink, and you empty your bladder at regular times. You will keep a diary during this time, and we may ask you to increase or decrease your fluid intake and help you work out your toileting schedule. For most people, it is important to get to the toilet regularly (every two to three hours for example).

Whilst there are more disabled toilets available than ever before, few have a hoist. Most females who use a wheelchair will prefer to toilet at home with their own equipment rather than in unfamiliar surroundings.

## **Fluid intake**

How much you drink affects your bladder. If you drink large volumes of fluids then you will pass more urine and if getting to the toilet is difficult, then this can be a factor in the bladder problem. However, reducing how much you drink can also irritate the bladder, so you need to find a balance that is right for you.

You need to drink to avoid dehydration. Going all day without a drink to avoid having to go to the toilet, can be harmful. Sometimes people do this as they feel embarrassed about having to ask for help. For those who have always managed to go to the toilet independently, suddenly having to ask for help can feel upsetting. This is particularly difficult for teenagers who may start to become weaker as their bodies are changing and personal care in adolescence requires sensitivity. It is important that you make sure carers are trained and feel confident assisting with your toilet routine. You may need to discuss your changing toileting requirements with your family or carers.

Certain drinks that contain caffeine such as coffee, tea, hot chocolate, and fizzy drinks can make you want to go to the toilet more often. This is because they are diuretics, and it might be worthwhile changing to caffeine-free drinks.

Try not to drink late at night or just before you go to bed to prevent waking up in the middle of the night to go to the toilet and disturbing your sleep.

## **Supra-pubic catheter**

Some people, especially women, may decide on a permanent solution to make toileting easier. A supra-pubic catheter is a surgical procedure to help empty your bladder using a tube. The doctor inserts a semipermanent tube into the lower abdomen just above the pubic bone. Your GP can refer you to a specialist who will discuss the pros and cons of this procedure more fully. This procedure is usually reversible.

## **Indwelling catheters**

These are used for both males and females. These are tubes that go into the bladder via the urethra and there are pros and cons. You should discuss this with your neuromuscular team and GP. This procedure may not be reversible as once you lose bladder control, it may not be possible to re-train it.

## **Aids**

The District Nurse, Occupational Therapist or Continence Nurse may be able to suggest some aids to help with toileting. It may be that you need a variety of different approaches involving the whole multidisciplinary team such as the District Nurse, Continence Nurse, Physiotherapist, Occupational Therapist, Dietician and GP.

## **Medication**

Depending on the cause of the incontinence, in some cases certain medications called antimuscarinics or anticholinergics, can help. Please discuss this with your GP if you feel this may be something you would like to find out more about.

## **Aids and adaptations**

Making things as easy as possible for you to go to the toilet is important. Sometimes a special toilet seat or a special toilet that helps wash and dry you, could help. An Occupational Therapist (OT) will assess you for this. Your OT will be based in the local social work department, and you can refer yourself.

## Conclusion

If you are experiencing bladder issues, please discuss this with your GP. There are a variety of ways to treat this. Bladder incontinence is a common symptom in neuromuscular disorders and there is no need to feel embarrassed about discussing it with your GP or healthcare professionals. If your incontinence continues, your local continence nurse can give you practical advice on how to manage this on a day-to-day basis to help you get on with your life. It may mean making some changes to the way you do things but once it's dealt with, there is no doubt you will feel better able to cope.

For further information, please contact Marina Di Marco, Consultant Neuromuscular Physiotherapist ([marina.dimarco@ggc.scot.nhs.uk](mailto:marina.dimarco@ggc.scot.nhs.uk) or telephone 0141 354 9205)