



## **NDF Patient Huddle**

# **Trials and Tribulations of Toileting for Women Living with GNE Myopathy**

By Mona Patel (UK) & Saskia Melches (Germany),  
NDF Certified Patient Advocates

Sun 5th May 2019

Sources: NHS England, 2018 etc.

## Session Agenda

- Welcome and Introductions
- Presentations by Mona & Saskia
- Question & Answer Time

Please feel free to ask questions at any point – this is your forum!

Authors: Mona Patel, UK & Saskia Melches, Germany

If you have any questions after you have read this presentation, please contact the NDF or your national Certified Patient Advocate – you can find a list here

<https://curehibm.org/about-ndf/who-we-are/ndf-certified-patient-advocates-for-gne-myopathy.html>

**Remember:** The huddles are a support group that are confidential, open, safe and non-judgmental - giving patients an opportunity to discuss any topic.

## Session Goals

To make 'comfort breaks' more comfortable for you by:

- Providing tips to manage toileting and keep your independence.
- Through discussing each other's experiences, challenges and finding solutions together.

Authors: Mona Patel, UK & Saskia Melches, Germany

The aims of this session is to to make 'comfort breaks' **more comfortable for you** and we hope to achieve this by:

- Providing tips to manage toileting and keep your independence. We shall talk a little about dealing with menstruation too.
- Through discussing each other's experiences, challenges and finding **solutions together**. The more open we are, then the more we can help each other.

# Types of Bladder Incontinence

## Stress Incontinence

Very common in women – 1 in 4 women.

Leakage of urine happens when running, sneezing, coughing or laughing.

Can affect women of all ages but often begins during pregnancy, after childbirth or menopause.

## Urge Syndrome

Sudden need to pass urine.

Need to urinate more frequently.

Bladder wall becomes over active .

Even though you feel like you're bursting to go, the amount of urine might be small.

**NB. We aren't sure if GNE myopathy causes bladder muscle weakness.**

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The are two main types of bladder incontinence so I'll explain each so you get to know which one you might have:

### Stress Incontinence

- This is very common in women and can affect 1 in 4 women at some stage of their lives.
- 'Stress' does not mean it's an emotional problem but it describes the physical effect when running, sneezing, coughing or laughing causes leakage of urine.
- Can affect women of all ages but often begins during pregnancy, after childbirth or menopause. Apparently, even smoking can cause it.

### Urge Syndrome

- This means that you have a sudden need to pass urine but may not make it in time to the toilet.
- Need to urinate more frequently - usually caused by the bladder wall becoming over active even if the bladder isn't full.
- Even though you feel like you're bursting to go, the amount of urine might be small.
- For some people the cause of an overactive bladder is unknown but certain diseases of the nervous system can prevent the brain sending the right message to the bladder to make it 'hold on'.

Some people can have both stress incontinence and urge syndrome!

**NB. We aren't sure if bladder weakness is caused by having GNEM. The more we inform them, then it will help the doctors with the natural research studies across the world.**

# Managing Your Bladder

Alcohol



Coffee



Citrus fruit & juices



Cola & soda drinks



## FOOD & DRINKS WHICH IRRITATE THE BLADDER



Tea



Green tea



Hot chocolate



Tomatoes

Authors: Mona Patel, UK & Saskia Melches, Germany

### Drinks which can irritate the bladder:

1. Alcohol
2. Coffee
3. Citrus fruit and juices (e.g. orange, lemon, grapefruit, lime and tangerine)
4. Cola and fizzy drinks
5. Tea
6. Green tea! Contains a lot of caffeine
7. Hot chocolate ☹️
8. Tomatoes (It's the acid)

# Managing Your Bladder

Decaffeinated coffee



Decaffeinated tea



Diluted fruit juice



## DRINKS WHICH DO NOT IRRITATE THE BLADDER



Herbal teas



Milk



Milk shakes



Water

Authors: Mona Patel, UK & Saskia Melches, Germany

Drinks which do not irritate the bladder:

1. Decaffeinated coffee
2. Decaffeinated tea
3. Diluted fruit juice (apple, pear and grape is recommended)
4. Herbal teas
5. Milk
6. Milk shakes
7. Water



**TAKE  
CONTROL.**

Next slides will focus on how you can get back some control of the situation...

## Look After Yourself

1. **Avoid constipation** by eating lots of fibre and drinking at least 1.5L of fluid each day.
2. **Keep your weight low** in order to ease the pressure on your pelvic floor.
3. **Retrain your bladder** by only going to the toilet when your bladder is full.

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1. Avoid constipation by eating plenty of fibre e.g. Wholegrain cereals, wholewheat pasta/bread, fruit, veg e.g. sweetcorn, broccoli, carrots, pulses/beans. Drink at least 3pts/1.5L of fluid per day but remember to avoid caffeinated drinks that irritate the bladder.
2. Try to keep your weight at a reasonable level so that it eases the load on your pelvic floor. This is difficult for those of us less mobile or in a wheelchair, but if we stick to eating and drinking well (point 1), then this will help.
3. You can re train your bladder. Try to only go to the toilet when you feel your bladder is full because going too frequently when you don't really need to can make your bladder smaller! Allow your bladder to get used to stretching and holding more urine. Try to hold on by distracting yourself or sitting on a hard chair.



## Pelvic Floor Exercise (PFE)

1. Can be done either lying down, sitting or standing.
2. Lift the area you are sitting on (the 'perineum') 'off' the chair.
3. Tighten the muscle upwards and inwards at the same time.
4. Don't clench your thigh/leg muscles nor your stomach muscles or buttocks to do this.
5. Breath normally!
6. Repeat x10 slow and x10 fast three times a day.

**May take 3 months to see any improvement - don't give up even after strengthening them!**

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The PF is like a bowl of muscle cradling your bladder, uterus and bowel – a bit like a hammock.

1. Can be done either lying down, sitting or standing – by your PF needs to work against gravity.
2. Sit in an upright firm chair. Lift the area you are sitting on (called the 'perineum') 'off' the chair. As though you are trying to stop the flow of urine at front or stop passage of wind at the back. **Don't do this whilst stopping your urine midstream.**
3. Try to tighten the muscle upwards and inwards at the same time ( for 2secs up to 10secs).
4. While you are doing this don't clench your thighs, leg muscles or stomach muscles or buttocks to do this.
5. Breath normally! Focus on lifting your perineum up and off the chair.

### How often?

Once you've learned how to do this exercise, you can develop a regular pattern. Aim for x10 slow contractions and x10 fast contractions three times per day.

Results may be gradual as it is with all muscle exercises. May take 3mths but don't give up even after strengthening them!

### Watch these helpful videos to learn more:

**Female pelvic floor muscle - 3D animation, Continence Foundation of Australia:**  
[https://www.youtube.com/watch?v=q0\\_JAoaM6pU&feature=youtu.be](https://www.youtube.com/watch?v=q0_JAoaM6pU&feature=youtu.be)

**Pelvic floor exercises by Nuffield Hospital, UK:** <https://youtu.be/dd1iVW3zFik>

## Pelvic Floor Devices

- **Pelvic Floor Trainers**

Tampon-like vaginal cones



- **Electric Pelvic Muscle Trainer**

Electric stimulation of the pelvic floor



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[Click on the hyperlinks embedded in the words below to learn more about each device:](#)

- [Pelvic floor trainer](#) – tampon-like vaginal cones

Contains 5 different weights

For insertion into the vagina.

By tightening the pelvic floor muscles, the cones are prevented from slipping out, you train the pelvic floor.

- [Electric pelvic muscle trainer](#) – electric stimulation of the pelvic floor

For insertion into the vagina.

Stimulates the pelvic floor muscles with electrical impulses.

You can choose different programs with the remote control.

# Practical Solutions

## Toilet seat raisers with lids



## Shower and commode Chair



## Bedpan



## Uplift Commode

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**Toilet seat raisers with lids & grab rails** – Different sizes available. Usually provided by an Occupational Therapist (OT).

**Shower and commode/toilet wheelchair** e.g. “Aquatec ocean” buy online.

The chair is mobile/portable, so it can be placed next to the bed at night. You don't have to walk to the toilet. It has a pan underneath. You have to clean the pan or someone may do it for you. The chair is mobile/portable, you can place it over the normal toilet or you may take it with you on a holiday or to the swimming pool etc. It has big wheels so you may push it by yourself. If you need to use it for longer, there is a soft seat pad.

**Bedpan** – To be used when lying in bed for pee and bowel movements. If you are not at home and can't use the toilet this maybe an option, e.g. if you are at the friends house etc.

**Uplift Commode** – It assists those with standing and sitting difficulties to use the commode independently. It is self-powered. It has adjustable height. It could be used by itself as it has a pan underneath or over a regular toilet.

## Practical Solutions

- **Disposable Catheters** - One-time drainage of urine.



- **Patient Lifter**



- **Portable and Fixed Hand-Held Bidets**



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**Disposable catheters** – are used only once to drain the urine. With these catheters you need strength in your hand you pull down and up your trousers, and to insert the tube that carries urine out of your bladder.

**Patient lifter** – It is used for transfers for example from the bed to a wheelchair or from the wheelchair to toilet. This helps you to sit normally on the toilet. With this lifter, your caregiver is able to adjust it so they are able to clean the genital area. This lifter is also able to help you stand upright.

**Portable & Fixed Bidets** Portable bidets are easy to travel with however requires strength in your hands to squeeze the bottle. There are a various types of fixed bidets and hand-held bidets which provide water and pressure control.

## Practical Solutions

- Female portable uterine devices

e.g. '[Pibella](#) Travel' or 'Comfort'.



- Speak to a bladder & bowel specialist - Get a referral

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**Female portable uterine devices** - allows you to pee standing up and sitting and without removing clothes e.g. 'Pibella Travel' - **Need to be able to stand and have strength in hands for handling.** 'Pibella Comfort' - allows you to pee lying down and sitting.

Shaped docking orifice encloses the exit of the urethra entirely so no leakage. Comes with pouch.

Buy online for £13 or \$15. **Watch Video** <https://pibella.com/about-pibella/documentary-film-for-nurses/>

**Speak to a bladder & bowel specialist - Get a referral** Continence service provides treatment such as pelvic floor exercises, bladder retraining, and lifestyle advice. Examinations of the pelvic floor are carried out, bladder scans and flow rates are undertaken if required...

## Practical Clothing

- Drawstring trousers
- Stretch waist trousers
- Skirts



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If you have or will have problems to pull up and down clothing or open and close them, then look for practical clothing, like:

- Drawstring trousers
- Stretch waist trousers
- Skirts short/long - with long socks and maybe even leg warmers in the winter.

These types of clothing are more practical and easier to wear.



# Permanent solutions

**A. Catheters** are a flexible tube used to empty the bladder and collect urine in a drainage bag or a valve to drain. Two types...

- **Urethral Catheter** - inserted through the tube that carries urine out of the bladder.

**Positives:** No need to pull trousers down & up. No wound if removed. Nurse has to put it in and change it.

**Negatives:** Urethra irritable. Unhygienic when menstruating. Can't use the toilet to pee. Irritates when sitting. No sex. High risk for a bladder infection.

- **Suprapubic Catheter** – inserted through a small opening made in your lower tummy/abdominal wall.

**Positives:** Can use the toilet to pee normally or pee wherever you are. Can have sex. No need to pull trousers down & up.

**Negatives:** Dressing needs to be changed every 2-3 days, Catheter needs to be changed every 4-6 weeks. If you remove catheter there is a hole and it has to heal. In Germany, only a doctor is allowed to put and change the catheter. Risk for a bladder infection.

**B. Endometrial Ablation** is a procedure that removes the lining of your uterus which reduces menstrual flow or stops them completely.

**Be bold! Your doctor may not offer any of these solutions however, we are the expert patients so we must ask and if needs be, challenge!**

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**A. Catheters** are a flexible tube used to empty the bladder and collect urine in a drainage bag or a valve to drain. They can either be inserted through the tube that carries urine out of the bladder (**urethral catheter**) or through a small opening made in your lower tummy/abdominal wall (**suprapubic catheter**).

## Urethral Catheter:

**Positives:** No need to pull trousers down & up. No wound if removed. Nurse has to put it in and change it.

**Negatives:** Urethra irritable. Unhygienic when menstruating. Can't use to the toilet to pee. Irritates when sitting. No sex. High risk for a bladder infection.

## Suprapubic Catheter:

**Positives:** Can use to the toilet to pee normally or pee wherever you are. Can have sex. **No need to pull trousers down & up.**

**Negatives:** Dressing needs to be changed every 2-3 days. Catheter needs to be changed every 4-6 weeks. If you remove catheter there is a hole and it has to heal. In Germany only a doctor is allowed to put and change the catheter. Risk for a bladder infection.

**Watch video on next slide or here:** <https://www.youtube.com/watch?v=4R66NEftTvA>

**B. Endometrial Ablation** - is a procedure that surgically destroys (ablates) the lining of your uterus (endometrium). The goal of endometrial ablation is to reduce menstrual flow. In some women, menstrual flow may stop completely.

Why it's done?

- Unusually heavy periods, sometimes defined as soaking a pad or tampon every two hours or less
- Bleeding that lasts longer than eight days
- Anaemia from excessive blood loss or caused by fibroids

## Watch Saskia's video on managing her suprapubic catheter

**Click here to watch the video:**

<https://www.youtube.com/watch?v=4R66NEftTvA>

Saskia Melches has her own YouTube channel called 'Drive my life'. She talks about life in a wheelchair and living with a rare muscle disease.

The channel also shows assistive devices as well as everyday bizarre situations.



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Saskia Melches, CPA has her own YouTube channel called 'Drive my life'. She talks about life in a wheelchair and living with a rare muscle disease. The channel also shows assistive devices as well as everyday bizarre situations.

There will also be an area in the channel where emotions will be discussed.

**Link:** <https://www.youtube.com/watch?v=4R66NEftTvA>



# Personal Hygiene

## ❖ Toileting

- Toilet/Feminine Wipes – Use soft and flushable ones.
- Incontinence care – ‘Tena Lady’ pads, underwear and nappies/diapers.
- Wash and dry toilet e.g. ‘Closomat’.

## ❖ Menstruation

- Tampons (with applicator).
- Bed Pads and Waterproof Mattress Covers.
- Incontinence care – nappies.

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## Personal hygiene

### Toileting

- Toilet/Feminine Wipes – Use soft and flushable ones. Use separate wipes for vaginal area as its more sensitive. Tip: Keep a packet in your bag at all times so you can use them for both areas. Tip: Don’t take wet wipes for babys for the vaginal area, it’s not good for the vaginal flora – higher risk for infections. Drying too.
- Incontinence care - Tena Lady pads, nappies and underwear/knickers etc. Great for when travelling.
- Wash and dry toilet e.g. Closomat

You have a special toilet seat, you need an electrical outlet and an additional water connection. The toilet seat has a seat warmer and the water for washing has a temperature control. After using the Closomat you use the remote control to wash your genital area and after there is a dryer to dry up. The Closomat remembers the pressure, the temperature of the water and seat and saves it for the next time you need to use it.

### Advantages

- Easy to clean
- No need to move arms to clean bottom
- It feels comfortable
- Does not irritate the anus/haemorrhoids

### Disadvantages

- If you can’t move on the seat then difficult to get into a perfect position
- Not completely dry

### Menstruation

- Tampons (with applicator)
- Bed Pads & Waterproof Mattress Covers
- Incontinence care – nappies

## Medical Solutions

### Treatments & Creams

- For piles/haemorrhoids use e.g. Hydrocortisone such as 'Anusol' or natural products e.g. Hametum, Witch Hazel (Hamamelis) or an ice pack.
- To protect the skin from moisture, chafing and contamination with bacteria or yeasts try 'Conotrane' i.e. benzalkonium chloride and dimeticone.
- To soothe burning/itching/pain in the intimate areas, try 'Vagisil' i.e. benzocaine/resorcinol topical
- To treat thrush (yeast infections), try 'Canesten cream' i.e. Clotrimazole.

### Drugs

- Oxybutynin Hydrochloride
- Tolterodine Tartrate
- Solifenacin

(Speak to your doctor/GP or Pharmacist for more advice)

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To soothe burning/itching/pain in the intimate areas, try 'Vagisil' i.e. benzocaine/resorcinol topical

To treat thrush (yeast infections), try 'Canesten cream' i.e. Clotrimazole. Or you can use a natural homemade remedy/treatment such as live plain yogurt!

- **Oxybutynin** reduces muscle spasms of the bladder and urinary tract.
- **Detrol** (tolterodine) LA is a muscarinic receptor antagonist that reduces spasms of the bladder muscles and is used to treat overactive bladder with symptoms of urinary frequency, urgency, and **incontinence**.
- **Solifenacin** reduces muscle spasms of the bladder and **urinary** tract. Solifenacin is used to treat symptoms of **overactive** bladder, such as **frequent** or urgent urination, and incontinence (urine leakage).

(We are not medically qualified/doctors, so please speak to your doctor/GP or Pharmacist for more advice).



## 1. Toileting in public toilets / restrooms?

**Accessible toilets across Europe are fully equipped to support disabled users:** Building regulations ensure that the toilets are larger, have grab rails, a shelf and hook etc.

**Many of the accessible public toilets have the RADAR Key feature** - The Royal Association for Disability and Rehabilitation, which is now Disability Rights UK, worked in partnership with Nicholls & Clarke, the inventors of the RADAR lock and together they created the National Key Scheme (NKS). The first RADAR locks were fitted in 1981 to help keep accessible toilets free and clean for disabled people. <https://news.motability.co.uk/everyday-tips/radar-keys-explained-what-are-they-where-can-i-use-them-and-how-do-i-get-one/>

**In Europe they have the 'Toilets for All' project** – People with disabilities like muscular dystrophy often need more than an accessible toilet. They need extra features, like a height adjustable changing bench and a patient lifter. In many places in Europe we have these toilets, all you need is to bring your own sling.

**In the UK, they also have the 'Changing Places' facilities** - People with profound and multiple learning disabilities, as well people with other physical disabilities often need extra equipment and space to allow them to use the toilets safely and comfortably. These needs are met by Changing Places toilets. **Learn more here:** [http://www.changing-places.org/the\\_campaign/what\\_are\\_changing\\_places\\_toilets.aspx](http://www.changing-places.org/the_campaign/what_are_changing_places_toilets.aspx)

## 2. The many ways toileting has affected women that are still getting their menstrual cycle and ways to cope with that change

I hope we have addressed this by providing some tips for you, but please let us know if you have any other questions or if you have any solutions/ideas.



We hope this resource is helpful, particularly for those women who weren't able to join the huddle or may be newly diagnosed or who have just joined our GNEM Family/community.

Thank you for your watching/listening 😊

Please keep your questions and ideas coming to us! [Contact page:](https://curehibm.org/contact-us.html)  
<https://curehibm.org/contact-us.html>