

Talk About...

Bladder and bowel issues for adults and children

4th edition

DEMENTIA AND CONTINENCE

CHILDREN'S MENTAL
HEALTH - BLADDER AND
BOWEL PROBLEMS

LIVING WITH ULCERATIVE
INTERSTITIAL CYSTITIS

MANAGING BLADDER AND
BOWEL PROBLEMS AT WORK

WORLD BEDWETTING DAY
2021



Bladder & Bowel UK

Supporting people with bladder and bowel problems

part of Disabled Living

Bladder & Bowel UK are part of Disabled Living. Registered Charity No: 224742

www.bbuk.org.uk bbuk@disabledliving.co.uk 0161 214 4591

Medicina ACElok Dressing – now available on prescription



Medicina is a British based company which specialises in the development and marketing of medical devices.

Medicina has developed a range of stoma care products for patients with gastrointestinal and urethral stomas. Most of these developments start with an idea from one of our customers. Please read Fran's story below.

The ACElok dressing (Product Code: SD03) has been specifically designed for placement over the ACE stopper to provide external fixation and cushioning. The dressing allows easy access for washout procedures and can be used for 3-4 days or until it becomes soiled. One ACElok dressing is available alongside every Ace Stopper. They are also supplied as a separate item in a box of ten units.



How the Acelok Dressing from Medicina Helps My Son

Fran Sawyer talks about her son (Alex) and his experience of using the ACElok dressing. Alex was born with a 6lb teratoma tumour on his back. At one year old, his parents discovered that he had a 10lb tumour growing up his spine. Due to all the surgery, Alex has two stomas, one for his bladder and one for his bowel.

To hold the channel open for the catheter to be emptied, his bladder stoma required an ACE stopper. As stomas require repetitively removing and replacing a plaster, Alex found that doing so made him very sore. He also used to worry about losing the ACE stopper.



To make Alex's life a little bit easier, I designed a patent called ACElok SD03 dressing that opens and closes with a hole in. This meant that he didn't have to change it every time he emptied his bladder. As I'm not medical trained (I'm just a mum!) it took me five years, but my passion is all about making disability easier.

The ACElok is now available on Medicina's website: <https://medicina.co.uk/acelok-dressing/>

Welcome



Welcome to the 4th edition of Talk About. Spring is now well and truly upon us; the daffodils are now in full bloom. The Bladder & Bowel UK are looking forward to more sunshine and brighter skies!

We are all certainly feeling a little more optimistic here at Bladder & Bowel UK and sense that we are all turning a corner, regarding the ongoing pandemic, restrictions and challenges that have come to us all over the past year. This newsletter brings some informative, practical information and stories that we would like to share with you all. We thank you all for supporting us at Bladder & Bowel UK.

The Bladder & Bowel UK team would love to hear from you

We welcome any feedback or ideas you may wish for us to include in future editions of our Talk About newsletter or additional resources you might like to see online.

Like everyone else, we continue to monitor the pandemic situation daily, following government guidance and supporting the wider community who contact us here at Bladder & Bowel UK for support with bladder and bowel issues.

Please feel free to forward this newsletter with anyone you feel may find it useful. They can ask to receive a copy direct to their own mailbox by sending an email to: bbuk@disabledliving.co.uk

Karen Irwin
Specialist Nurse/Service Manager

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How to Keep your Bowels Healthy



Your bladder and bowel are key to your health and wellbeing. If they are not looked after properly then they may become a problem to you! Read on to find out how to maintain a healthy bowel.

To maintain or achieve a healthy bowel, it is important to eat meals regularly to boost metabolism, ideally three a day. Food choices are important in the maintenance of a healthy bowel.

A healthy metabolism will promote a healthy weight, overall health and wellbeing. Eating breakfast everyday will boost your metabolism and aid overall health of your digestive system.

The bowel needs fibre to assist with production of a healthy stool / poo and to stimulate a bowel movement.

Fibre rich foods include:

- Wholegrains including breakfast cereals
- Whole wheat pasta and rice, wholegrain, bread and oats
- Fruit such as berries, pears, melon and oranges

- Vegetables such as broccoli, carrots and sweetcorn
- Peas, beans and pulses such as lentils, kidney beans and butter beans
- Nuts and seeds – including almonds, hazelnuts and pumpkin seeds
- Potatoes with skin on – boiled or baked

To increase your fibre intake you could:

- Choose a high fibre breakfast cereal e.g. wholegrain cereal like whole wheat biscuit cereal, bran flakes or porridge. Try adding some fresh fruit, dried fruit, seeds and/or nuts
- Go for wholemeal or seeded wholegrain breads
- Choose wholegrains like whole wheat pasta, bulgur wheat or brown rice
- Eat potatoes with skins on baked potato, wedges or boiled new potatoes
- For snacks try vegetable sticks, rye crackers, oatcakes, unsalted nuts or seeds



- Include plenty of vegetables with meals especially green leafy vegetables such as Kale and Spinach
- Add pulses like beans, lentils or chickpeas to stews, curries and salads

Recommended daily intake of dietary fibre for an adult is 30g per day (based on guidelines published in 2015 by Department of Health).

Other advice:

- It is important to include all food groups in all meals – protein, carbohydrates and fats
- Drink between 2-5 litres of fluid a day, water-based fluids are most healthy e.g. cordial, water
- It is also important not to defer the need to empty your bowels for too long as this can lead to constipation
- Exercise and keeping active contribute to a healthy bowel so maintaining or increase some daily activity will help prevent constipation

If you have any concerns about your bowels, including an altered bowel habit, please consult with your GP. If you want any more information, then please contact BBUK's helpline today.

[CLICK HERE](#)

Bladder & Bowel UK

National Confidential Helpline

Information and signposting to anyone affected by a bladder or bowel problem. Individuals, their families, carers or clinicians may contact our helpline.

Bladder & Bowel UK Just Can't Wait Card

Please complete an online request form via the link - <https://www.bbuk.org.uk/just-cant-wait-cards/>

To obtain your free card - please send a stamped address envelope to: Bladder & Bowel UK, 10 Priestley Road, Worsley, Manchester, M28 2LY

www.bbuk.org.uk



bbuk@disabledliving.co.uk



0161 214 4591



Bladder & Bowel UK
Supporting people with bladder and bowel problems

part of Disabled Living

Connect with Bladder & Bowel UK on Social Media

**Bladder & Bowel UK
are active on Facebook,
Twitter, and LinkedIn.**

If you have anything that you
wish for us to share, please just
get in touch, or tag us in your
posts.

Please follow us, like and
connect with us!



Solving a drinking problem – if you struggle to reach, lift or hold drinks, we are here to help.

We are a small charity dedicated
to helping vulnerable people drink
without needing to call for help.

We deliver the Hydrant drinking
system free of charge to those
in need.

This can be done directly or
through carers or other
healthcare professionals.

How to get one delivered?

Simply email details of where you
would like a Hydrant delivered to:
requests@thehydrationfoundation.org

the**HYDRATION**foundation



www.thehydrationfoundation.org
contact@thehydrationfoundation.org
0800 0436 003

Time to Take Action - World Bedwetting Day

Tuesday 25th May 2021



Bedwetting, also known as enuresis or nocturnal enuresis is one of the most common medical conditions experienced by children. Bedwetting describes children who are passing urine during sleep after they have reached their fifth birthday, if they have been toilet trained during the day for at least six months. Some children do become dry with time, but without treatment bedwetting can continue into adolescence and beyond. Children who are wet most nights are least likely to get better without treatment.

Is bedwetting a problem?

Younger children and their families may not be bothered by wet nights. However, as children become more socially aware, they may be increasingly embarrassed about the issue. It can result in reduced self confidence and self esteem and may stop children from participating in some social activities, such as sleep overs. Bedwetting may be stressful for families, who may also be concerned about their child being called names or bullied if others find out. There are other impacts including, with the cost and time taken for extra washing, and the purchase of nappies or pull ups, if these are used.

Where can I get more information about bedwetting?

There is lots of information about bedwetting on the internet, and friends and family may offer suggestions. The difficulty is knowing which

recommendations are up-to-date and reliable.

Websites such as Bladder & Bowel UK at www.bbuk.co.uk and Stop Bedwetting at www.stopbedwetting.org have useful and relevant information, that has been produced by healthcare professionals who are experienced in working with children and young people in the UK who have bedwetting.

What causes bedwetting?

Bedwetting is caused by different problems. These include either producing too much urine during sleep, or having a bladder that is not holding the urine well enough. All children who wet the bed also have a problem of being unable to wake up to the bladder signals.

What is the best treatment for bedwetting

The right treatment for a child or young person is the one that is most likely to treat

the cause of the wetting. If they have a problem both with the amount of urine they produce and their ability to store it properly, they may need more than one treatment at the same time. Not all treatments are right for everyone, so assessment is important. Therefore, you should discuss the issues with your child's healthcare professional. They should ask some questions about the bedwetting and other aspects of your child's health and medical history, and discuss treatment options with you.



The main treatments are:

- A medicine called Desmopressin. Desmopressin works by helping the kidneys to make less urine at night, so the bladder can hold onto what is made. This is safe and is effective for children and young people who are wetting because they are making too much urine at night.
- An alarm (also known as an enuresis alarm). These work by making a noise as soon as the child or young person starts to pass urine. Many children and young people need help to learn to wake to the alarm. However, they work well for those whose bladders are not holding enough urine, or who are struggling to wake up to the full bladder signals.

- Medicine that helps the bladder to work more effectively. This works well for children and young people whose bladders get 'twitchy' while they are filling. Many, but not all, of these children and young people have to get to the toilet quickly in the day or appear to leave it to the last minute to go. Some will also get damp underwear if they cannot get to the toilet quickly enough in the day.

Your child's healthcare professional should be able to provide more information and advice about bedwetting and discuss the right treatment for you and your child, or refer you to a special clinic.

There is more information:

On the Bladder & Bowel UK website at www.bbuk.org.uk. Information on bedwetting is at <https://www.bbuk.org.uk/bladder-resources/>

On the Stop Bedwetting website at <http://stopbedwetting.org/>

Bladder and Bowel UK also have a confidential helpline. You can contact the helpline by filling in the online form at <https://www.bbuk.org.uk/helpline-enquiries/> or by telephone at 0161 214 4591.

World Bedwetting Day with the theme Time to Take Action is on 25th May and is designed to raise awareness of bedwetting. Look out for the Bladder & Bowel UK blogs with more information on bedwetting that will be shared at <https://www.bbuk.org.uk/blog/> in the run up to 25th May.

Davina Richardson
Children's Specialist Nurse
Bladder & Bowel UK

Mental Health and Bladder and Bowel Issues in Children and Young People



Historically, wetting and soiling in childhood were thought to be caused by an underlying psychological or behavioural problem. A journal article written in 1972 stated that “...enuresis has long been considered a sign of emotional disturbance...” and that most children with soiling have an underlying emotional disorder.

Thankfully, there is a better understanding of both these problems now. It is recognised that nearly all wetting and soiling problems in childhood are the result of an underlying medical problem, such as constipation. Furthermore, the underlying condition means that most affected children are not able to control the bladder or bowel leakage. There is also an awareness that any behavioural or psychological issues are the result of the wetting and soiling, and not the cause of them.

Families will often report that their child appears not to be bothered by the wetting or soiling and will deny that their underwear needs changing. This increases the overall stress within the household. However, parents and carers need to understand that the denial aspect may be because the child has genuinely not realized that they have been incontinent. For other children and young people, it is a natural coping mechanism to help them manage the problems that are outside their control.

Many studies have highlighted the effect wetting and soiling problems have on the mental health and well-being of children. For this reason, families should always seek medical advice to help resolve the problems. There is often a mistaken belief that children will grow out of any wetting or soiling problems. This and embarrassment may result in parents delaying seeking help. However, in many cases the problems get worse, not better, with time.

A study carried out in 2018, included interviews with young people who had bladder or bowel problems. It highlighted some of the emotional issues they experienced because of their continence problem. Many struggled to hide their problem from their peers and felt constantly embarrassed and frustrated that no one appeared to understand what they were going through. One young man described his problems as “not life threatening, but life ruining”, which reflects the emotional impact continence problems can have.

A recent article in The Guardian looked at the link between mental health difficulties and disabilities in people with spinal cord injuries. It stated that those whose injuries resulted in lack of bladder and bowel control, were more likely to have mental health problems.

Studies have also looked at the mental well-being and quality of life of informal caregivers who are looking after a family member with a bladder and/or bowel problem. They found that in many cases, caring for a family member with ongoing problems negatively affected the carers quality of life and mental health. Individuals who contact the Bladder & Bowel UK helpline often tell us how stressful this issue is. It can also cause rifts between family members if they disagree about how the problems should be managed.



Incontinence in an elderly person is often the trigger factor for them moving into a care home, as the stress and day to day issues of caring for a relative with a continence problem is often too much for the family member to bear.

Continence problems affect individuals of all ages. We need to be mindful of how having an ongoing bladder or bowel problem affects the individual's mental health and well-being and that of their family. As well as treating and managing the underlying bladder or bowel problem, it is important that affected individuals are treated holistically so any associated stress and anxiety can be addressed.

Furthermore, families and carers should be provided with the appropriate advice and support to help them manage the individual's problems.

Providing the right information and support and ensuring any wetting and soiling problem has been assessed, with the appropriate treatment put in place, can go a long way towards reducing stress and anxiety. So, if you or someone you care for is struggling with a continence issue and it is affecting either yours or their mental health, then do speak to a healthcare professional. They should provide the opportunity to discuss any mental health issues, by asking questions in the right way and having a non-judgmental listening ear. They may be able to provide support or referral for the bladder and/or bowel issue as well as for improving mental health.

Bladder & Bowel UK have lots of information and resources on their website at www.bbuk.org.uk to support people of all ages with bladder and or bowel difficulties. These are all free to download and print.

Bladder & Bowel UK also have a confidential helpline staffed by children and adult nurses who are specialists in bladder and bowel care. To send an enquiry, please visit:

<https://www.bbuk.org.uk/helpline-enquiries/>

Davina Richardson,
Children's Specialist Nurse
Bladder & Bowel UK

**[CLICK HERE TO VIEW OUR CHILDREN
AND YOUNG PEOPLE RESOURCES](#)**

International Nurses Day 2021 - Davina's Journey into Bladder and Bowel Nursing



For International Nurses Day coming up on 12th May, Davina Richardson from Bladder & Bowel UK talks about her journey into the world of a Specialist Bladder and Bowel Care Nurse.

In the mid-1980s all nursing education and most nursing roles, with the exceptions of health visiting and district nursing, were hospital-based. There were few specialist nurse roles; those that did exist were often pioneering and not universally available. Bladder and bowel care were considered part of basic nursing care; nothing more and nothing less.

Davina's Journey into Bladder and Bowel Nursing

The rapid changes in the world over the last few decades have also affected nursing. There has been an increase in focus on public health, on prevention, on delivering care to people where they are. It therefore seemed a natural progression for me to move away from acute hospital work to a community role. The approach is different, some of the roles I undertook were with teams that were considered innovative at the time. The privileges of being able to support children and their families were no less profound, challenging or rewarding.

About sixteen years ago I spotted an advert for a children's continence nurse. Not really understanding what the job would entail, I did not apply. However, just after the closing date a school nurse, pointed out the potential: I would have my own caseload and be



Davina's graduation photo

able to offer continuity of care, while developing something new. That put a different light on it, so when the job was re-advertised, I applied.



When offered the post had no idea where it would lead, or that all these years later I would still be happily working in the same specialism. Bladder and bowel care is not considered glamorous. Most people remain embarrassed and unwilling to talk about private bodily functions, so that there is a lack of awareness of what is considered healthy and what may require intervention. Some friends and family still do not understand why I do 'that job'.

A love of children and young people and a desire to support them and their families was what brought me into children's nursing. I never doubted that it would be a profession that I would still be involved in when the time eventually comes to retire. However, I had not imagined how much difference supporting and promoting bladder and bowel health would make to children and their families.

Having control of toileting needs allows children and young people to reach their potential, develop their independence, increases self-esteem and self-confidence, can reduce challenging behaviours and can even improve enjoyment of school and academic achievement, whilst reducing stress and improving quality of life for the whole family

There are potential benefits to the NHS when children and young people improve in this area. Good bladder and bowel nurse-led care makes a huge difference to quality of life but can also help preserve valuable NHS resources. It can reduce the need for outpatient appointments with consultants and attendances at accident and emergency departments, as well as admissions to hospital for related problems.

Davina's Role at Bladder & Bowel UK

My current role with Bladder & Bowel UK includes providing information to support individuals who have questions about toilet training, day and night time wetting, constipation and soiling, as well as using products to contain incontinence. I undertake teaching to health care professionals as well as families, work with national organisations and corporate colleagues to support and promote specialised bladder and bowel care. It is interesting, varied, rewarding and no two days are ever the same. I feel very privileged to be able to work with wonderful colleagues both at Bladder & Bowel UK, in the NHS and from companies and groups across the UK as well as with the very special individuals and families who use our helpline services.

Get in Touch with Bladder & Bowel UK

If you would like to speak to one of our Specialist Nurses via our confidential helpline, please complete a web form: <https://www.bbuk.org.uk/helpline-enquiries/> and a member of the team will get back to you.

Living with Ulcerative Interstitial Cystitis: Lucille's Story



Lucille Whiting, Founder and Lead Designer Maker at Sophia Alexander Gold Fingerprint Jewellery, tells Bladder & Bowel UK about her journey of living with ulcerative interstitial cystitis.

19 Years Before My Diagnosis

I've suffered from what were thought to be recurrent bladder infections since my late teens, often needing several courses of antibiotics in a space of a month. I was both working and attending college at the same time, and was very conscious of being unreliable, so my flares were both a worry and an inconvenience.

If an infection flared while I was actually at work, I'd go and get antibiotics, drink as much water as I could, lie down in the tearoom for a while and then return a few hours later when I started to get some relief.

I adapted, wearing loose clothing, drinking a lot of water and making sure I had always had a bottle of Potassium Citrate solution to hand. These things all helped, but nothing stopped the seemingly regular flares.

At one point, my GP referred me to the local hospital to have scans on my bladder to check that it was emptying properly, but when those scans showed nothing abnormal, I carried on the same as before.

The infections just became part of my normal way of life.

Starting a Family, a Business and Recurrent Miscarriage

A few years later, at the age of 22, I gave birth to my first son. I'd had one very early miscarriage, but this was considered normal, albeit unlucky.

After a 6-month maternity leave, I returned to work part-time. The part-time hours, although very welcome, started to take their toll. I always seemed to be rundown and my flares were becoming more frequent, so after a few months, I decided that something had to change. I handed in my notice and set up a small, independent keepsake business casting baby hands and feet in bronze. It seemed like the perfect solution. I could largely work from home, I loved working with families and babies, and I had a strong background, training and experience in metalwork.

Fast forward a few years and now with 2 small children, it was becoming increasingly obvious that although the work was wonderful, it had a very local reach. Most of my customers were travelling a long way to reach me. Some as far as far as Central London. I was getting a lot of requests to provide home visits

and I was increasingly unable to manage the travelling.



Then I started to suffer from recurrent miscarriage and although I was thoroughly investigated, no cause was ever found. Over 13 years, I had 5 children and 9 miscarriages. I needed to adapt again.

In addition to wanting home visits, clients had also started asking for fingerprint jewellery. This time, it really was perfect. I totally fell in love with working in precious metal and the jewellery could be made remotely, meaning I could carefully pace myself to avoid difficult flares. It was a fine balance and a challenge, but it was doable.

A Turn for the Worst

A few months after the birth of my 5th child, my pain returned with a vengeance. It never went away again.

I didn't have bad flares anymore, just a constant indescribable pain. Like a bad urine infection, that never went away, day or night.

I was adding sodium citrate crystals to my drinking water, but in such huge quantities that it made me sick. By this point, I had built up a resistance to several antibiotics. At least 5 first-line antibiotics hadn't worked in years, but this time, nothing worked or brought relief. It was relentless. That was when I realised that the flares were not infections.

After one particular unsuccessful course of

antibiotics, a local doctor took a urine sample for testing – and found no infection. I made a phone appointment with an on-call duty doctor. To me, the response was horrifying. No infection, so no antibiotics. It was just bladder pain. It was common and there was nothing to be done. After the initial panic had subsided, I made an appointment with my own family GP who has always been wonderful. As soon as he heard what was going on, he immediately referred me to a Urologist.

Finally, after just over a year of pain and almost 20 years of flares, I had a cystoscopy which diagnosed Chronic Ulcerative Interstitial Cystitis.

So what is Ulcerative Interstitial Cystitis?

Put in the simplest terms, Ulcerative interstitial Cystitis, or IC is an invisible, lifelong chronic condition that affects the lining of the bladder.

There are different stages and different severities which is why patients experience everything from random one-off flares, to constant pain.

One of the biggest problems in the early stages, is misdiagnosis because it presents with exactly the same symptoms as a urine infection. The crucial difference being that no bacteria is present in the urine when tested.

The bladder wall becomes inflamed and red patches can be seen during a cystoscopy. These areas can bleed which explains the presence of blood in patient's urine. These patches are known as Hunner's patches, lesions or ulcers (even though they don't resemble ulcers at all).

Symptoms also widely vary, which again, can make diagnosis difficult, but they most commonly include increased urinary frequency, urgency and in my case, pain. For the patient, Interstitial Cystitis can cause severe limitations. It's painful, debilitating and disruptive. It's estimated that over 60% of I.C sufferers find their condition severely impacts their ability to work full time, yet at the same time, it's not classed as a disability.

At this present time, there is no known cause for I.C, although it has strong links to several autoimmune conditions. There is no cure and there are no standardised treatment. Symptoms are managed with medication.

I take a combination of nerve blockers and pain killers to make me less aware of the pain, but they do not remove it entirely and there are unwelcome side-effects.

Over time, I have found that avoiding certain foods and drinks can help, but again, everyone is different, so what negatively impacts me wouldn't necessarily impact another sufferer in the same way.

Slow Growth, Quiet Resilience and Learning to Thrive

Over the course of the last two decades, whether I've liked it or not, I've had to accept that my condition physically slows me down and it has undoubtedly shaped the way my life has turned out. I've rebuilt a different kind of life. I've had to learn my limits, learn to pace and learn to work with what I've got.

My main symptom has always been pain, but pain is exhausting, both physically and mentally. When my pain became permanent, I had to learn to adapt to my new normal quickly. Interstitial cystitis won't stop me getting where I want to go, I just have to try a little harder than most to get there.

So here are a few things I wish someone had told me couple of decades ago:

Treatment plans and medication

If you are not happy with your diagnosis or treatment plan, you can ask to be seen another doctor, consultant, medical team or hospital. I have literally walked out of a consultant's office who told me I'd have to "just learn to live with the pain", phoned my own GP and got an alternative plan put in place. Never ever feel that you are stuck. I'm currently under a team and find having input from several consultants with different specialities absolutely invaluable.

Staying Calm in a Crisis

Chronically ill people are by far, some of the most resilient people I have ever met. There is no good way to find out that you are never going to get better. Being told that this is your new-normal is a lot to accept. You have to be a pretty positive person to bounce back from that, but we do! I have skills I never had before. I'm now much better able to deal with stress, setbacks and life's bombshell moments.

Have a Goal That Keeps You Looking Forward

Always having something new to work towards helps me to stay positive. For me, I enjoy learning new skills, training to do new things and building my independent business. I love my work, but of course, goals are uniquely personal to everyone.

Being Realistic

I can achieve almost anything I put my mind to, just at a much slower pace. I've have had to accept that bad flare days will happen and I'm not going to be able to work 14 hours a day, 7 days a week like I could 20 years ago. There will be days when the illness wins. I don't like it, but I've come to terms with it. Establishing good daily habits is crucial to keeping a healthy mindset and making steady progress.

I now try to always set myself one or two really short, manageable tasks each day, so that even if the whole day goes awry, or I feel terrible, I still feel like I've done something positive and moved forward.

Spoon Theory and Being Organised

Being permanently unwell is tiring and uses up a lot of energy – and I only have a certain amount of energy. I find planning ahead using both apps and physical planners helps to stop me becoming overwhelmed. I make a lot of lists! I prioritise my children and my work. I have to be really honest about what actually needs to be done. What's urgent and what can be left? I tick off what I can, and I'm always prepared to carry things over.

Work, That Works for Me

For a lot of people, having the ability to work flexibly

becomes vital. If you are at the beginning of your chronic illness journey, plan for the future. What will life look like if you can't continue to do a normal 9-5 job? My company was born out of a "when life gives you lemons" situation, but it's been a lifeline. It's allowed me to work around my deteriorating health, whilst caring for a young family and building something I'm really passionate about.

If being self-employed isn't something you'd like to do, what career moves could you make? What training do you need to look into? Increasingly, there are many jobs that allow you to work from home, more so since recent Covid-19 crisis made it, so the entire world was made to work from home.

Unsolicited Advice

Telling people that you have a chronic illness can be an interesting chance, you will suddenly find yourself on the receiving end of an unnerving amount of unsolicited advice. Family, friends, random people in hospital waiting rooms. You name it, everyone now is a leading expert on how you should be curing your incurable condition.

Now, don't get me wrong, it's lovely that people care and sometimes it can be useful, but a lot of the time, it oversteps a line and becomes invasive. How you deal with unsolicited advice is totally up to you, but personally I'd nip it in the bud really early on because no, neither turmeric or essential oils will cure my I.C. no matter how many times people suggest them.

Comparison-itis

You really can't compare yourself to anyone else. It's not a level playing field. It's so hard when you feel like you've been left behind and it often feels like everyone else is progressing faster and achieving more.

Facebook updates and those perfect Instagram squares have a lot to answer for! Social media can sometimes create the illusion of perfect lives but stop a second. You're being shown a snapshot of

what people want you to see. Chances are, you do it too!

You've just never thought about it that way before. Do what you can, achieve what you can at your own pace. Focus on you. That's all that matters.

Chronically Isolating

Being chronically ill can be isolating. I stopped being able to attend conferences and networking events years ago, so I know exactly how difficult it can be to 'just go and meet people'. I do have good remote working relationships with some incredible people, but for the past few years, I've found online membership communities, full of like-minded people, invaluable. I have conversations with people across the globe.

One thing a lot of people don't realise is that there are some really active chronic illness communities on platforms like Instagram, or if you don't like the idea of that, use the hashtag search facility to look up things you're personally interested in.

Slow Living and Self Care

A lot the time we can pretty mean to ourselves. We're unsympathetic, we give ourselves no time-off and we expect way more than we would from anybody else. Particularly people who are feeling pretty rubbish a lot of the time!

Taking Care of Your Mind

Taking care of your mind, as well as your body shouldn't be a luxury or an afterthought. Unless burning out or feeling a lot worse is what you're shooting for, it's important and necessary.

We now live in a world where we're always switched on but try your hardest to slow down and set some time aside for yourself at least semi-regularly. It makes the biggest difference. A small amount of time each day is perfect (see point #4), but anything is better than nothing.

Visit: <https://sophia-alexander.com/>

**Lucille Whiting, Founder and Lead Designer,
Sophia Alexandra Jewellery**



What's New?

Bladder & Bowel UK have free, downloadable resources on the website for you, your family, or carers to access. We are currently expanding our online resources and will be keeping you informed about any updated or new information leaflets that are added to the website.

Resources

In our children's resources area under toilet training, you will see there is an updated version of the Toilet Training: A Skill Development Programme document.

Many families are anxious about toilet training. However, for those whose children have developmental or learning disabilities this milestone may seem unobtainable. However, clinical experience shows that most children can learn the skills needed for toilet training and can successfully become clean and dry. Visit: <https://www.bbuk.org.uk/children-young-people/children-resources/> to see more.

New Enquiries

Bladder & Bowel UK receive several enquiries, regarding the use of 'Continence Products during Menstruation'. We thought it might be helpful to put together an information leaflet which talks about:

- How continence products work.
- How sanitary protection differs from a continence product.
- Some suggestions to help the decision about whether to use sanitary protection inside a continence product.
- Additional Information.

To access more information, please visit:

<https://www.bbuk.org.uk/wp-content/uploads/2021/04/The-use-of-continence-products-during-menstruation.pdf>

We have an additional two new resources on Continence Products, which can be found in both the adult and children's resource area:

- 'How to Get the Best out of Continence Products'
- 'Disposable Products to Contain Incontinence'.

Both these resources have practical advice and helpful information and includes information on:

- Where you buy products from and top up supplies.
- NHS product provision explained.
- Change in need, or the product no longer works.
- Storage, fitting the product, types of products and other helpful tips.
- Changing and disposal of used products.

For further information, view our resources:

ADULTS

CHILDREN

All in a Day's Work: Managing bladder and bowel problems at work



We know from the BBUK helpline that there are people who struggle to manage their bladder and bowel problems at work. You may work with someone who has problems without knowing about their difficulties. There are simple things that employers can do to support people to manage their bladder or bowel difficulties when they are at work.

Bladder and bowel problems in people of working age are more common than you may think:

- It is estimated that over 1 in 20 women aged between 15 and 44 years and up to 1 in 7 women aged between 45 and 64 suffer with bladder problems.
- Over 1 in 33 men of working age have bladder problems.
- It is estimated that 1% of the adult population have bowel problems

The good news is that a lot can be done to manage, improve and sometimes cure these difficulties. Bladder and bowel problems can have a huge impact on a person's quality of life. Bearing in mind people spend up to 60% of waking hours in work, it is important to feel comfortable, happy, stress free and supported in the work environment.

Despite being so common, bladder and bowel difficulties are often hidden. People may suffer in silence, feeling too embarrassed to talk about such

a personal problem. As a result, many don't get the support from their employer. If an employer was made aware that a member of staff has a problem, they could make changes to working practices and the environment; they may also offer emotional support. An employer can't help if they don't know about the problem.

Let's put things into perspective:

- In company with 3,500 employees (2,000 women and 1,500 men), potentially 45 men and between 100 and 285 women depending on age may have bladder or bowel problems.
- In a company with 65 employees (5 men and 60 women), potentially between 3 and 8 women depending on age may have bladder or bowel problems.

Do these comments sound familiar?

The people who contact the BBUK helpline speak openly about the challenges they face at work.

Do you have the same or similar problems?



Do you work with somebody who may have a bladder or bowel problem?

"Very, very difficult to take pads to the toilet for changing in an office environment and lack of disposal bins makes things more difficult."

Pharmacist

"Going away on courses is worrying." **Secondary School Teacher**

"Travelling with colleagues is a problem. Always afraid of searches etc. at the airport."

Co-Director/PR Agency

"I was leaving my desk every half hour. This does not look good at work."

Ex Science Teacher

"I have been unable to leave my place of work when necessary because I have been on my own with the children. I have eventually had to go home in a mess and very distressed."

Nursery Nurse

"I was leaving my desk every half an hour. This is not good work and of course it makes it hard to advance in the company."

Barman/waiter - ex Paralegal

"On a bad day, it is very hard to concentrate on the business in hand whilst being aware of 'trouble down below!'"

Business Strategy Consultant

"My need for disposable diapers got out and everything went downhill. Construction workers aren't the most-easy going bunch. I lost the respect of the crews and so couldn't do my job anymore."

Construction Manager

Should I tell my manager? Should I tell my colleagues?

Some people who told their colleagues or employers about their continence problems have had a negative response.

However, there are employers and colleagues who have been very supportive and understanding. Consider who you could share your difficulties with, who is most likely to support you. You can discuss this in more detail with the staff on the BBUK helpline.

The people at work who have the most influence to help you manage your difficulties are your Manager or Employer. In larger organisations the Occupational Health Nurse or Human Resources Manager may be the best people to help you. This is part of their job - they have a duty to help under The Equality Act 2010.

People with bladder or bowel problems may not consider themselves as disabled. However, the Act applies to people who are incontinent.

Some people will never tell others about their bladder or bowel problems. They may feel that the subject is taboo, embarrassing or private. However, they may still need your support in the workplace. There are other ways to make employers and colleagues aware of what they could do to help:

- Leave a copy of this article lying around.
 - Email a copy to your HR department.
- highlighting you thought they may find it useful.



Some people found it was much better when they told their boss:

"I made my new employer aware of my incontinence prior to starting work and found him very understanding..."

Buyer

"I have found a company where only the owner and office manager know and neither of them have a problem with it..."

Construction Manager

"When I returned to work after 13 months sick leave for a bladder operation, the personnel officer was supportive. A bidet was installed."

Ex Residential Childcare Officer

"In fact, many people go out of their way to be supportive."

International Sales Manager

"I have no problem with my employer or colleagues. Being open and honest about everything from the beginning has been a great advantage."

Welding Inspector

"The two ladies I work with know the full extent of my incontinence... they have been brilliant!"

Accounts Clerk

"Only one of my work colleagues is aware of my problems and when she found out she was very helpful and supportive."

Pharmacist

"Without my staff's support it would be impossible to continue my job."

Teacher

There are things that can help with managing bladder and bowel problems:

Products, medical treatment and emotional support.

There are thousands of products available in the UK to help people manage their continence problems. Even if someone has tried one of these products in the past without success there are new, improved products being developed all the time. These may be much better than the old ones.

- Pads • Pants • Sheaths • Catheters • Urinals and much more

The staff on the BBUK helpline can advise on a range of options that may be very discreet and suit the work environment. You can contact them on 0161 214 4591.

If you have not sought help for your bladder or bowel condition, BBUK can provide you with information about your local continence service. This specialist service can provide information about medication and treatments available.

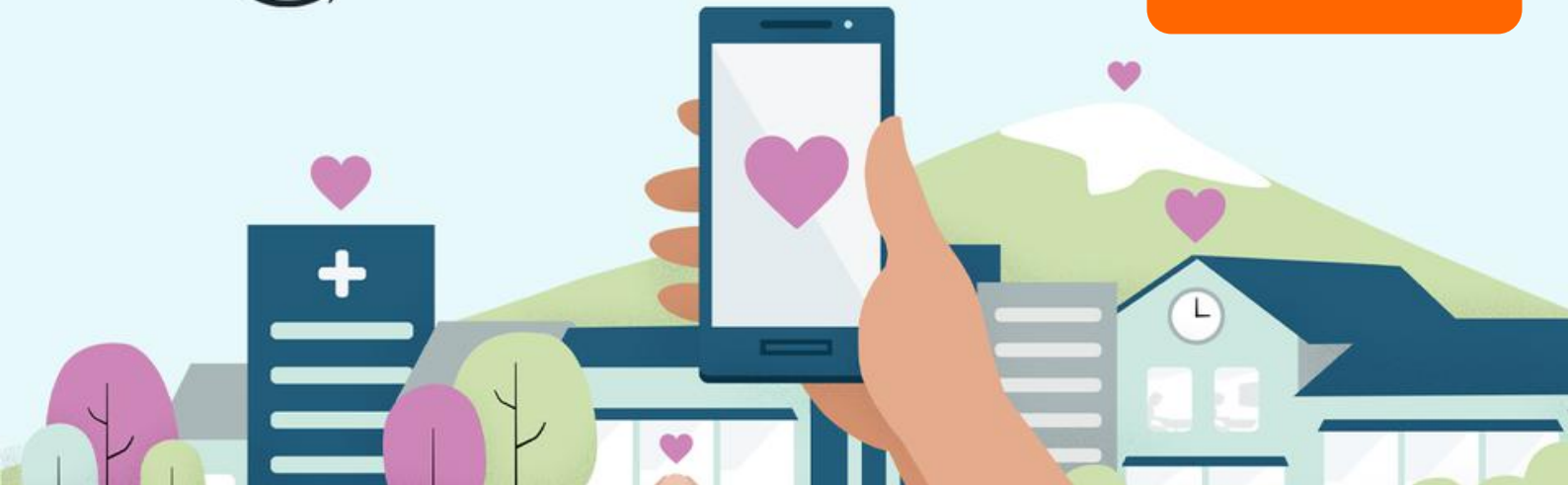
To make a helpline enquiry today, visit:
<https://www.bbuk.org.uk/helpline-enquiries/>

Donate to Bladder & Bowel UK with AmazonSmile

Turn on AmazonSmile in the Amazon app to generate donations.

smile.amazon.co.uk

[CLICK HERE](https://smile.amazon.co.uk)



When you purchase items on AmazonSmile, a small donation will be given to Bladder & Bowel UK (part of Disabled Living) at no extra cost to you!

Visit the Continence & Stoma Products Section on the Supplier Directory

There is a section on the Disabled Living Supplier Directory dedicated to continence and stoma products. In addition there are a wide range of categories providing information about companies and organisations that provide equipment, products and services to support disabled children, adults and older people.

You'll find the Supplier Directory on our website homepage: www.bbuk.org.uk



**Supplier
Directory**

[CLICK HERE](http://www.bbuk.org.uk)

Shop Online with Bladder & Bowel UK Equipment and Products to Make Life Easier



**OVER 250,000
ITEMS IN STOCK!**

Speak to continence specialists
for free impartial help
and advice on:
0161 214 4591

Offering you choice from a wide range of manufacturers including mobility aids, daily living products, and continence suppliers together with telecare and telehealth equipment.

www.bbuk.org.uk/online-shop

Tel: 0161 214 4591



Bladder & Bowel UK

Supporting people with bladder and bowel problems

part of Disabled Living

in partnership with



Dementia and Continence



Find out about new technologies for individuals and those caring for people with dementia experiencing bladder and bowel issues.

Having good bladder and bowel health makes an essential contribution to an individual's wellbeing and overall health at every stage of life. This involves being in control of one's bladder and bowel emptying or, where this is not possible, optimising bladder and bowel treatments and longer-term management strategies, to minimise the impact of incontinence is equally important.

Poor continence care can have a negative effect on an individuals' physical, emotional, and financial wellbeing. Early identification and continence assessment, by an appropriately trained and skilled professional, is key. Unfortunately, many people are not aware that there are specialist NHS bladder and bowel services available to access.

Bladder & Bowel UK commonly support individuals, as well as their families and carers, by providing information, support, and advice and signposting to services.

We are also often asked by product developers or inventors of new technologies, to reach out to yourselves and seek public opinions, encouraging people to share their experiences and most importantly voice their opinions and views, which

may impact and influence the development phases of new projects. It is paramount that public, patient and clinician views are actively supported so that the opinions of all stakeholders are considered.

For an individual living with dementia, bladder and/or bowel issues can present several challenges, not only for the individual, but for those who support them. It is essential that every effort is made to overcome, treat, and manage incontinence effectively, to improve the quality of life of the individual and their carers.

How many people can be affected with continence issues ?

It is suggested that 4-7% of women under 60 years old and 4-17% of those over 60 have daily episodes of urinary incontinence. Furthermore, prevalence figures increase with age. It is also estimated that 61% of men in the general population experience lower urinary tract symptoms.

6.5 million adults in the UK suffer with some form of bowel problem with an estimated 1-10% of adults being affected by faecal incontinence. Nearly two-thirds of these individuals also experience urinary incontinence.

It is well documented that the incidence of dementia is increasing as the population ages. It is estimated that 850,000 people are living with dementia in the UK and this figure is projected to be 1.233 million people by 2030. One study suggested that 53% of people with dementia can experience incontinence, compared to 13% of those without dementia.

Effect of incontinence on individuals and their carers

The effect of incontinence on individuals and their carers can have a huge effect on quality of life, relationships, and ability to continue caring for their relative in their own home, to name but a few. It is not uncommon to hear that adult incontinence produces a marked loss of self-esteem, loss of independence and depression. In older people, incontinence and associated bladder and bowel disorders may also be associated with physical problems such as skin breakdown, falls, urinary tract infections. These, in turn, can often cause or escalate confusion. Confusion can also lead to falls, as well as head injury or fractures, requiring hospital admission. Incontinence has also been cited as a significant reason for admission to a care home.

Managing a person's continence can restore their dignity, regardless of cognitive state. Enabling people to stay at home longer, maintaining independence, whilst being supported, is a key aim.

New technologies

Bladder & Bowel UK have been asked to engage with the public to seek their opinions on new innovations, including product development or the development of new technological support systems to help and enable individuals with bladder and bowel issues.

Any new development has a potential, if taken forward, to present a real opportunity to improve quality of life, health, and wellbeing for people with dementia, who also have bladder and/or bowel health issues.

Bladder & Bowel UK have recently been involved with a project which has potential to not only help improve continence care for those with dementia but enable individuals to access information to support and promote independence of their continence needs.

During the pilot study, we were able to engage remotely with health care professionals, service users and family members to seek their opinions regarding this new proposed technology to support individuals with dementia who experience bladder and/or bowel issues, and those caring for them.

The feedback we received was valuable. Some of the comments included:-

- The information will be provided in 'real time' over a longer time frame, offering more accurate data collection.
- The idea and concept are good.
- Useful for holistic assessment.
- I think the visuals overall are easy to identify with.
- It will improve health and well-being of individuals.
- I think it would enhance the care given.
- This project is about looking to the future for the care, interventions, and support of people with early onset dementia.
- When it is developed can really make a difference to a person's dignity, their quality of life and impact on carers.
- Like the three-pronged approach involving patient and carer alongside the clinician.

Investment into new technologies to help address the dementia challenge will be welcomed as positive steps forward. This will help improve and transform the lives of those living with dementia and those who care for them.

Can you help us at Bladder & Bowel UK?

We would be keen to see further development of this project and would love to hear from you. Please consider participating in any future developments, sharing your views and opinions.

**Karen Irwin, Service Manager/Specialist Nurse
Bladder & Bowel UK**

The MultiCath Trial - New Research Into Intermittent Catheterisation



Intermittent catheterisation (IC) is an important management option for people who cannot empty their bladder naturally. Problems with bladder emptying may be a consequence of neurological disease or spinal cord injury, or, for men, an enlarged prostate causing outflow obstruction. IC avoids the need for an indwelling catheter and associated complications.

People needing IC are taught how to insert a catheter, drain the bladder, and then remove the catheter. Today, single-use, disposable catheters are the most commonly used option in the UK. When clean IC was introduced to the UK in the 70's however, plain, uncoated catheters were routinely washed and re-used. This is still practised by some people in the UK and, more extensively, in other countries, and for decades sterilisable metal catheters have been an option for women.

Over the years new types of catheter have been developed, for example, with special coatings designed to make catheterisation easier and safer (find out more about different intermittent catheters in the [Continence Product Advisor](#)).

Such catheters are all manufactured and licensed for single use only.

Reusable silicone catheters are now being made for both men and women but are not yet available in the UK. Currently there is considerable uncertainty as to whether any particular catheter design is better than another for preventing urinary tract infection or for other important factors such as urethral trauma or quality of life.

Combining the use of re-usable and single use catheters (mixed use) may be attractive to some users because it potentially offers the advantages of both catheter types. For example, using a reusable catheter reduces the number of catheters required when away from home, and may have environmental and cost benefits as fewer are thrown away (each year in the UK approximately 50,000 mainly plastic catheters contribute to landfill and, in the USA,

research suggests that, annually, the waste from catheters is enough to fill 80 Olympic size swimming pools). Using a single-use catheter by comparison may be more convenient, for example at work, and requires less preparation and no cleaning.

The purpose of the Multicath programme (funded by the National Institute for Health Research (NIHR)) was to develop a cleaning method for reusable catheters and then to test its safety, effectiveness and user acceptability in a trial. We worked with IC users to develop the method, based on soap & water and Milton, and users tested it by cleaning and re-using their catheters multiple times. When their catheters were examined under a microscope, we found that the cleaning method had effectively removed bacteria without affecting the catheter surface and the IC users reported that the method was acceptable to use. We have also interviewed IC users to understand the factors that are important to them; for example, how to manage when away from home.

In the Multicath trial we are now aiming to test if mixed use is safe and acceptable compared with single use only when used by a larger group of IC users (520 men and women).

Participants will be asked either to try mixed use or to continue with their usual single use catheter only. This is decided randomly by computer. Throughout the study we will be in monthly contact with participants to find out about their experiences of catheter use and to

collect urine specimens. We provide the equipment required for mixed use including the reusable catheters – see pictures.

Do you use intermittent catheters? Are you interested in government-funded research to try out new options for catheter users?

If you are over 18 years old and use intermittent catheters to empty your bladder then you may be eligible to take part in the MultiCath trial and we would like to hear from you.

Please contact Margaret Macaulay, Research Nurse, for an informal chat:

Tel: 07960 136241 or email:

m.macaulay@soton.ac.uk or please visit the trial website www.soton.ac.uk/multicath for further information.

Thank you!

Listen to IC users talking about their experiences of reusing catheters

This refers to independent research funded by the National institute for Health Research (NIHR) under its Programme Grants for Applied Research (PGfAR) (Grant Reference Number RP-PG-0610-10078). The views expressed are those of the authors and no necessarily those of the NHS, the NIHR or the Department of Health.

Margaret Macaulay, Senior Research Nurse & Multicath Project Manager



Disabled LIVING

THIS IS WHO WE ARE AND WHAT WE DO....

DISABLED LIVING

A charity which provides impartial information and advice about products, equipment (assistive technology) and services for disabled children, adults, older people, carers and the professionals who support them. We have a range of services which you can access via our helpline, through the website or at our Kidz to Adultz exhibitions.

www.disabledliving.co.uk

EQUIPZ

The team comprises occupational therapists, trusted assessors, moving and handling specialists, physiotherapists, nurses and continence specialists. We respond to enquiries via our helpline and website. Some people opt to visit the Disabled Living Centre based in Manchester for a free equipment assessment.

Helpline: 0161 214 4590

BLADDER & BOWEL UK

The team provide information and advice for children, young people and adults with bladder and bowel problems. We provide a confidential helpline managed by a team of specialist nurses and knowledgeable information staff. In addition, the website offers a wide range of downloadable free resources.

Helpline: 0161 214 4591

www.bbuk.org.uk

KIDZ TO ADULTZ EXHIBITIONS

We organise the largest FREE UK exhibitions totally dedicated to disabled children, young adults, their families, carers and the professionals who support them, with over 100 exhibitors at each event. We currently deliver 5 events nationally in Coventry, Farnborough, Newport, Edinburgh and Manchester.

www.kidzexhibitions.co.uk

TRAINING

We run a comprehensive training programme for professionals and carers. Most of our courses are accredited by Open Awards and others provide CPD opportunities. Our training courses can be 'tailor made' to suit your organisations requirements and can be delivered throughout the UK.

www.disabledliving.co.uk/training



Kidz to Adultz Magazine Issue 11 - Out Now!



We have introduced you to all of Disabled Living's services.

We also publish the Kidz to Adultz Magazine which is full of interesting articles to support children and young adults with disabilities and additional needs.

We would like to hear from you if you have an article we can publish to support children and young adults with bladder and bowel problems.

Web: www.kidzexhibitions.co.uk

Tel: 0161 214 4592

Email: info@disabledliving.co.uk

[CLICK HERE TO READ ISSUE 11](#)

Issue 12 available on 24th May!

It's Showtime!

Save the date for our future events...



VENUE TO VIRTUAL

COMING SOON!

June 2021
Online

SOUTH

NEW DATE!

Tuesday 17th May 2022
Farnborough International Exhibition
& Conference Centre, Farnborough

NORTH

NEW DATE! NEW VENUE!

Wednesday 17th November 2021
ACC Liverpool, Liverpool

WALES & WEST

NEW DATE! NEW VENUE!

Thursday 7th July 2022
The International Convention Centre
(ICC), Newport

MIDDLE

NEW DATE!

Thursday 17th March 2022
Ricoh Arena, Coventry

SCOTLAND

**NEW DATE! WE'RE BACK!
(HELD EVERY 3 YEARS)**

September 2022
Royal Highland Centre, Edinburgh

RESEARCH ALERT !!!

Researchers at King's College London are conducting a study to develop a manual to guide prevention and treatment of incontinence associated dermatitis (IAD) – sore skin as a result of urinary or faecal incontinence.



WANT TO GET INVOLVED?

- If you have experienced or are experiencing incontinence (with or without IAD) or cared/care for someone with incontinence (with or without IAD)
- are aged 18 years old or over
- are willing to participate in four online workshops (one every 3 months) using Microsoft Teams

Please contact Sue or Sangeeta for further information
email: sue.woodward@kcl.ac.uk
email: sangeeta.sooriah@kcl.ac.uk

Have you read our latest edition of our highly commended Connect magazine?

Featuring all our exciting news, updates and stories from our inspiring stoma and continence customers, Connect is available quarterly to all our customers as part of our award-winning service.



Get in touch today to find out more about our service and to request your copy:



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Loo of the Month

**Would you like to
feature here?**

Do you have a product or piece of
equipment you would like to
highlight? We have space
available in upcoming editions.

Email:
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