

Your Bladder Health

Summer 2020

Issue 93

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Sacral Neuromodulation - A Pacemaker for the Bladder by Professor Hashim Hashim

The Pelvic Floor Muscles and The Bears by Jilly Bond

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We welcome contributions from members and medical practitioners.

For advertising and article contributions please contact the BHUK team on 0121 702 0820. Submissions to arrive no later than **30th September 2020**

Bladder Health UK reserves the right to edit any correspondence received

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Warm Welcome



Welcome to the summer edition of 'Your Bladder Health' which comes to you via email during the Covid-19 pandemic.

We hope you and your loved ones are keeping safe and well during this national crisis!

The BHUK Team has continued to work throughout remotely, from home. We are thankful that none of us has as yet, had the virus!

We would firstly like to thank all of you who did so much this year to sell raffle tickets for our annual draw despite the challenges this presented! We are truly grateful!

Unfortunately, our members event in Sheffield, planned for autumn has had to be cancelled due to the pandemic. We do hope that we will be able to re-arrange it for next year once the situation changes.

We hope you will enjoy the range of articles we have provided in this magazine.

On Page 6 we find out from another sufferer what it is like to live with a supra-pubic catheter and our nurse, Paula Pitcher gives us some great advice on caring for an SPC. Professor Hashim from North Bristol

NHS Trust tells us about the new rechargeable SNS devices for overactive bladder in his article on page 14

On page 22 Jilly Bond talks to us about the impact of a heightened arousal level on the pelvic floor and a painful bladder.

On page 32, CBT therapist Jennie Spain talks about Acceptance & Commitment Therapy which can make living with chronic pain a little easier!

Finally, we are delighted to share that our new website will be launching on 27th July 2020! Please do come and visit the site and take advantage of the up-dated range of information it provides.

We hope you enjoy the rest of the summer even if it is only from the back garden!

BHUK Office Team

This magazine is produced and printed with the aid of an Educational Support Grant from Aspire Pharma





BHUK News

Spring Raffle Winners



Congratulations to the lucky winners of our Spring Raffle!

1st Prize - £250 - Mrs P M Armstrong

2nd Prize - £150 - Will Whyler

3rd Prize - £100 - Pat Lewton

This year we would like to say a special 'thank you' to all of you who bought tickets despite the challenges that presented during the Covid-19 pandemic. In total we raised £3,402.00 an increase on last year's figure of £2,634.00 which will all be put towards supporting the charity!

Annual General Meeting 2020

Unfortunately, this year's AGM was cancelled due to the Covid-19 situation and the requirements for social distancing.

We would like to thank all members who returned their voting slips and can advise that on the basis of these, we were able to re-appoint all Trustees on the committee to serve for another year.

We will be re-arranging the AGM next year but keep in touch regularly with our Chair and Trustees via audio call.



STUDY DAY FOR MEMBERS - SHEFFIELD

Thank you to those members who registered their interest in attending a study day in Sheffield in the Autumn. Unfortunately, due to the on-going situation with Covid-19, we have had to postpone this event. We will notify everyone of a revised date when we are able to go ahead.



ADVICE LINE - 0121-702-0820

Our Advice Line is open at present during the Covid-19 crisis for those who need a little extra support. The line is very busy, so please do leave us a message if you can't get through and we will call you back within 48 hours.

Covid-19 Statement

At the onset of the pandemic, we received a number of calls and emails from BHUK members concerned about the potential impact of Coronavirus on their symptoms.

We sought guidance from our Medical Panel who advised that there is no evidence that those suffering from IC/BPS or chronic or recurrent UTIs would be at any greater risk of complications from

Covid-19 than the general public unless for any reason they are immunocompromised.

They also advised that there was no evidence that being on long or short-term antibiotics increased the risk of complications from viral respiratory infection but if a patient is weakened by a viral infection, they can become more susceptible to secondary bacterial infections.

Do We Have Your Up-To-Date Email?

During the present crisis with Covid-19, please help us to reduce costs by ensuring that we have your correct email address.

Also please respond to our initial request to renew your membership as quickly as possible to limit the number of reminder letters we need to send out.



KEEP IN TOUCH

You can keep up to date with what's going on at BHUK by following us on social media! We have platforms on Facebook, Twitter and Instagram.

facebook.com/bladderhealthuk
twitter.com/@bladdersupport
Instagram.com/bladderhealthuk
www.bladderhealthuk.org





Living With A Supra-Pubic Catheter By BHUK Member Lisa Barrett



Lisa Barrett

BHUK member, Lisa Barrett was diagnosed with Fowlers Syndrome in 2014, having already been diagnosed with Interstitial Cystitis in 2001. She had previously suffered from recurrent UTIs and retention severe enough to cause her hands and feet to swell.

The introduction of a supra-pubic catheter improved her quality of life immeasurably. In this article Lisa shares her journey and the process she went through to adapt to her new normal.

Constant retention of urine was ruining my life! I was in hospital every few weeks with pyelonephritis (kidney infection) and even had sepsis twice. At times things were so bad I wondered if I might die!

My consultant showed me how to self-catheterise to ensure that I could empty my bladder and referred me to a consultant at Southmead Hospital in Bristol for further tests to establish why I could no longer pass water.

Fowlers Syndrome

The consultant at Bristol performed Video Uro-Dynamics to study the pressure and flow in the lower urinary tract. Subsequently, he diagnosed me with Fowlers Syndrome, a cause of urinary retention (inability to pass water normally) in young women. Urinary retention in young women is

uncommon but when it occurs it can be very debilitating. In Fowlers Syndrome the abnormality lies in the urethral sphincter's failure to relax to allow urine to be passed.

He explained that the condition was almost certainly at the root of the constant infections as my inability to empty my bladder was leaving a stagnant pool of urine in my bladder making me prone to infection.

The consultant advised me that although there was no cure for the condition, there were some options which would help me to live positively with it. He suggested putting me forward for a treatment called Sacral Nerve Stimulation (SNS). This would involve implanting a device just beneath the skin in the upper buttock which would stimulate the nerves which control the bladder.

Sacral Nerve Stimulation

Two months later, I received a phone call to invite me to come in for a trial of the new device. The hospital explained that the operation would be carried out under local aesthetic and would encourage my sphincter muscle to begin working again.

Medtronic Interstim Device



I felt very apprehensive but nonetheless went ahead and had the operation done as a day patient. I went home the same evening with instructions that I would have to wait two weeks to see if it had been successful in ensuring that my bladder would empty. Unfortunately, despite putting the device on the highest setting, my bladder still would not empty - I was devastated.

Shortly afterwards I returned to Bristol to have the trial device removed. My consultant then suggested an operation to insert a supra pubic catheter (an in-dwelling catheter that can be inserted into the bladder through an incision in the stomach). The catheter would drain into a bag attached to my leg or alternatively, I could opt to have a flip-flow valve on the end of the catheter which would

enable me to empty my bladder intermittently.

Supra-Pubic Catheter

I knew this really was my best option but I certainly wasn't looking forward to it! I remember having thoughts about how my body image would change. Would I smell of urine? What if the bag were to split? Would I ever feel like me again? I found out in due course, that all these feelings were normal and no leaflet would answer these questions for me.

I felt so lucky to have the support of Bladder Health UK during this challenging time!

The Operation



On the day of the operation, my consultant explained that I would be given some pain medication while under general aesthetic as I would probably feel some pain and discomfort afterwards.

I woke up a few hours later and the nurse explained that my bladder was



Living With A Supra-Pubic Catheter By BHUK Member Lisa Barrett

quite badly damaged by the constant infections. She explained that the Supra Pubic Catheter was just below my pubic bone. I felt re-assured that the operation was over and a few hours later I was allowed home. The nurse had ordered all the catheter supplies that I would need to get me through the next few weeks and explained to me that a district nurse would come out to see me during the next few days to explain to me what I would need to order each month and where I could get these supplies from.

Growing Confidence

I felt quite numb for a few days after the procedure but once I knew how to empty the bag and attach a night bag on my own I began to feel more confident.

My first catheter change at my local hospital was painful but I was told that the next change would be done in the comfort of my own home and that made me feel a little better.

Over the next twelve weeks I became more confident and was delighted that I had not had to cope with retention or an infection for three months! It was at this time that my daughter, who was only six at the time, said to me

“Mummy - you don't have to live at the hospital any more!” It was then that I realised how much my illness had affected not only me but my family too!

The district nurse came out to me change the catheter and while there were a few teething problems, I realised I was starting to get my life back after years of suffering.

I started to go out with friends and even went to supermarket which had previously been impossible as I would have been bent double with pain.

I tried the flip-flo valve but this didn't really suit me as it gave me painful spasms. Instead I chose to continue with free drainage and a leg bag. I also have some belly bags which are great for summer and when I want to wear a dress or some shorts.

Having the supra pubic catheter was the best option for me. It has stopped me from living a life where I was constantly in and out of hospital. It has been six years now since I had the procedure and I am able to enjoy life to the maximum now. I will be forever grateful to the consultant at Bristol as now have a life I can live and not one where I simply exist!

Caring For A Supra-Pubic Catheter **By BHUK Nurse Practitioner, Paula Pitcher**



Paula Pitcher is Bladder Health UK's retired nurse specialist, having worked for many years in the Uro-Gynaecology Department of Birmingham Women's Hospital.

She offers some advice on caring for a supra-pubic catheter.

What is A Supra-Pubic Catheter (SPC)

It is a hollow tube that is inserted into the bladder via a small incision into the abdomen just below the tummy button. The procedure is carried out in a hospital by a professional using an aseptic technique. A balloon is inflated into the catheter to prevent the SPC from falling out.

The catheter is attached to a drainage bag that can be attached to your leg. An alternative is a catheter valve / flip flow that can be released every 3 – 4 hours to allow the urine to drain.

The catheter will be changed every 4-12 weeks as decided by your health care provider. The first catheter change is usually carried out in a hospital setting by a nurse/ doctor trained in the procedure. Thereafter it can be done in your home if there are no problems.

What Are The Advantages of an SPC

Your doctor and nurse, along with you, will decide if a SPC is needed and would be beneficial to you. It may be for short or for long term.

An SPC may be required:

- If you are not able to tolerate a urethral catheter
- If you have an increased incidence of urinary tract infection (UTI) with a urethral catheter
- If there is an increased skin breakdown with urinary leakage
- If you have an abnormal urethral anatomy ie. urethral obstruction or stricture
- If the person is sexually active and a urethral catheter would be in the way. The catheter tubing should be placed along the tummy, so it's not going to



Caring For A Supra-Pubic Catheter By BHUK Nurse Practitioner, Paula Pitcher

be pulled during intercourse.

- If a person has restricted hip mobility, making it difficult to insert a urethral catheter.
- If a person has faecal incontinence and an SPC would reduce contamination compared to a urethral catheter.

What Are The Disadvantages of an SPC?

The disadvantages of an SPC would include:

- Leaking from the urethra when the catheter is shut off
- If the SPC is pulled out it may require another operation to reinsert it.
- If the tummy is quite large it may be difficult to change
- It may cause pain and discomfort
- Urine can leak around the insertion site

Post-Operative Care

A district nurse should be in contact with you after 2/3days to see how you are getting on with the SPC. The hospital or district nurse will register you with a delivery service for equipment you may need.

You will be advised to increase your fluid intake to 2-3 litres a day over the initial 3 days to minimise bleeding. If the bleeding persists for longer than 3 days and there is an increase in pain, seek medical advice.

It is suggested that a SPC stay in for at least 4 weeks so that a tract can be established. For the first couple of weeks your doctor may suggest that the SPC is on free drainage.

The SPC, after a couple of weeks, can have a catheter valve (flip flow) attached to the end of the tubing. This can be released every 3-4 hours to maintain bladder tone. The SPC, at night, can then be attached to a catheter bag and be on free drainage. This may not be advised to all people, so discuss with your specialist.

If your catheter falls out contact your hospital clinic. The catheter will need to be reinserted within a couple of hours. If this isn't possible a urethral catheter will need to be inserted in the meantime.

LIBRARY LENDING SERVICE



We have a selection of books on chronic bladder illness available for loan via our Library Lending Service.

To borrow a book from the list in your New Members Pack you will need to send a cheque for the required amount into the office. We will post the book out to you and you will then return it to us once you have read it.

Choose from a selection of available titles including:

‘Hold It Sister’ by Mary O’Dwyer

‘IC Naturally’ by Diana Brady

‘A Headache in the Pelvis’ by David Wise Ph.D.

‘Cystitis - A Time To Heal With Yoga and Acupressure’ by Dawn R Mahowald, CY

Dr Ammey A Ripoll MD

The Better Bladder Book by Wendy Cohen RN

Painful Bladder Syndrome by Philip Weeks

Solving the IC Puzzle by Amrit Willis

BANANA BREAD By Megan Fernandez



If you are at a loose end while stuck indoors why not do some baking and rustle up this lovely, bladder-friendly banana bread recipe!

Ingredients

Cup and a half of flour of your choice

3 mashed bananas

Teaspoon of baking soda

Half a small cup of good oil (I use rapeseed oil)

4 tablespoon of Greek yogurt or dairy-free alternative

4 tablespoons of maple syrup or organic honey or sweetener to taste.

2 free-range eggs (whisked)

Add cinnamon or All-Spice to taste

Sift the flour into a large mixing bowl, add the ingredients, fold and mix until the mixture is the consistency of batter.

Grease a loaf tin and bake at 180° for approximately 30-40 minutes. Press the cake - if it springs back it’s cooked!

Enjoy served with ice-cream!



Your Questions Answered

By Mr Ased Ali MCh, FRCS (Urol), Consultant Urologist, Mid-Yorkshire Hospitals NHS Trust

Q Are there other conditions that can affect the need to go to the toilet but aren't bladder problems? I get growing discomfort after going to the toilet. This discomfort is often accompanied by what feels like trapped wind. I have had a 'weak bladder' for decades and also have some sort of blood circulation problem.

A A number of other conditions can influence bladder symptoms in men, these include prostatitis, UTI, STD, inflammatory bowel disease, IBS, prostate enlargement, narrowing of the urethra, weak pelvic floor, obesity, etc.

A combination of a detailed history of the condition, physical examination and relevant tests can usually help identify the most likely cause or causes of bladder symptoms.

Q I am struggling to obtain Ranitidine at the moment which keeps my symptoms stable due to a disruption in the supply. I am wondering if you can suggest any suitable alternatives as my symptoms are returning.

A Like Ranitidine, Cimetidine is in the same class of drugs known as H2-receptor antagonists and therefore, should have a similar

impact on your symptoms.

Q I have recurrent infection and while I am taking an antibiotic as a preventative, I am still getting breakthrough infection. It has therefore, been suggested that I begin Hiprex as well as the antibiotic. I can see the Hiprex is only suggested as a preventative when an infection has cleared and at the moment, I am not sure that it has. Can I take it anyway? How long is it safe to continue with the Hiprex, as it seems that I might need it for quite a while if it is successful.

A It is correct that Methenamine Hippurate (Hiprex) is primarily for the prevention of UTI but there is no issue to taking it concurrently with most antibiotics, however you should make sure that your doctor knows that you are on it. No maximum duration has been specified for Methenamine Hippurate, however it is a very old drug and many patients have taken it for years without ill-effect.

Q I have been diagnosed with Follicular Cystitis but have been given very little information on this condition. I am awaiting a follow-up appointment which has been

Important Notice. The answers to the questions are not intended to be comprehensive and must only be taken as general advice. You need to discuss any concerns about your symptoms with your GP or Urologist.



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delayed due to the situation with Covid-19 and I wondered if you could tell me a little about it and what I can expect treatment-wise.

A Follicular cystitis is an inflammatory disease of the bladder that is more common in women. Similar to UTI, pain when passing urine is the most common feature. On cystoscopy, white, grey or pink nodules are usually seen together with a generally reddened lining of the bladder. There are specific findings on microscopic examination of biopsies too. It is a rare finding and the cause is not well understood. Various treatment modalities are available including antibiotics, anti-inflammatory drugs as well as surgical removal of the lesions. Although symptoms are mild and non-specific in some, it can be more disabling and non-responsive to medication in a minority. Such resistant cases have been treated with more aggressive treatments including radiotherapy or even bladder remove where symptoms are disabling.

Q I have had IC for a number of years but following an increase in my symptoms for a few weeks, I went to my GP. He could see no leucocytes on the dipstick but sent

the sample away anyway. It came back positive for Proteus Mirabilis which was cleared with a course of antibiotics. Two weeks later the infection returned and again, there were no leucocytes on the dipstick. I have now, once again, had to have a course of antibiotics. I do not understand how it is possible to have an infection without leucocytes present. Can you explain?

A The detection of leucocytes via dipstick is based on a chemical reaction involving leucocyte esterase. Leucocyte esterase is produced by a type of white blood cell involved in infection known as neutrophils. The presence of this enzyme in the urine reacts with a chemical on the dipstick which results in a colour change. The leucocyte esterase test is only between 50-70% sensitive depending on which study you look at. Dilution of urine and the time of the day the sample is taken can further affect the detection of any substance within the urine.

Sincere thanks to Mr Ali for kindly answering your questions. Please send your urology questions in by Friday, 11th September 2020 for inclusion in the Winter issue of 'Your Bladder Health'



Sacral Neuromodulation - A Pacemaker for the Bladder

By Professor Hashim Hashim MBBS, MRCS (Eng),
MD, FEBU, FRCS (Urol), Consultant Urologist,
North Bristol NHS Trust



Professor Hashim Hashim is a world-renowned Functional Urology Surgeon based at North Bristol NHS Trust. In this article he and Pauline Bueno, Senior Fellow in Female and Functional Urology discuss the benefits of neuromodulation as a form of treatment for overactive bladder and non-obstructive urinary retention. They also tell us about the new, rechargeable, MRI-safe devices which have recently become available.

Professor Hashim

What Is Overactive Bladder?

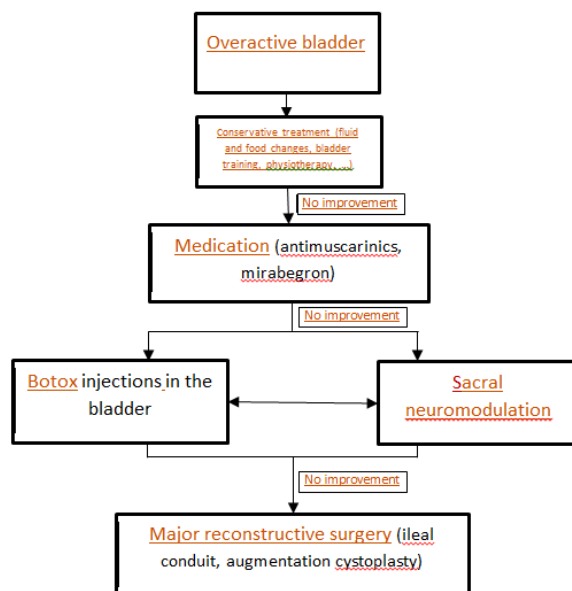
Overactive bladder syndrome (OAB) with or without urgency incontinence, and urinary retention without an obstruction are urological entities that have a huge impact on a patient's quality of life. Unfortunately, they can be difficult to treat in some cases, being refractory (resistant) to available non-surgical treatments.

OAB is a clinical diagnosis including a sudden, difficult to defer, desire to pass urine (urgency) which can be accompanied by waking up at night to urinate, going often to the toilet during daytime and/or leakage of urine, because you are unable to reach the toilet in time (urgency incontinence)^{1,2}. The main causes for an overactive bladder are related to

alterations of the muscle in the bladder (myogenic) or nerves (neurogenic) involved in bladder and urethral function and sensation³.

Treatment

Treatment for OAB and urgency incontinence includes a stepwise approach, from the least invasive including lifestyle changes (fluid manipulation, bladder training) to medications to minimally invasive surgical options, like botulinum toxin injections and sacral neuromodulation (SNM)⁴ and then major surgery (see algorithm 1).



Algorithm 1

What Is Non-Obstructive Urinary Retention (NOUR)?

Non-obstructive urinary retention (NOUR) happens when the bladder does not empty completely with voiding, but there is no mechanical obstruction to the urine coming out.

Causes for this kind of retention are sometimes not well understood or they can happen in patients with neurological conditions too. Women with Fowler’s syndrome, a condition where there is urine retention due to failure in relaxation of the urethral sphincter, are included in this category. Fowler’s syndrome usually occurs in young women and can be associated with polycystic ovary syndrome.

Treatment options for NOUR could range from physiotherapy (pelvic floor relaxation), having to catheterize the bladder to empty it, medications, or more invasive management including sacral neuromodulation SNM⁵ and surgery.

SNM is considered a surgical procedure, although it is minimally invasive when compared to more complex reconstructive options for OAB and NOUR, like surgical removal of the bladder or enlarging the bladder’s capacity with bowel.

What Is Sacral Neuromodulation?

The urinary tract is regulated by complex mechanisms through the nervous system. As far as we know



Sacral Neuromodulation - A Pacemaker for the Bladder

By Professor Hashim Hashim

OAB and NOUR could result from the nervous system not working properly or be due to problems within the muscle of the bladder wall.

What Is SNS?

Sacral neuromodulation (SNS) is a medical device that was implanted for the first time in 1982 in San Francisco, California as a result of decades of research in neurophysiology and electricity. It was initially approved by the US Food and Drug Administration in 1997 for urgency incontinence and in 1999 for urinary retention and overactive bladder. It has also been approved for faecal incontinence since 2010.



The Medtronic Interstim Family

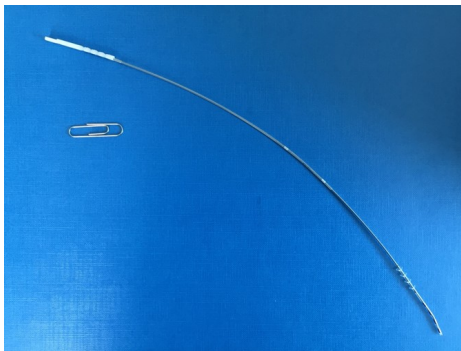
The exact mechanism of how this device works is still not completely understood. There are various theories of how SNM modulates the nerves responsible of controlling the bladder and pelvic floor. These are afferent nerves, meaning that they carry signals from the bladder to the spinal cord and brain and they are situated at the level of the sacrum, where a lead is placed that runs parallel to them. This lead is connected to a pulse generator that sends electrical impulses to the nerves through the lead.

How Is The Procedure Done?

There are two phases for implantation of SNM: a test phase and a permanent placement of the device. There is no diagnostic test that will tell us if the device will work or not and the test phase is the only way of finding out whether this is the correct therapy for a particular patient. Symptoms will be assessed using a bladder diary and quality of life questionnaire during the test phase for a period of one to two weeks. If there is a significant improvement in symptoms, then the permanent device will be inserted.

The test phase involves the insertion of a temporary lead (percutaneous

nerve evaluation, PNE), usually under local anesthesia and ideally X-ray guidance, as a day-case but can also be done in the out-patients department. The lead stays in place for up to two weeks and during this timeframe there is an external device (pulse generator) connected to the lead. In some cases and in some countries the PNE lead is not utilized and a tined-lead is used in what is called an advanced-lead evaluation phase. This will be the same lead used for the permanent implant. There are advantages and disadvantages to each technique.



Tined lead used for permanent sacral neuromodulation. Electrodes that run parallel to nerves are on the lower right corner of the image. The side of the lead on the left upper corner is connected to the battery.

If the test phase is unsuccessful then the PNE wire/lead is removed in clinic and if the advanced test lead was used, then it will be removed in the operating room under sedation. If the PNE test phase is successful then, after

the lead is removed the second stage is planned, where the tined lead and battery generator will be internally placed in the operating room under sedation or general anaesthesia with X-ray guidance as a day case-procedure. During surgery, a pouch will be created in the upper outer part of the buttock to store the battery. This battery will be connected to a lead that is designed to stay inside the body.

SNM Technology - MRI Compatible

There are currently two companies that provide SNM devices. Until 2019, all devices on the market were not compatible with MRIs, which made some patients not suitable for this therapy. Currently the Medtronic and Axonics devices are safe to use with MRI.

New Rechargeable Devices!

Another innovation in 2019 is that there are rechargeable pulsed-generators which are charged every week, on average, with an external belt charger. These new batteries can theoretically last for about 15 years as opposed to the previous 5 to 7 years on the previous non-rechargeable devices.

Due to the rechargeability, the size and weight of the battery has been considerably reduced from 4.4cm x 5.1cm x 0.8cm and 22 gr (Medtronic Interstim II) to about 80% smaller,



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almost the size of a small USB stick (see figure 2). Medtronic's rechargeable device measures 1.7cm x 4.7cm x 0.5cm and the Axonics device is 4.5cm x 2.3cm x 0.6cm. Obviously, choice of device will depend on several factors including one's body size, lifestyle, preference, availability etc.

How Effective is SNS?

Success rate varies depending on the indication but it is, on average, 50-75% successful and it has the best effect when the patients are carefully chosen for this type of therapy. Some of the most common side effects are failure to improve symptoms, pain at implant site (battery or lead), a need for replacement of the battery, removal or relocation of the implant, lead

movement (migration) or infection (see North Bristol NHS Trust leaflet).

Where Can This Treatment Be Obtained?

In the UK, there are several major centres providing this for urological patients with the five biggest centres in England located in Bristol, Birmingham, London, Newcastle and Manchester.

You can find out more about neuromodulation by visiting the Medtronic website <https://global.medtronic.com/xg-en/healthcare-professionals/products/urology/sacral-neuromodulation-systems/interstim-ii.html>

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A Natural Approach To Bladder Health



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INTERNATIONAL RESEARCH

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QUESTIONNAIRE-GUIDED EVALUATION OF THE EFFECTIVENESS OF LONG-TERM INTRAVESICAL 0.2% CHONDROITIN SULFATE THERAPY IN INTERSTITIAL CYSTITIS

Kocaturk H, Atasoy N, Bedir F, Altay MS, Demirdogen SO, Koc E, Yilmaz S. Int Urogynecol J. 2020 Feb 11. doi: 10.1007/s00192-020-04245-0. [Epub ahead of print] PMID: 32047969

The purpose of this study from Turkey was to investigate the long-term feasibility, safety and effectiveness of intravesical chondroitin sulfate therapy in patients with one or more forms of chronic cystitis.

The study included 62 female patients with interstitial cystitis/painful bladder syndrome (IC/PBS) who received intravesical chondroitin sulfate (40ml/80mg) therapy between 2014 and 2018. A total of 15 doses of intravesical treatment were applied, once weekly in the first month and once monthly from the second month onward. A 3-day voiding diary, a visual analog scale (VAS), the O'Leary Sant indexes (ICSI/ICPI), the Pelvic Pain and Urgency/Frequency Symptoms (PPUFS) Scale and PPUF Bother scores were recorded and evaluated through prospective comparison before treatment and at the first month and first year. Patients were also assessed using the Global Response Assessment (GRA) at the end of the first month and first year to assess the effectiveness of responses to treatment.

In the first month of treatment, 0.2% chondroitin sulfate was ineffective in 22.5% of patients, with mild improvement observed in 40.0% and moderate-good improvement in 37.0%. Evaluation at the end of the first year revealed mild improvement in 21.0% of patients and moderate-good improvement in 79.0%. Statistically significant improvements were observed in all scoring systems at 1 and 12 months compared with pre-treatment values.

The authors concluded that long-term intravesical chondroitin sulfate therapy is a safe and highly successful therapeutic modality that produces significant improvement in patients' quality of life and symptoms in the treatment of IC/PBS.

THE ROLE OF GLYCOSAMINOGLYCANS (GAGs) IN THE MANAGEMENT OF CHRONIC PELVIC PAIN: A SYSTEMATIC REVIEW

Lacovelli V, Bianchi D, Pletto S, Pacini P, Fede Spicchiale C, Finazzi Agro E. Minerva Urol Nefrol. 2020 Mar 16. doi: 10.23736/S0393-2249.20.03672-3.[Epub ahead of print] PMID: 32182229

Glycosaminoglycans (GAGs) are involved in the pathogenesis of several urologic chronic diseases. Thus, GAGs replenishment therapy is widely reported as a therapeutic tool for chronic pelvic pain (CPP) conditions such as IC/BPS and prostate pain syndrome/chronic prostatitis.

In this article we reviewed the current status of the evidence on the clinic applications of GAGs in the CPP. A literature search from inception was performed according to the Preferred chronic debilitating condition. Surgery is reserved for severe refractory cases; however, there is no consensus on patient selection or optimal approach.

The purpose of this study was to evaluate the evidence relating to the safety and efficacy of surgical interventions for treating BPS/IC. PubMed and Scopus databases were searched for original studies using keywords 'cystectomy', 'interstitial cystitis' and 'bladder pain syndrome'. Articles were reviewed and screened by three independent reviewers. A total of 450 patients underwent surgery: subtotal cystectomy with cystoplasty (48.6%), cystectomy and orthotopic neobladder (21.9%), cystectomy and ileal conduit (11.2%) and urinary diversion only (18.3%).

Symptomatic improvement occurred in 77.2%, with higher rates in the total cystectomy and orthotopic neobladder group. Thirty one patients (6.9%) required secondary total cystectomy and/or ileal conduit diversion; 48.4% subsequently improved. Seventeen studies reported 102 complications overall (26.5%). Overall mortality was 1.3%. Overall surgical intervention is associated with 23% risk of failure to improve symptoms. Higher rates of improvement were reported in patients with total cystectomy. Interpretation should be guarded given the small patient number, multiple centres and variable outcome measurements. There is a need for prospective randomised studies to answer questions regarding patient selection and optimal surgical approach.

PATIENT SUMMARY: In this review, the authors looked at the outcomes of surgery for treatment - refractory bladder pain syndrome/interstitial cystitis. They found overall symptom improvement in 77.2% of patients with a complication rate of 26.5%. However, there remains a need for further studies of higher quality to identify patients who will have symptom improvement and the best surgical option.



The Pelvic Floor Muscles and The Bears

By Jilly Bond MSc, Pelvic Health Physiotherapist



Jilly Bond

Jilly Bond MSc is a pelvic health Physiotherapist and researcher based in Wales, UK, with a specialist interest in pelvic pain. She spent nearly a decade in the NHS before moving to lead a private hospital pelvic health service and then her own clinic. She received her masters degree in pelvic health physiotherapy in 2017, looking at treatments for bladder pain syndrome. Her research interests include understanding neurocentric treatment mechanisms in visceral pain and somatoperceptual distortions.

She has sat on both the executive committee for the UK Pelvic, Obstetric and Gynaecological Physiotherapy specialist interest group, the POGP Journal committee, is a regular speaker at international conferences, runs live and online professional development courses for physios and patients and her YouTube channel has free resources for patients.

With bladder pain syndrome (BPS) affecting everyone differently it can be difficult to know what to do and where to seek help. The reason for this is that bladder pain syndrome isn't just a bladder disorder, we know a host of other systems can have an effect on the symptoms you experience, such as hormones, autoimmune issues, genetics, emotions and structural adaptations that occur in the nervous system. As a clinician and researcher I like to think about the "hardware" – what's happening at the tissues, the bladder, pelvic floor and pelvic organs, and "software" – what's happening in the nervous system & brain of my patients. Identifying the main drivers of pain and dysfunction in each

individual is key to targeting treatment that will work.

Research

Research over the last 15 years has shown us that BPS always involves both hardware and software changes that occur over time, and it always involves pelvic floor dysfunction. If the pelvic floor is not treated then bladder pain doesn't change. Many nerves are shared within the pelvis between structures and because of this, pain and dysfunction within the pelvic floor muscle can affect how your bladder functions and is perceived by the brain. Changes in the tension, blood flow and function of the nerves in the

pelvic floor may also have a role in increasing the inflammation within the bladder, and vice versa. “Software” changes over time also include maladaptations to the areas of the brain responsible for how full your bladder feels (meaning you feel too full), how much attention you pay to your bladder (it’s on your mind constantly) and how tense your pelvic floor is (very).

Chronic “Threat”

Over time your Limbic system, an area usually responsible for emotions, takes control of managing the chronic “threat” state of your tissues. Therefore your pain and emotion become intertwined, and symptoms can be emotionally overwhelming. This is what we call “centrally driven”; dysfunctions produced by changes in brain function. This is a natural part of the brain adapting to deal with a persistent threat, and is not something you’ve caused.

The Pelvic Floor

The pelvic floor is a bowl-shaped group of muscles at the base of the pelvis. When they activate they lift up and forwards together, creating an upside-down bowl shape, lifting your pelvic organs and compressing the urethra. In BPS they become overactive and tense, possibly as a “guarding reflex” response to the inflammation and pain in the bladder

region. This reflex causes an ongoing involuntary muscle spasm which itself over time can alter blood flow and neural activity within the muscle causing further pain and tension. Many people have this diagnosed as myofascial pain syndrome, levator ani syndrome, pelvic floor dysfunction, tension myalgia or trigger points. We also see changes in how the muscle functions if it’s held tight in spasm for a prolonged period, and that can lead to poor functional movement which in some cases allows urinary incontinence to occur. People often report that when their pelvic floor is assessed they experience pain or their bladder pain. Using tampons or having sex can also be too painful. We usually attribute this to an overactive pelvic floor muscle. Physiotherapy treatment can then focus on “relaxing” this to reduce symptoms. Although working to relax the pelvic floor is an effective treatment for bladder pain and urgency, the mechanism by which it works is not quite that straight forward.

An overactive pelvic floor muscle is not necessarily a painful one. Only when there is some potential for threat does a chronically tight pelvic floor become painful and then dysfunctional. Many people who enjoy regular sports or the go to the gym will have transiently overactive pelvic floor muscles without pain. The process of reducing the tension of an overactive pelvic floor muscle, either manually



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By Jilly Bond MSc, Pelvic Health Physiotherapist

yourself, with your physiotherapist or by doing relaxation exercises, aims to target both the tissue and central drivers of muscle overactivity – adaptations in the muscle’s blood flow, how it moves and is controlled, and how under threat the brain considers it to be.

Predictions

Pain is experienced as the result of a decision within your body and brain that the information from your tissues suggests you are under actual or potential threat. Currently our best understanding of pain is that the brain makes predictions based on the best available data – what you feel, see, hear, touch, taste and smell, the information coming in from your bladder and pelvic region, as well as your previous experiences, your thoughts and beliefs, your current emotional landscape and the environment you’re in. However, if there has been longstanding inflammation we know the sensory signals from the pelvic region can be “turned up” in the spinal cord, or blurred so that information from your pelvic floor, bowel, uterus, kidneys or other pelvic organs can become confused with the perception of information from your bladder. This

leads to a situation where much of the information from the pelvic region coming into the brain may be incorrectly perceived as coming from the bladder, and then be flagged as potentially threatening. Therefore, in persisting bladder pain we don’t necessarily have accurate sensory data upon which to base a prediction about what may be happening. We think this leads to more “fixed” predictions by the brain in order to protect you from potential threat. It makes sense to have a brain default set to negative in order to keep you alive, and this inevitably perpetuates the continuing situation of pain, inflammation and dysfunction in the bladder and pelvic floor.

‘The Bears’

In our understanding of “threat” it’s important to remember that the region of our brain responsible for these decisions is poorly evolved. We live with a hindbrain that sees black and white; threat and no threat; running from a bear or not running from a bear. It lacks the shades of grey that our modern lives demand, responding to an unexpected bill or traffic jam as if running from a bear by releasing stress hormones such as adrenaline or cortisol to allow us to

fight, flight or freeze. It's well documented that these every-day stressors can increase inflammation at the bladder in patients with chronic pain as the result of a complex and beautiful bid by the body to protect us from a threat. This creates more "hardware" tissue drivers of threat as the bladder becomes inflamed and sore, and so the cycle continues. When you have chronic pain the threat doesn't necessarily have to be the part that hurts, it just has to be a threat to you, physically or emotionally, to produce an increase in your symptoms.

If your body considers you under persistent threat what do you do? Applying what we know from research looking at other areas of the body to the pelvis shows us that working to develop your proprioception, or your ability to know where your body is in space, alongside having an improved understanding of your pelvic anatomy can help your brain to make more informed predictions about what might be going on, i.e. that your bladder isn't actually fighting bears. We use images, anatomy education and a graded exposure to normal functions of the pelvic region as part of a desensitisation programme aiming to allow the pelvic floor to move normally and function freely, encouraging a more relaxed level of resting muscle tension, improved blood flow and appropriate degree of sensitivity.

Treatment

Treating bladder pain requires many small changes individual to each person that summated, bring great relief. And reducing the general threat level within your body is a simple and effective way for everyone to start regaining control. One of my favourite pieces of research observed the resting tone of womens' pelvic floors whilst watching different films, and found involuntary increases in muscle tone when exposed to scary movies or significant threat. If we want to reduce the tone of the pelvic floor and it's dysfunction, which will be heightening bladder symptoms, then reducing threat is a good place to start. One of the easiest steps to take straight away is to look for those everyday stressors, or bears. I ask my patients to draw out their bears in a spider diagram. Putting your stressors down on paper can allow you to begin to work to neutralise those you're able, or mitigate the ones that are unchanging.

If you're struggling then seeking support from a counsellor through your GP can help. Reducing the number of bears you're fighting overall can bring down the heightened arousal level of your body, allowing your brain to be less sensitised about what's happening with your bladder region and reduce pelvic floor spasm.

Pelvic floor relaxation exercises in sitting, lying down with your knees spread and feet together, or in a



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“happy baby” yoga position are all great ways of encouraging more normal pelvic floor movement. By focussing on deep diaphragmatic abdominal breaths you can improve relaxation of the pelvic floor by increasing your intra-abdominal pressure.

Mindfulness

Mindfulness is also an excellent way of increasing your “parasympathetic” system, which is the opposite to fight or flight. Spending more time in that state of general relaxation can reduce your threat level and the pelvic floor tension and pain that comes with it. Mindfulness can be done in any comfortable position and there are many free apps available to guide you through it such as Calm, Headspace, and Insight Timer. If you prefer to move then practising Qi Gong may be for you, a relaxation version of Tai Chi in standing that is freely available online.

Recovery and reframing your life with bladder pain syndrome symptoms is different for everyone, and involves many small changes. Addressing your centralised drivers should be one step, and it’s something you can tackle today. Physiotherapy has a lot to offer those with BPS symptoms, in collaborating to identify and treat your specific drivers. And remember, Physio should never hurt.

If you’d like to hear more I have an online course covering everything your physiotherapist would tell you about BPS and some simple exercises to get you started on your recovery. You can also find my YouTube playlist dedicated to information about BPS and physiotherapy, and I’m always interested to hear from you should you want me to cover more issues in the videos.

COMING SOON - NEW WEBSITE!

We are launching our brand new website at the end of July, newly up-dated for 2020 and with a fresh new look and lots more useful information designed to help you live positively with bladder illness! Please do take time to come by and visit at www.bladderhealthuk.org



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Yoga is supposed to be relaxing. How can you focus on your breathing and feel calm when you're worried about a leak the whole time?

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ACCESS TO TOILETS OUTSIDE THE HOME DURING THE COVID-19 PANDEMIC

Now that lockdown measures during the Covid-19 crisis have eased a little and shops are beginning to re-open, we are starting to leave our homes a little more often! BHUK know that some toilets still remain closed and this is an issue that we are striving to address via our involvement with a like-minded body of charities and individuals known as 'The Toilet Consortium'.

Following an appeal by BHUK on our social media platforms, one of our members asked a question at 'The Daily Briefing' on the BBC about when we could expect toilets to re-open and we continue to push for this as we know how vital it is for our members

to be able to access toilet facilities when they are out and about.

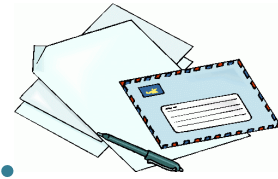
We have also become aware of a site called Lockdown Loo (lockdownloo.com) who have mapped toilets all over the UK which have now re-opened for use. To find an open toilet in your area use the search facility the map provided on the site.

The use of toilet facilities during the pandemic has caused members some concern as the virus is easily transmittable via urine and faeces. We therefore suggest taking the following precautions to minimise the risk when you are using toilets outside your own home.

TIPS FOR USING PUBLIC TOILETS DURING THE COVID19 PANDEMIC

1. Create yourself a hygiene pack of antibacterial wipes, soap, Water Wipes (to use instead of toilet paper), paper hand towels, tissues and nappy sacks
2. Minimise what you touch with your hands.
3. Wipe the toilet seat with antibacterial wipes and dry with paper towels supplied by you from your pack.
3. Wash your hands thoroughly with your antibacterial handwash before using the toilet
4. Dry your hands with paper towels supplied by you in your pack.
5. Use the wipes in your pack after you have used the toilet rather than toilet paper provided but don't flush them down the toilet.
6. Close the toilet lid before flushing the toilet
7. Wash your hands thoroughly with antibacterial handwash and dry them with paper towels from your pack. Take your rubbish home with you.

Your Letters



HRT HAS HELPED MY SYMPTOMS

I have suffered for a number of years from recurrent UTIs and it was only by phoning the BHUK Advice Line and speaking to the nurse that I addressed the connection between hormones and the issues I was having. I had always been very wary of HRT but the nurse explained that topical HRT remains largely localised and in fact, a whole year's worth of topical HRT is only equivalent to one dose of systemic HRT.

I have now started to use Ovestin 1mg cream and it has relieved some of the burning and dryness on my perineum. I have only had one infection over a six month period too rather than the one a month I was getting!

Denise Newcombe

Do keep your letters coming in! We are always interested in sharing the experiences of members! Please note that Bladder Health UK reserves the right to edit any correspondence received.

MY OWN SOLUTION

I have Fowlers Syndrome and have had problems with catheters for years, both with a suprapubic catheter and an indwelling one too! I have never found anything that actually helps avoid the leg sores and blisters that I get from leg straps, the problem with the bag showing through clothes and it also detaching through either movement or bladder pressure making it pop off.

About a month ago I began to use a bum bag which has alleviated those issues. I tuck the tube into the bag and the rest into the my pants and this works really well for me.



I have used belly bags in the past which are similar but gave me sores. This for me, is so much better!

I hope this tip is helpful to someone else.

Sabrina Binns

undraising News

Many thanks to the following fabulous fundraisers who have given so generously during the last few months! A big 'thank you' also to those who have managed to put a little extra in with their renewal, your support means so much to us, particularly at this difficult time!

Jean James	£30.00	Gillian Smith	£100.00
Anne Dare	£50.00	Frouke Bates	£100.00
Isobel Sim	£30.00		

Special Thank You!



Special thanks to member, Ruth Chambers who donated an amazing £1,250 towards our funds! Thank you so much Ruth!

A huge 'thank you' also to everyone who put a little extra in with their raffle tickets! It really does make a big difference to us - particularly at the moment!

RAISING MONEY THROUGH EASY FUNDRAISING!

Do you shop on-line? Did you know that if you are doing your shopping via EasyFundraising you could raise a donation for BHUK and it won't cost you a penny!

There are over 3,000 shops and sites on board ready to make a donation, including Amazon, John Lewis, Aviva, Trainline and Sainsbury's.

It's quick and easy to do—just follow these simple steps:

1. Head to <https://www.easyfundraising.org.uk/causes/bladderhealthuk/> and join for free
2. Every time you shop online, go to Easyfundraising first to find the site you want and start shopping.
3. After you've checked out, that retailer will make a donation to your good cause at no extra cost whatsoever!

There are not catches or hidden charges and BHUK will be really grateful for your donations!

Fabulous Singing from Jenny Barlow



Jenny Barlow

Many thanks to BHUK member and vocalist Jenny Barlow who held a concert via Facebook in April to raise funds for Bladder Health UK and to brighten up everyone's lockdown!

We tuned in and thoroughly enjoyed the event along with other members and members of Jenny's family and friends and are delighted to say that as a result, over £100 was raised!

Guess The Name of the Bear Competition!

Lisa Barrett, moderator of our closed Facebook page was determined to raise some funds for the charity while we were in lockdown!

She organised a competition on our closed IC/BPS Facebook page to guess the name of the bear!

Many of the page members took part in the competition and altogether raised £90.00 for our funds! A big ' thank you to all of them! The prize was won by Megan Fernandez who guessed the bear's name was Loopy!

Lisa's nine-year-old daughter, Ruby, also helped with the competition and generously donated £20.00 of her pocket money! Thank you Ruby!



Sophie's Memory Fundraising



Sophie's Memory Fundraising supported us once again during the Covid-19 crisis by making and selling face coverings and donating £120.00 of the proceeds to Bladder Health UK! Thank you to them for thinking of us!

COPING WITH ANXIETY LINKED TO CHRONIC PAIN

By Jennie Spain, CBT Therapist,
Post Grad Dip BSc (Hons) ENBA40, RMN



Jennie Spain

Jennie Spain is a Cognitive Behavioural Psychotherapist who runs her own private practice 'CBT for You' based at Daleswood Health in the West Midlands. She was a Senior Sister in Mental Health for 26 years and also now works in a Neuro Psychiatry Department within the NHS.

Jennie has a specialist interest in Acceptance and Commitment Therapy (ACT) an evidence-based psychological therapy. The effectiveness of ACT in the

treatment of chronic pain conditions such as Interstitial Cystitis/Bladder Pain Syndrome, as well as depression and anxiety has been evidenced in over 300 randomised, controlled trials in Peer Reviewed Journals.

The purpose of this article is to present ACT as a therapeutic approach, with reference to long term health conditions and especially pain.

Values

As human beings, we experience our own 'mental health' differently because every individual has different genes and bodies, life experiences, relationships, personalities, interests, hobbies, goals etc.

And because of these differences, each of us has our own sense of what is important, of what 'touches' us inside. Of what means the most in our lives in a heartfelt way. Like relationships and love. But also, important parts of who we are that are harder to define, like integrity, independence, being able to help others. In ACT, we use the term

values to 'sum up' all of these parts. Values can be difficult to 'catch' and put words around. We know what we do, but can lack true clarity as to why we do.

At times, the more we strive to reach for what is truly meaningful to us, then the more out of reach these things seem. Our thoughts and emotions can trip us up, distract us or get in the way of our fulfilment. Especially if we are living with pain and/or a long-term health condition.

Fight, Flight or Freeze

There is an evolutionary reason why this might be. Most people reading this have probably heard of the Fight, Flight or Freeze (FFF) response.

Human brains are hard wired to react to danger and threat. Cavemen faced

situations which were truly life threatening. Like being eaten by lions. Through our evolution, we have needed to react to life threatening situations to ensure we don't die. Running away from a lion, fighting one, or freezing: staying so still we might not be noticed, are behaviours we are driven to do when our fear response is triggered by a threatening stimulus. To give us the best chance of survival.

Our brains respond to fear in the way they always have, across thousands of years and that is why we have survived as a species. Think about it, if just one of your ancestors, through all of time, had failed in their quest not to die, by not responding to the stimulus triggering this fear response, would you be here reading this right now?

Our brains release hormones when we are scared to maximise our survival by 'priming' our bodies to FFF. These hormones make our muscles tense, tighten our stomachs, squeeze our internal organs, make us urinate or defecate, change our breathing, heart rate, vision, make us tingly, tighten our throat. To help us survive threat. This is what anxiety feels like in our bodies.

In addition, human beings are the only species on earth who use complex, flexible language to communicate. Humans communicate with each other, but we also communicate internally. We can all notice when we experience thoughts. My dog Teddy is always pleased to see me. Even if I shut him outside in the rain and cold,

he would wag his tail and jump up at me when I let him back into the warm. But if I shut you outside in the rain and cold, would you do the same when I let you back inside? Or would you experience some thoughts about what being outside was like?

It was horrible,' 'I feel really angry!' Or maybe you would experience some thoughts about my motivation? 'What did she do that for?' 'What an awful person!'

Our minds advise us all of the time. Our minds plan, remember, instruct, problem solve, analyse, criticise, day-dream, worry etc.

Anxiety

Anxiety is a highly unpleasant emotion. Our bodies feel as if they are in pain when we are anxious. Our heart can beat so strongly and painfully, people even experience the thought 'I am going to die, I am having a heart attack.' The experience of anxiety itself can become the threat. 'You won't be able to cope if you feel like that again.' We become anxious about experiencing the anxiety. And THAT IS EXHAUSTING!!!!

We struggle with it. Our instinct is to avoid the lion. When we avoid the lion, we feel relieved because we've escaped death. By avoiding the lion, we have also avoided the FEELING that the lion produced, the fear and anxiety. The trouble is, that fear and anxiety are normal human emotions. And if we build our lives avoiding our

COPING WITH ANXIETY LINKED TO CHRONIC PAIN

By Jennie Spain

emotions then that might mean we start to avoid doing what is important to us, what is meaningful in our lives. It feels safer, less threatening. Even as I am writing this, I notice I feel sad because of the people I have met in my career who have built their lives around not experiencing anxiety and how this impacts on them living their best lives.

Chronic Pain

Let us be completely honest in the context of what this magazine is about. Having a long-term health condition often means being in chronic pain. I am assuming if you are reading this, then this maybe something you are struggling with. Pain is a threat stimulus, because originally, in evolutionary terms, it is a signal of physical damage. Pain activates our Flight Fight or Freeze response. We experience anxiety if we are in pain. Physical symptoms of anxiety happen; including bladder pain. Pain warns us that something needs attending to in our bodies and quickly. Which increases our anxiety. Which increases our pain. Which increases our physical sensations, which increases our anxiety etc. And the struggle begins. The struggle to not be in pain, to not feel anxious, to do ANYTHING to make this pain go away, to not be ill again. Our minds

may advise us we could end up in hospital, or we may need surgery, or we will burden our families if we do not STOP this pain and illness and anxiety. We may notice our minds tell us we are weak for not being able to stop it, or useless, or not good enough. And there, I notice I feel sad again. Because while we engage in this struggle, we are not engaging in our lives. Instead of doing stuff that matters, we are struggling and doing stuff to avoid or stop the painful experience. Because we are human and that is how we are all made.

Imagine if your pain or your anxiety was a big monster who had one end of a tug of war rope. And you had the other. If the monster tugged you forward, you might tug the rope back. Especially if there was a big pit of fire in between you and it was you or him! He might tug again if he really wanted to play and you might pull back. You might start to notice you felt angry or frustrated. My question is what would happen if you decided to let the rope go? What would that be like for you? Notice how you feel when you think of that now.

What about if you started to notice what advice your mind was giving you about your pain and anxiety. If you noticed your thoughts and were able to stand back from them a little? If you could learn to 'unstick' from them.

You could make a list of the thoughts you experience when you notice pain; 'I'm too tired' or 'I can't do this' for example. Notice what the worst thing your mind is telling you will happen. What would it be like if you could hold that thought more lightly? Notice if the thought is helpful. If you were being the best version of yourself, would you act upon that thought? Or would you choose a different behaviour? What would that behaviour be? What would your loved one notice about your behaviour that is different? What does that mean to you now? How would that different

behaviour serve you?

Lots of questions, right? Lots of different answers. How can I move forward in life, towards what's meaningful to me whilst holding the difficult stuff that shows up when I try? The first step is asking the question. The second maybe reading about ACT. The third might involve choosing to look for an ACT Therapist. Someone who is truly willing to meet you where you are now, to help you find **your** answers. To find your true voice, your guide, your moment. This is your life.

Reading List:

The Confidence Gap From Fear to Freedom Dr Russ Harriss

ACTivate Your Life J Oliver, J Hill and E Morris

You Tube Support Videos; ACT Auntie

To find an ACT Therapist or for more information about therapists in your area go to ACBS for Peer Reviewed ACT Therapists.

ACT Therapy - My Experience

I consulted with Jennie myself last year in the hope of improving the level of anxiety I was experiencing around my Chronic UTI and IC. I had been inspired to do this after hearing of the success of one of the members in the West Midlands Group with the Expert Patient Programme which works on a similar ethos.

I felt that my constant checking for toilets, thinking/planning about how not to get another infection, making excuses not to go out and not socialising as I would have liked to do as a result of the anxiety around my bladder was having as big an impact on my life as the bladder illness itself.

My sessions with Jenny helped me to separate my anxiety from my pain, gave me strategies to cope with the anxiety that the pain was generating and allowed me to push the boundaries of what I had previously felt was possible with bladder illness. Susannah Fraser (BHUK)



Network Group News

Keeping In Touch With Other Sufferers During Covid-19

During the Covid-19 pandemic all face-to-face group meetings have had to be suspended. Keeping in touch with one another has therefore, presented something of a challenge but with the help of modern technology it's a challenge we're rising to!

Zoom

A few of our groups have been able to have meetings via an app called 'Zoom'. Zoom is a cloud-based, teleconferencing system which allows virtual meetings to be held. It is completely free to use, easy to get to grips with and allows a group of people to meet virtually for 40 minutes completely free of charge.

If you have an iPhone or an iPad you can download the app from the App Store. Alternatively, you can access Zoom from your laptop or computer.

If you are feeling fed-up and isolated at this time, why not find your closest local group close and join in a meeting from the comfort of your sofa at home without the need to travel. If you do not usually attend a local group because the travelling is too difficult or it is too far away for you to get to, Zoom provides the perfect opportunity for you to connect with others!

We now have groups that meet regularly on Zoom to obtain details please email Susannah Fraser (susannah@bladderhealthuk.org)

Facebook

We also have a closed Facebook page for all those suffering from IC/BPS which now has over 400 members. If you are a sufferer and would like to join us on the page, please send us a request at the following link on Facebook. https://www.facebook.com/groups/ICBPSSupportGroup/?ref=br_tf&epa=SEARCH_BOX

We are watching the advice given by Government and will be advising our groups when it is safe to commence face-to-face meetings again.

BURY GROUP

We usually meet every 6 weeks at 'Owens' a restaurant 'in Ramsbottom for lunch. We should have been meeting at the end of April but were unable to because of the lockdown.

Instead we decided to have a Zoom meeting. I had done Pilates on Zoom and it was brilliant! We arranged the meeting for the same time as our intended meeting at Owens. We carried out a trial run the night before and after a few minor problem it worked just fine on the day! It was so nice to see everybody and we were really pleased that Susannah from the BHUK Office could join us as well.

We all discussed our bladder problems and offered support where necessary. Every one of us was suffering one way or another. We discussed how we we're all coping with the lockdown and on the whole we all seem to be coping OK.

We swapped tips on where the best place to buy food is and where not to go! Zoom has been a godsend for us folk of a certain age who are not able to go out except for one walk a day! Pilates, yoga, cookery programs quizzes and lots more are offered via Zoom.

Our meeting worked so well we did it again the following Monday. Not quite the same as the restaurant but the next best thing!

We are a very friendly group and if anyone would like to join us on Zoom!! or at Owens for lunch and a chat contact Bladder Health UK.

Marie Jeffries

WEST MIDLANDS GROUP

We have had two Zoom meetings since the lockdown began. The first was attended by ten of us and it was lovely to see some faces we hadn't seen at the meetings for a while.

One of us was having problems getting their regular instillations during lockdown and was wondering about the possibility of carrying out the instillations herself. We pointed her in the direction of the 'What's New' section of the BHUK website as a few of the distributors offering instillations had some options available. She was worried about having to self-catheterize and another member of the group said that if she decided to go ahead she would be happy to advise her as she regularly self-instills DMSO.



Network Group News

During the second meeting we talked mainly about the role of hormones on our symptoms. Several of us were trying topical oestrogen for the first time and it was very reassuring to hear from others in the group about how soothing this was for their symptoms. One of us had been prescribed the cream and was nervous about going ahead and using it but several other members managed to reassure her and we hope that she will be giving it a try soon.

We chatted generally about how we had been coping during lockdown and while we had all be coping well, we really valued being able to catch up with one another about our bladder problems.

We plan to continue to meet via Zoom for as long as the lockdown continues—it is amazing how much chat we can pack in to 40 minutes!! If you live in the midlands area of the country and would like to join us, you would be very welcome. Please contact Susannah in the BHUK office for my contact details and the passwords and dates for the next Zoom meeting,

Alan Troman

GLASGOW GROUP

A few members joined in with our June 'Zoom' meeting and we found it a really good way of keeping in touch during lockdown. We are planning to have another meeting next month and anyone in our area is welcome to join us!

Anne Cameron

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About Bladder Health UK

Bladder illness is a subject that few people talk about but research indicates that 4 million people in the UK have some form of bladder illness. Bladder Health UK provides much-needed support and advice for patients, many of whom cannot work or go out because of their condition, often resulting in isolation and depression. The charity is active on behalf of sufferers working with healthcare practitioners, government and funding research into the causes and treatments of bladder illness.

Bladder Health UK is not government funded and relies on fundraising, charitable donations and membership subscription to sustain its valuable work.

Help us to help more sufferers!

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