Bridge

BLADDER & BOWEL CONTROL HEALTH

SPRING
2023

Women's Health Week Edition

Continence Foundation of Australia

A young woman's endometriosis story

Leanne's journey - travelling with incontinence

Helpline Q&A - trauma-informed care

Persistent pelvic pain

National Continence Helpline 1800 33 00 66
A free service staffed by Nurse Continence Specialists who can provide information, referrals and resources 8am - 8pm AEST weekdays.

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Go to www.continence.org.au/life-incontinence/personal-stories#sharestory

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NOTE FROM THE CEO

Welcome to the Spring edition of the Bridge Magazine where we reflect on Women's Health Week (WHW) and our community partnership with Jean Hailes, dedicated to the health and wellbeing of all women, girls and gender-diverse people.

In this edition we focus on persistent pelvic pain, which affects up to one in four women and one in ten men worldwide. As this is a WHW issue, we look specifically at persistent pelvic pain in women and how it can impact a woman's health and wellbeing.

We focus on all types of pain including endometriosis, period pain, joint pain and persistent pelvic pain. In a recent Jean Hailes survey on pelvic pain, nearly half (44.9%) of respondents said the pain sometimes had an impact on their quality of life, stopping them from working, exercising and enjoying everyday activities. As a society, we need to be more understanding of the impacts of persistent pelvic pain and how it affects women in the workplace and in the home.

We talk to Jean Hailes' physiotherapist, Amy Steventon, about pain education and how to help people better understand and manage their pain. We also share a couple of lived experience stories, including a young woman's journey with endometriosis and pelvic pain and another story of a woman who fulfilled her long-time dream to undertake a famous walking track in Spain, whilst managing incontinence.

Our Helpline Q&A focuses on trauma-informed care and how to find safe and trustworthy services and support for those who have experienced trauma. The nurse continence specialists who staff our National Continence Helpline are currently undergoing trauma-informed training and are always able to assist with confidential advice and referrals.

Please share this edition with everyone, especially the women in your life. Anyone looking for more advice and information about bladder, bowel and pelvic health can phone the National Continence Helpline on **1800 33 00 66** or visit our website continence.org.au

Rowan Cockerell,
CEO,
Continence Foundation of Australia

IN THIS ISSUE

The Foundation is working on a rebranding process and would welcome your input. If you are interested in participating please scan the QR code.

A YOUNG WOMAN'S ENDOMETRIOSIS STORY

I am 27 years old and wanted to share my story in the hope that it would help others who are going through a similar experience.

I was born in India and moved to Australia with my family when I was three. I have always had debilitating period pain. Mum always said that I needed to put up with it, as it had been the same for her. I could never use a tampon as it was too painful. When I was 15, I remember a GP suggesting I should go on the oral contraceptive pill, but Mum said I wasn't sexually active, so I didn't need contraception.

I never slept well and always felt tired. I started experiencing back and abdominal pain even when I didn't have my period. I was always needing to go to the toilet, which led me to drop out of playing hockey, because I was too scared I'd have an accident. I stopped going out with my friends and I worried about everything. My GP diagnosed me with anxiety and suggested I see a psychologist, but I didn't go because I didn't want them to tell me that what I was feeling was all in my head.

FINALLY... A REASON FOR MY PAIN

When I was 18, I saw a different GP who referred me to a gynaecologist. She was the first person to tell me it wasn't normal to experience such terrible period pain and that I might have endometriosis. I had my first surgery when I was 19 which did find endometriosis. It was amazing to finally understand why I had all these problems.

SURGERIES, PAIN AND OTHER PROBLEMS

After my initial diagnosis of endometriosis, I had another two surgeries to remove the endometriosis and had an intrauterine device (IUD) inserted. After each surgery I would feel better for a while, but then my pain and symptoms would return and then they started to get worse. I kept missing days of work because of my pain. I had been in a few short-term relationships, but sex was always extremely painful. I was really struggling to understand why I was still having pain. My gynaecologist had even said the endometriosis was much less at my last surgery, so I couldn't understand why I continued to experience pain and the impact it was having on my life was increasing.

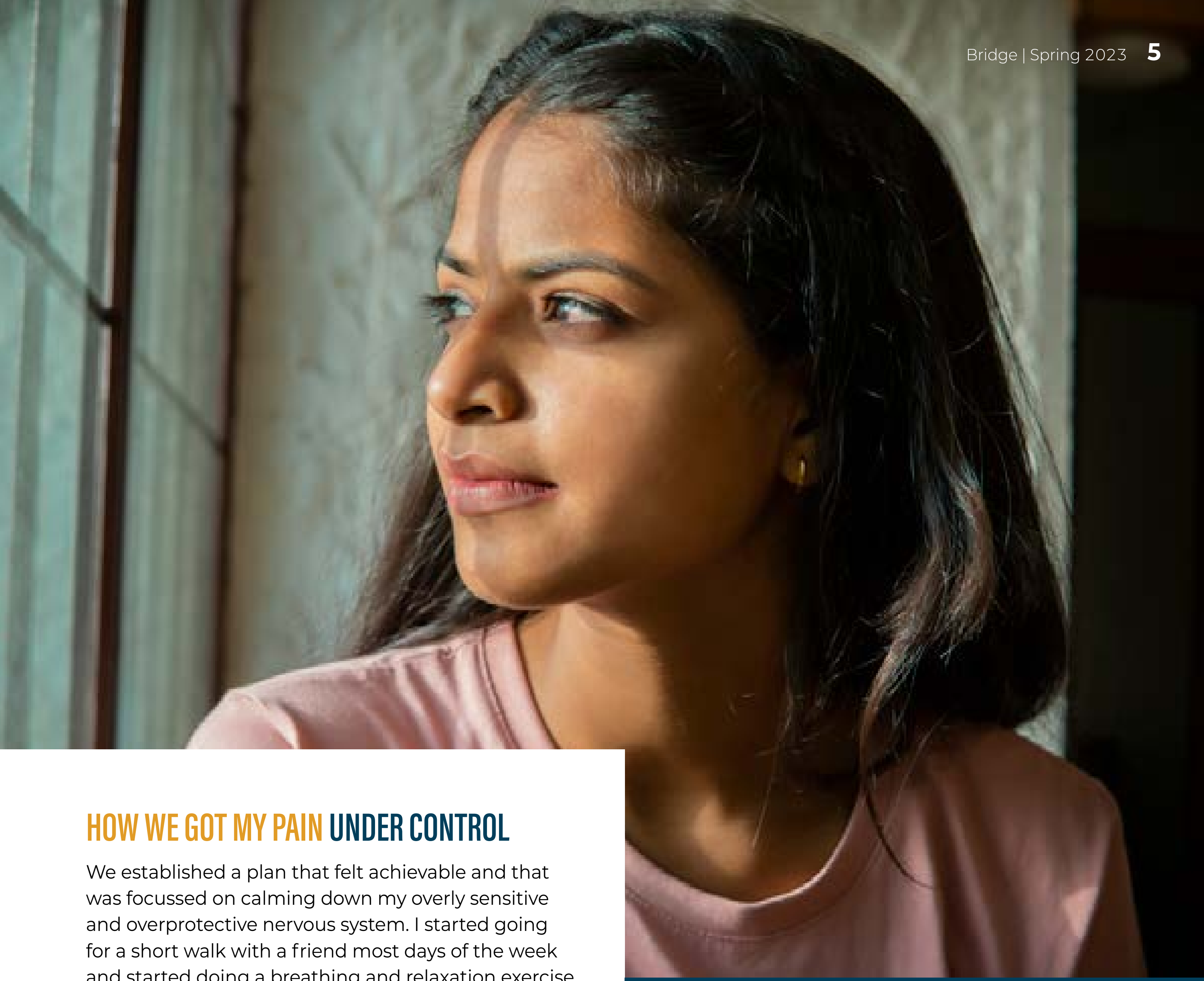
My gynaecologist suggested I see a pelvic health physiotherapist. From the first appointment, my physiotherapist really listened to me and I felt she genuinely cared about me. She asked about the impact endometriosis was having on every aspect of my life at the time; my mood, my work, my friendships, my thoughts, my openness to having a relationship and my dreams for the future. I felt heard. For the first time I felt hopeful; that I might be able to find some joy in life.

EVERYTHING MATTERS

I was so surprised to learn that there were many things, apart from my endometriosis, that could be contributing to my pain and symptoms and there were more options than surgery, medication and heat packs. My physiotherapist taught me that pain is one of the body's warning or danger detection systems and years of pain had made my nervous system sensitive and overprotective.

My physiotherapist helped me to understand that what I was thinking and feeling, together with all the things and people in my life (e.g friends, family and work) could be contributing to making my pain worse. Even things like sleep, my diet and general physical activity could either turn my pain volume up or down. We discussed how my nervous system works and that pain is produced by the brain, however this doesn't mean that it is in my head. I learnt that it is possible for the brain and nervous system to change and calm down. I finally started to have hope that I could change my pain, slowly and with support.

> *For the first time I felt hopeful; that I might be able to find some joy in my life."*



HOW WE GOT MY PAIN UNDER CONTROL

We established a plan that felt achievable and that was focussed on calming down my overly sensitive and overprotective nervous system. I started going for a short walk with a friend most days of the week and started doing a breathing and relaxation exercise in a position that I found comfortable. I noticed that I could calm my pain down if I did this exercise when I felt really uncomfortable. Just from these two simple things, I started to feel a little brighter in myself.

My physiotherapist also talked to me about the science of pain. Wow. I'd always been told that it could only be the endometriosis itself that causes pain. Now I know that pain is both physical and emotional. I also learned that pain is only one of the ways the brain protects me. My bladder urgency and my fatigue were also telling me that my nervous system had become sensitised and overreactive.

When I was ready, my physiotherapist assessed my pelvic floor muscles. I had no idea how much tension I was holding in my pelvic floor muscles and in my abdominal muscles. This tension was leading to my bladder symptoms and was contributing to why I couldn't use a tampon and why sex was painful. Learning how to relax these muscles was a turning point. I loved the feeling that the exercises my physiotherapist suggested I do each day reduced all that tension. After a while, I explored using a vibrator to learn how to keep my pelvic floor muscles relaxed.

WHAT IS AN INTRAUTERINE DEVICE (IUD)?

An intrauterine device (IUD) is a small contraceptive device that is placed inside the uterus. It is used to provide long term contraception and hormonal IUDs may make periods lighter and less painful.

WHAT IS ENDOMETRIOSIS?

Endometriosis is when tissue similar to that in the lining of the uterus (or womb) grows outside of the uterus, generally in the pelvic or lower abdominal area, including the ovaries, fallopian tubes, vagina, bladder and bowel. Some of the signs and symptoms of endometriosis include pain in the pelvic area, painful periods, heavy periods, infertility (or difficulty getting pregnant) and pain with sex.

My physiotherapist felt a bit like a health/life coach. She was in my corner and helped me troubleshoot and navigate problems and issues that came up. After a while, I agreed to see a psychologist so that I could work on changing the thoughts and feelings that were getting in the way of me feeling better.

MY NEW LIFE

I knew it would take time, and there have been ups and downs, but I finally feel like I am in control of my pain and my life. When things aren't going well, rather than panicking, I am able to reflect on what is happening in my life at the time and work out why my pain has flared. I now have a range of effective strategies to deal with my pain but overall I have so much less pain than I ever thought was possible.

> ***I knew it would take time, and there have been ups and downs, but I finally feel like I am in control of my pain and my life."***

I have met a gorgeous man and am in a very happy and supportive relationship, where intimacy is better than I ever imagined. When we go out with friends, I hardly ever have to cancel plans anymore. I don't even think about where the toilets might be. Plus, I have finally managed to build up a little bit of sick leave at work.

I realise I have to keep working at this. I know what I need to do to keep my nervous system calm. I have to exercise (and doing it with friends is just the best) and I need to prioritise my sleep. I need to make time for mindfulness and relaxation. I need to surround myself with people that care about me and are positive. Overall, I need to be kind to myself.

This story has been reprinted with kind permission from Pelvic Health Physiotherapist, Shan Morrison at Women's and Men's Health Physiotherapy in Melbourne.

> *"My skin was happy for one of the first times in 5 years. They don't cause itching, or pain. After you remove them you cannot tell where they were. They are sturdy and they didn't fall off (or even lift)."*
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> *- Kelly, CathGrip® User*

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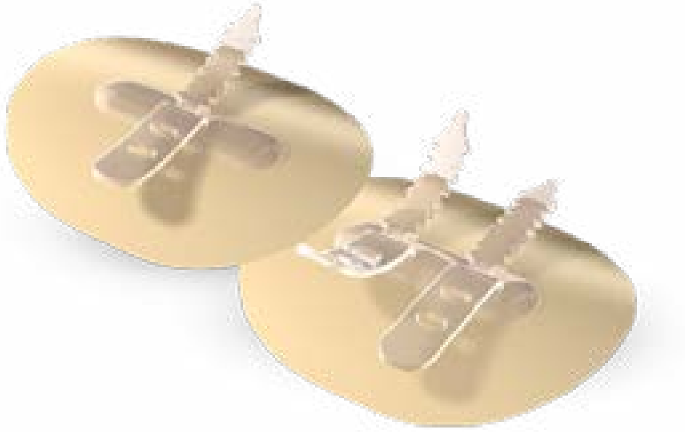

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LEANNE'S JOURNEY
TRAVELLING WITH INCONTINENCE

> *Buen Camino, my fellow pilgrims. Remember, the way always presents."*

Many years ago, when I was living in London, I worked with a woman who embarked on the Camino de Santiago solo in Spain. Each week, I would watch as she prepped and trained for this magnificent achievement. She didn't know it, but at the time she lit a fire in me that I have been stoking for 22 years; that I too one day would do my own Camino trek.

Early last month, I completed a section of the 'Portuguese route' on the Camino de Santiago de Compostela, with my husband Patrick and my children Connor and Molly. The Camino de Santiago, also known as the Way of St. James, is a famous pilgrimage of medieval origin where people journey to the Cathedral of Santiago de Compostela in Galicia in the northwest of Spain. The full route distance is 800 km which can take anywhere from two to three weeks or longer; however, we gained our certificate walking the last 136 km over seven days. The weather in Vigo Spain where we started was a sweaty 35 degrees Celsius and the 'flat route' was far from it, with undulating hills that made your heart pound and your legs cramp.

Leanne and family, the Camino de Santiago. Spain

Along the way, we stopped in Redondela, Arcade, Caldas de Reis, Pontevedra, Padron, Teo and very gratefully made it into the square of the famous Santiago De Compostela (Cathedral of Santiago). The Way of St James, or 'The Way' as it is referred to, shows pilgrims that whatever life challenges we are facing, we can just wake up, grab our bags and start walking. We walked with no intention of speed or conforming to rules, just walking and being present. Sometimes when you are in nature and surrounded by your thoughts you can be lucky enough to have reflection time or a profound breakthrough. I had certainly experienced my own breakthrough that I'm extremely grateful for.

I have faecal incontinence because of a birthing injury 12 years ago. I had to have an ileostomy initially, then a reversal (where my bowel was reconnected and

LEANNE'S ESSENTIAL TRAVELLING TIPS

- ✓ Keep track of your water intake. Don't share your water bottle, so you know exactly how much you're drinking.
- ✓ I took sanitiser, wipes, nappy bags for used wipes and change of underwear in my daily pack (just in case), which was important as some public toilets were without paper/soap.
- ✓ Keep up your fibre intake with fruit and vegetables as best you can by ordering extra fruit salad or side salads where possible.
- ✓ Ultimately believe the day will go well and remember 'the way always presents' meaning whatever you need, it will come... and it does! Buen Camino!

returned to my abdomen) and had to 'learn to poo' again at age 34. I was in nappies with my two young children and in fact my son was toilet trained before me. It's been incredibly isolating and difficult at times, however five years ago I set myself a goal to complete my own 'pilgrimage' around my local area. I realised that even though the doctors told me I may never be able to walk around the block due to faecal urgency and incontinence, I wanted to find out exactly what my body was capable of. I ended up walking 100 days in a row, starting from the letterbox to the end of the driveway, back to the letterbox and repeating. Soon I could walk as far as six km without having an accident. I knew then that my body was capable of far more than I had thought or believed.

The Camino de Santiago trip was back on the cards! My dreams were renewed, and I was pursuing them with gusto. In July this year we set off for Portugal, spending days in Lisbon and Porto before commuting to Vigo, Spain to start the Camino de Santiago.

In the lead up to the trip, I was extremely worried about bowel or faecal urgency, as I have short notice between needing to go and going. As you can imagine this was nerve-wracking, being in the middle of a walking trail, in a foreign country, not knowing where the next toilet would be. I'm extremely happy to report that I was able to manage my incontinence throughout the trek, with preparation, a practiced routine, monitoring my diet and fluid intake and having the necessary supplies on hand.

I learnt that incontinence is no reason to put off a long-held dream. In fact, I would say completing the Camino with my family far surpassed my dream. It was thrilling, joyful, challenging, peaceful and self-fulfilling. It was also a great reminder that while incontinence is part of my life, I can still live my life to the fullest and follow my dreams.

WHAT IS AN ILEOSTOMY?

An ileostomy is a type of stoma. It is a procedure performed to help direct digestive waste out of the body, often due to bowel conditions such as bowel cancer, inflammatory bowel disease (e.g Crohn's disease) or bowel trauma. This involves surgically making an opening that connects the small intestine or bowel to the outside of the abdomen. For some people, this surgery is temporary, often to allow the large bowel or anus to recover and can be reversed once the body has healed.

WHAT IS A STOMA?

A stoma is a small surgical opening made on the abdomen and is most often connected to the bowel directly, or a piece of bowel joined to the bladder to allow waste (urine or faeces) to be diverted out of the body. It is covered with a collection bag or pouch which needs to be emptied regularly. A stoma may be temporary or permanent, depending on the cause. The most common reasons for needing a stoma include bowel or bladder cancer, inflammatory bowel disease, diverticulitis or an obstruction to the bowel or bladder.

WHAT IS A STOMA REVERSAL?

A stoma reversal is surgery to reattach the ends of the bowel together after a period of rest following previous surgery. The stoma is often used for a period of time to allow for healing of a section of the bowel or the anus.

HELPLINE Q&A
TRAUMA-INFORMED CARE

Trauma can have a profound and long-lasting impact on individuals. If you have experienced a traumatic event in your life, you may benefit from trauma-informed care. Many people experience trauma in their lives and often more than once. The experience of trauma is very individual as is the impact.

Experiencing trauma can affect you psychologically, physically and socially. It can result in a person not feeling safe, not feeling they have a voice, not feeling valued, not trusting other people and not being able to connect with support and services. People can struggle to engage with health services because of experiencing trauma.

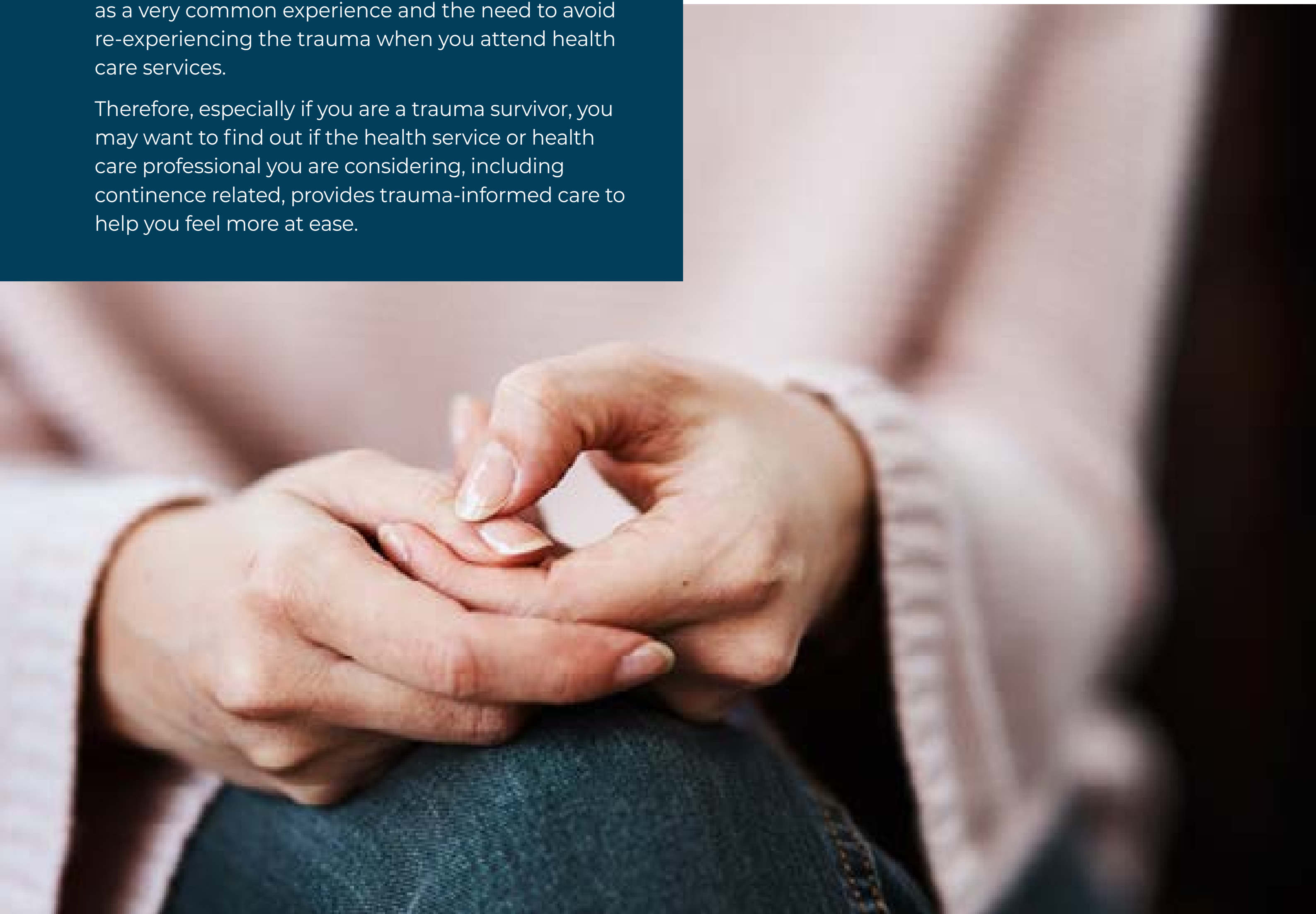
Trauma-informed care aims to provide you with support and not reinforce the impacts of the trauma you have experienced. Trauma-informed care aims to increase awareness of the prevalence of trauma as a very common experience and the need to avoid re-experiencing the trauma when you attend health care services.

Therefore, especially if you are a trauma survivor, you may want to find out if the health service or health care professional you are considering, including continence related, provides trauma-informed care to help you feel more at ease.

WHAT DOES TRAUMA-INFORMED CARE LOOK LIKE?

Based on the Substance Abuse and Mental Health Services Administration (SAMHSA) Trauma-Informed Approach, it should involve the following four 'R's as key assumptions:

- **Realisation.** The service-wide realisation or knowledge of trauma and its impacts on clients, families and communities.
- **Recognise.** All staff can recognise the signs of trauma.
- **Responds.** The service responds by using a trauma-informed approach in all areas. This includes staff training and service policies.
- **Resist re-traumatisation.** Re-traumatisation of clients and staff is avoided, if possible. Staff are aware of practices that may be triggers to cause re-traumatisation of clients.



THE SAMHSA TRAUMA-INFORMED APPROACH ALSO FOLLOWS SIX KEY PRINCIPLES:

Safety. Ensuring physical and psychological safety. This includes an environment which is safe, including interactions with staff.

Trustworthiness. Maximising trustworthiness through consistent and clear boundaries.

Peer support. To help establish safety, hope, trust and collaboration by involving people with lived experience.

Collaboration and mutuality. Sharing of power and decision-making with clients, staff and the service.

Empowerment, voice and choice. The individual's strengths and experiences are recognised to promote recovery from trauma. Choice and control are maximised for clients with supported decision making.

Cultural, historical and gender issues. Cultural stereotypes and biases are not reinforced. The service offers culturally and gender responsive services and is aware of historical trauma.

Using these key assumptions and key principles, a health/continence service can better support you, especially if you are a trauma survivor. Having a service that actively promotes the provision of trauma-informed care including through staff training, plus active leadership and modelling, will create a safer environment for you to receive support with continence care.

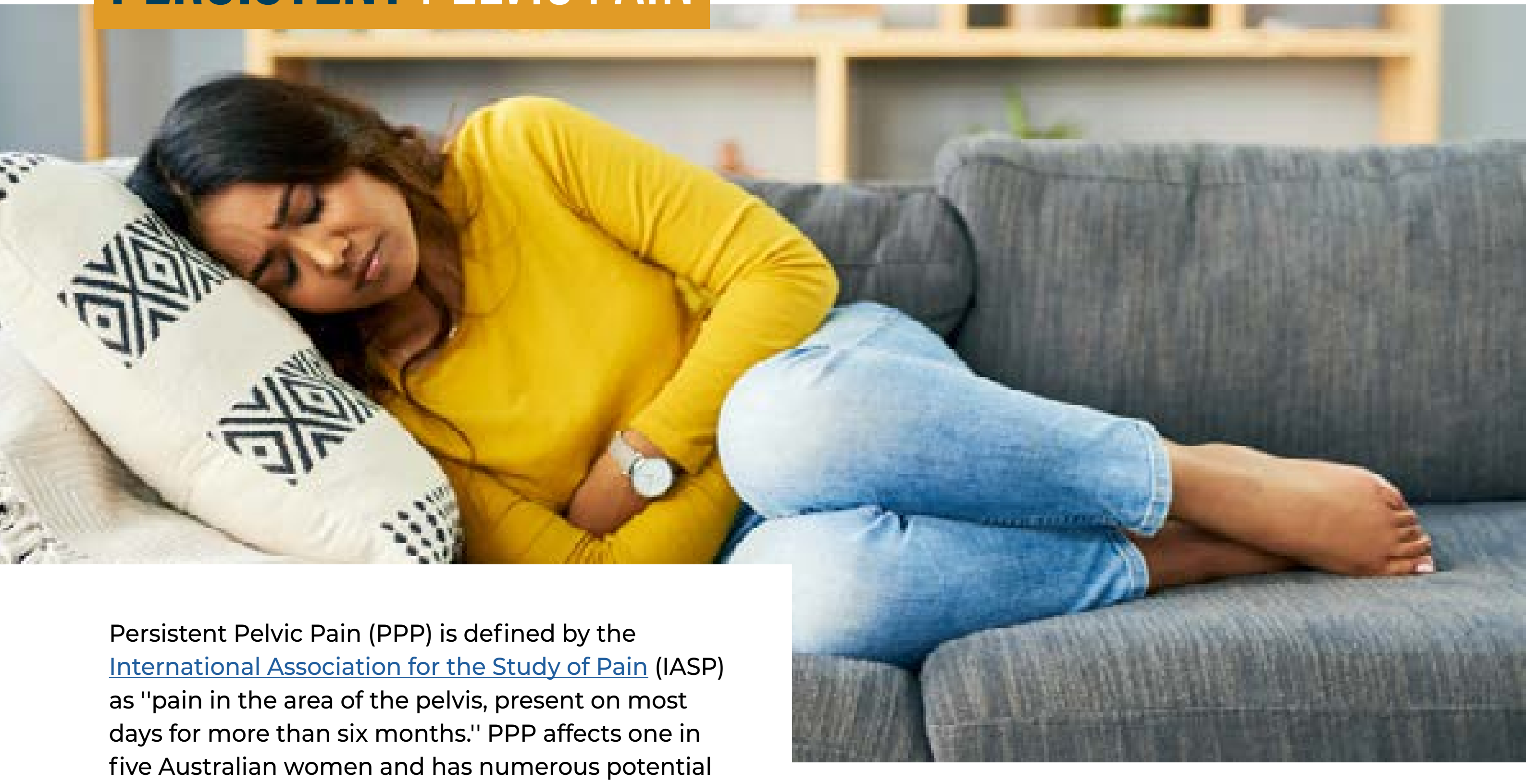
The nurse continence specialists on the National Continence Helpline are currently undergoing training in trauma-informed care. This will allow us to be more aware of and to implement the four 'R's, realisation of, recognise, responds to and resist re-traumatisation of trauma, when speaking to callers to allow us to provide a safe and trustworthy service.

Please call the **National Continence Helpline** on **1800 33 00 66** to speak to a nurse continence specialist for free confidential advice, information and resources from a trauma-informed service.

If this article has affected you in any way, please call: **Lifeline: 13 11 14** or **1800 RESPECT: 1800 737 732**

Reference: SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach (2014)

PERSISTENT PELVIC PAIN



Persistent Pelvic Pain (PPP) is defined by the International Association for the Study of Pain (IASP) as ''pain in the area of the pelvis, present on most days for more than six months.'' PPP affects one in five Australian women and has numerous potential causes.

We spoke to Pelvic Floor Physiotherapist, Amy Steventon, Bachelor of Physiotherapy and Post Graduate Certificate Continence and Pelvic Floor Rehabilitation, from Jean Hailes for Women's Health. Amy has worked with and supported numerous women who experience PPP.

Amy Steventon,
Pelvic Floor Physiotherapist,
Jean Hailes for Women's Health

WHAT IS PAIN?

The IASP defines pain as ''an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.''

Pain is part of your body's protective system to keep you safe. 'Danger' detectors in the body send information via nerves to the brain when a body part (or tissue) is under threat of damage or has been injured. This information is processed and interpreted together with all the other information available to the brain. This includes past experiences, general health, attitudes and beliefs around pain, your mood, stress levels and the environment around you. Combining all this information together, the brain then determines whether the tissues are at threat of damage or have been injured. If your brain decides the tissues are at risk of, or have been injured, pain will be produced so that you act to protect yourself.

> ***It is the brain not the body part, that creates pain.***

There are different types of pain and the pain experienced may be a combination of the following:

Acute (nociceptive) pain is felt when a body part is at risk of being damaged (e.g pulling your finger away from a hot object before it gets burnt) or when there has been an injury (e.g spraining your ankle). This pain improves quickly as the tissues heal.

Neuropathic pain is pain resulting from nerve injury such as a spinal cord injury or multiple sclerosis.

Persistent/Chronic (nociplastic) pain occurs when pain becomes persistent. This is long-lasting pain that goes on for more than three months or past normal tissue healing time. When pain has occurred for this long, the nervous system changes and the 'danger' detectors in the body become much more sensitive.

They can send more messages of 'danger' to the brain, even when the tissues are actually safe.

When this happens, the nervous system becomes overprotective. This occurs because over time the pain system learns to be more effective at protecting a certain body part. It's like a car alarm that is oversensitive or triggered by the slightest movement or noise. In this situation, pain doesn't mean there is any tissue damage. It is the sensitivity of the nervous system (of which the brain is a part) that is creating the pain, not any actual damage or harm in the tissues.

When your pain system becomes over sensitive or overprotective, pain can be experienced with things that don't normally hurt (allodynia) or greater pain can be felt with something that would normally cause mild pain (hyperaesthesia). This can occur in the part of the body where the pain first started (peripheral sensitisation) or pain can become more widespread (central sensitisation). People with central sensitisation often experience pain in more areas of their bodies and/or more often. For example, the pain was initially in the pelvis and is now also felt in other parts of the body, or the pain may have started just with menstrual periods but is now felt on most days of the month.

By understanding the involvement of the nervous system in pain perception, i.e how you feel pain and your response to pain, it helps to explain some of the individual differences we see in people with PPP. Hypersensitivity to noise, light, temperature, clothing and stress are other indicators of an oversensitive nervous system.

Psychological factors such as stress and trauma, social factors (such as relationships, family situation and work), as well as past experiences, can powerfully influence how the brain produces pain. These factors usually have a greater influence on persistent pain, compared to acute pain.

The encouraging thing to realise about persistent pain is that because so many factors affect pain, there are many things that can be done to change pain. Just as the nervous system has learnt to be overprotective and produce pain, it can also unlearn pain and become less protective again. By understanding that pain is more than a physical sensation; it is also influenced by sleep, exercise, general health, attitudes, beliefs, mood, environment and the people around you, it allows you to understand there are many ways you can affect your pain – both moment to moment and over time. This can be a very empowering feeling to know that you can take control of changing your pain.

WHAT ARE THE MOST COMMON INITIAL CAUSES OF PERSISTENT PELVIC PAIN?

PPP is a complex condition and many things may contribute. This may include biological factors such as period pain, endometriosis, adenomyosis, irritable bowel syndrome (IBS), pelvic floor muscle (PFM) dysfunction, painful bladder syndrome (PBS), urinary tract infections (UTIs), vulvodynia, chronic pelvic pain syndrome, inflammation and hormonal changes.

PPP can be impacted by psychological factors such as how a person thinks about their pain, stress, past trauma and the bi-directional effects of pain on sleep and mood. Social factors may also play a role in a person's experience of pain, including relationships, social connections, work situation, family dynamics etc.

Pain may have started with a physical cause, but this initial cause of pain may no longer be present. However, for some people, the pain persists and then becomes the disease or condition. This is because the changes over time in the nervous system make it 'overprotective' or 'over sensitive.'

WHAT IMPACT CAN PERSISTENT/CHRONIC PAIN HAVE ON YOUR HEALTH?

Persistent or long-term pain can have a significant impact on your mental health and emotional wellbeing. It can cause or add to your stress levels, result in anxiety and/or depression and lead to social withdrawal or avoiding people and activities. Living with any chronic condition can be debilitating and draining. Chronic pain in particular, can impact the quality of your sleep, your mood, appetite, energy, concentration and motivation. It can also place significant stress on your relationships, both intimate and other.

This can become a vicious cycle, particularly if people become more socially isolated, depressed, less active and able to function due to pain, which can all contribute further to anxiety, depression and reduced activity levels.

Many body systems can be involved in PPP, including the bowel, the urinary tract, the reproductive and immune systems. Often other persistent or chronic pain conditions co-exist with PPP e.g chronic fatigue syndrome, fibromyalgia, chronic migraines, chronic tension headaches, chronic lower back pain and temporomandibular disorders.

HOW DO YOU HELP PEOPLE TO BETTER UNDERSTAND THEIR PAIN AND WHAT TECHNIQUES/APPROACHES DO YOU USE WHEN WORKING WITH A CLIENT WITH PERSISTENT PELVIC PAIN?

I work as part of a multidisciplinary team. We aim to build a supportive team around the person in pain, using a biopsychosocial approach (BPS). This approach places the person's pain story, their symptoms and goals at the centre of the picture. It takes into consideration not only the possible biological (physical) causes of pain, but also and just as importantly the psychological and social issues that may be impacting their experience of pain.

Firstly, it's important to validate the pain. That is, acknowledging the experience of pain as real no matter the cause. It is important to reassure the person that their pain does not necessarily indicate tissue damage by explaining that their oversensitive nervous system will be involved in producing their pain. Then, we look at realistic goals, pain reduction if possible and ongoing pain management.

One of the important aims of treatment is to improve function and quality of life. It may not be completely removing the pain, but working with techniques and approaches which empower the person to better self-manage.

Trauma-informed care is also part of all assessment and treatment. This allows the person to feel emotionally and physically safe, build trust with their healthcare professionals and collaborate with them to make informed choices and decisions.

Pain education is a very important first step in treatment. It's important for me to understand what the person believes is causing their pain. This can create opportunities to talk about how pain is produced, and the many ways pain perception or experience can be altered. By explaining the concept of central sensitisation, it helps people to think differently about their pain and understand that pain doesn't mean their body is damaged, that pain doesn't equal harm. This can be reassuring and build a more positive perception of pain, replacing thoughts of 'being broken', catastrophising and hypervigilance (constantly assessing or checking for threats or pain) with more positive thoughts and hope for recovery.

It's important to empower people with strategies that help manage their pain. I feel my role is to be their coach, to teach skills so they can manage their pain rather than be dependent on a healthcare professional. This helps to improve self-efficacy, that is an individual's belief in their ability to cope, self-manage their symptoms and their effects. Research and clinical evidence both demonstrate that higher self-efficacy is a positive predictive factor of treatment success.

Enablement is another powerful tool. This can be achieved once the person understands that how they think and feel about their pain can make it better or worse. They can be empowered to use this in a positive way to change their pain, slowly, gradually, over time.

Treatment techniques that can be useful for persistent pelvic pain:

- Pain education. Pain education changes pain more than any other treatment modality. Teaching pain science (how pain is made) empowers people to understand their pain and not be threatened by it. Pain education teaches skills to manage pain; understanding what makes their pain better or worse.
- Downregulate the sympathetic nervous system (SNS) with diaphragmatic breathing techniques, meditation, mindfulness and mindful movement, such as yoga, Qi gong and tai chi. All these can reduce the sensitivity of the overprotective or over sensitive nervous system. This can help to 'turn the pain down.'
- Pelvic floor muscle exercises. Usually with persistent pelvic pain the pelvic floor muscles become overactive, tight and painful. Relaxation or 'down training' exercises can help to restore the normal function of these muscles.
- Movement. Many people are often scared to move because of pain. This is called 'fear avoidance,' but this in turn increases stiffness and weakness and can make pain worse, becoming a vicious cycle. I teach clients that it is safe to move and how to move correctly. Regular movement and exercise also increase endorphin (happy hormone) levels, helping us to feel better. It's important to pace exercise at a rate and level that is suitable for the individual, so they avoid a 'boom and bust' cycle.

- Stretches for the internal and external pelvic muscles, as well as stretches for other parts of the body that have become stiff through disuse, poor posture or maladaptive holding patterns because of prolonged pain.
- Encouraging a relaxed posture helps the pelvic floor and abdominal muscles to relax. Using regular 'body scanning' can help to improve awareness of muscles that are held habitually tight, which can increase muscle overactivity and pain. Once the person is aware of which muscles they are holding tightly, they can consciously work to relax them.
- Hot or cold applications, e.g heat or cold packs.
- Transcutaneous electrical nerve stimulation (TENS) machine. This is a method of pain relief where small electrical currents are sent across the skin.
- Toolkit for 'speedhumps.' Speedhumps are when a person experiences a temporary increase in pain. It is helpful to have a toolkit of skills that can help to manage or reduce this. Tools in the toolkit may include stretches, deep breathing and relaxation exercises, walking in fresh air, support from family/friend/healthcare provider, rest, heat/cold or TENS. Speedhumps may also require increased pain medication for the short-term relief of pain.

Depending on the individual's needs, I may use hands-on treatments such as massage and/or stretches, gentle touch to desensitise tissues, teach diaphragmatic breathing techniques and improved body awareness and relaxation. I may also utilise equipment such as vaginal trainers. These help to desensitise tender vaginal tissues, promote safety through touch, reduce pelvic floor muscle spasm, encourage pelvic floor muscle relaxation and reduce fear or pain around this region. Biofeedback (information to help a client understand how their body is functioning), can also be helpful to retrain the pelvic floor muscles.

Graded exposure to activities or situations that may have been avoided due to fear of bringing on pain is used to help reduce the threat of these activities by experiencing them in a safe way with minimal discomfort. If required, treatment for difficulties with sexual function, plus bladder and bowel symptoms such as incontinence or difficulty emptying are also included.

HOW CAN SOMEONE LIVE WELL WITH PERSISTENT/CHRONIC PAIN?

There are so many things you can do to change pain, even if the pain cannot be completely removed. These are my top recommendations for living well with pain:

1. Education and understanding of how the brain produces pain. Knowing pain does not equal damage can reduce the perceived threat of pain and turn down the 'danger' messages going to the brain.
2. Desensitising the nervous system with techniques such as meditation, movement such as yoga or Qi gong, general exercise and breath work.
3. Support. Having a strong support network is crucial. This may include but is not limited to family/friends/partner and a supportive medical team as well as allied healthcare professionals. Build a team around you to support you.
4. Recognising and understanding what turns up the 'danger' messages for you and what turns up the 'safety' messages and learning how to manage these.
5. Toolkit. Ways to help you manage a 'speedhump' or pain flare:
    - Gentle exercise
    - Stretches/yoga
    - Heat/cold
    - Massage
    - Sleep
    - Focus on joy – sunshine
    - Friends
    - TENS
    - Talking.

WHAT RESOURCES CAN BE USEFUL TO HELP PEOPLE MANAGE THEIR PAIN?

Working with a supportive multidisciplinary team of healthcare professionals who focus on client centred care, i.e where you, the client are at the centre of the care plan and management. Understanding your pain and the importance of pacing, graded exercise and exposure, as well as setting realistic and achievable goals.

Healthcare professionals who can help:

- General practitioner, gynaecologist, urologist, colorectal/gastroenterological specialist, vulval dermatologist
- Pelvic health physiotherapist
- Pain psychologist, psychotherapist or psychiatrist
- Nurses, such as a nurse continence specialist and other allied health practitioners including a dietitian, nutritionist and occupational therapist
- Sexual medicine specialist, sexologist or sexual health physician
- Pain medicine physician.

Useful websites and resources:

- Continence Foundation of Australia
- Jean Hailes
- Pain Australia
- Pelvic Pain Foundation of Australia
- Tame the Beast – rethinking persistent pain
- Pain revolution
- MindSpot – chronic pain course
- Curable App
- This way up - chronic pain course

MARGARET'S STORY “I’M ALIVE, I’M ALIVE, I’M ALIVE”

Margaret worked as a nurse continence specialist at Caboolture Community Health in Queensland for many years. People could self-refer to the clinic where they ran a three-month continence treatment program after an initial assessment by Margaret and a pelvic health physiotherapist.

Margaret loved her work as a community nurse, sometimes sharing her own personal journey with incontinence when listening to and supporting her patients.

You see, Margaret's own medical journey began in 2000 when she was 47. At that time, she was working on a medical ward and had developed two herniated discs.

> *I was in a lot of pain and I couldn’t sleep, but I was still going to work to support my husband who was having chemotherapy treatment for lung cancer.”*

The nurse unit manager, who noticed her limping and in evident pain, sent Margaret to the emergency department (ED) to assess the nerve function in her leg. With no reflexes in her right leg, she was referred to the Royal Brisbane Hospital where urgent spinal surgery was recommended as she was fast losing the use of her leg.

“The pain relief was amazing after the surgery” says Margaret, “but I was completely unprepared for what else happened.”

A couple of months later she started to lose control of her bladder and was advised to have further surgery. Unfortunately, this resulted in Margaret developing both neurogenic bowel and bladder symptoms. She initially had long term constipation, which was followed by recurrent diarrhoea, making her incontinent.

Margaret

“I put up with this for six months thinking it was the ‘new normal’ then I went to my GP. He referred me to a gastroenterologist who confirmed it was a permanent problem,” says Margaret.

After urodynamic testing at the Royal Brisbane Hospital, Margaret was told she would have to learn to self-catheterise as she had bladder neck dyssynergia. This is where her nursing background was useful. Knowledge and understanding of anatomy and an ability to locate and feel her urethra made it easier. Plus, it was something she could teach others.

“What was initially psychologically devastating became easier over time,” she says. Now, Margaret receives Botox treatment every six months to prevent her bladder from becoming overactive (i.e needing to empty often and suddenly). “It has become a lot more manageable, and I get a lot more sleep now.” she says.

WHAT IS BLADDER NECK DYSSYNERGIA?

Bladder neck/sphincter dyssynergia - also known as detrusor sphincter dyssynergia (DSD), is a neurogenic disorder where there is poor coordination between the bladder or detrusor muscle trying to contract to empty and the external urethral sphincter relaxing to open. Normally, these two separate parts work together. With DSD, when a person tries to pass urine, the urethral sphincter doesn’t relax properly as the bladder contracts, the pressure in the bladder increases and the urine flow is interrupted or intermittent. This can be the result of a neurological condition like a spinal injury or multiple sclerosis.

A LIFE-CHANGING OVERSEAS TRIP

In 2016, Margaret was excited to receive an invitation to join a cruise ship in the Mediterranean. “It was the first time I had ever travelled overseas,” says Margaret. “It was an absolutely marvelous trip until two weeks into it, I experienced a perforated bowel.''

Margaret’s bowel perforation developed as a result of a bowel obstruction. Unfortunately, there was no capacity to airlift Margaret so she stayed in the ship’s hospital quarters until they reached Crete in Greece, the nearest port with a hospital.

“The doctor on the ship had told me I might not make it,” says Margaret. “I had septicaemia (blood infection/poisoning), peritonitis (inflammation in the abdomen) and pneumonia.”

Once in Crete, Margaret was admitted to a small day surgery hospital. “It was like going back in time,” she says.

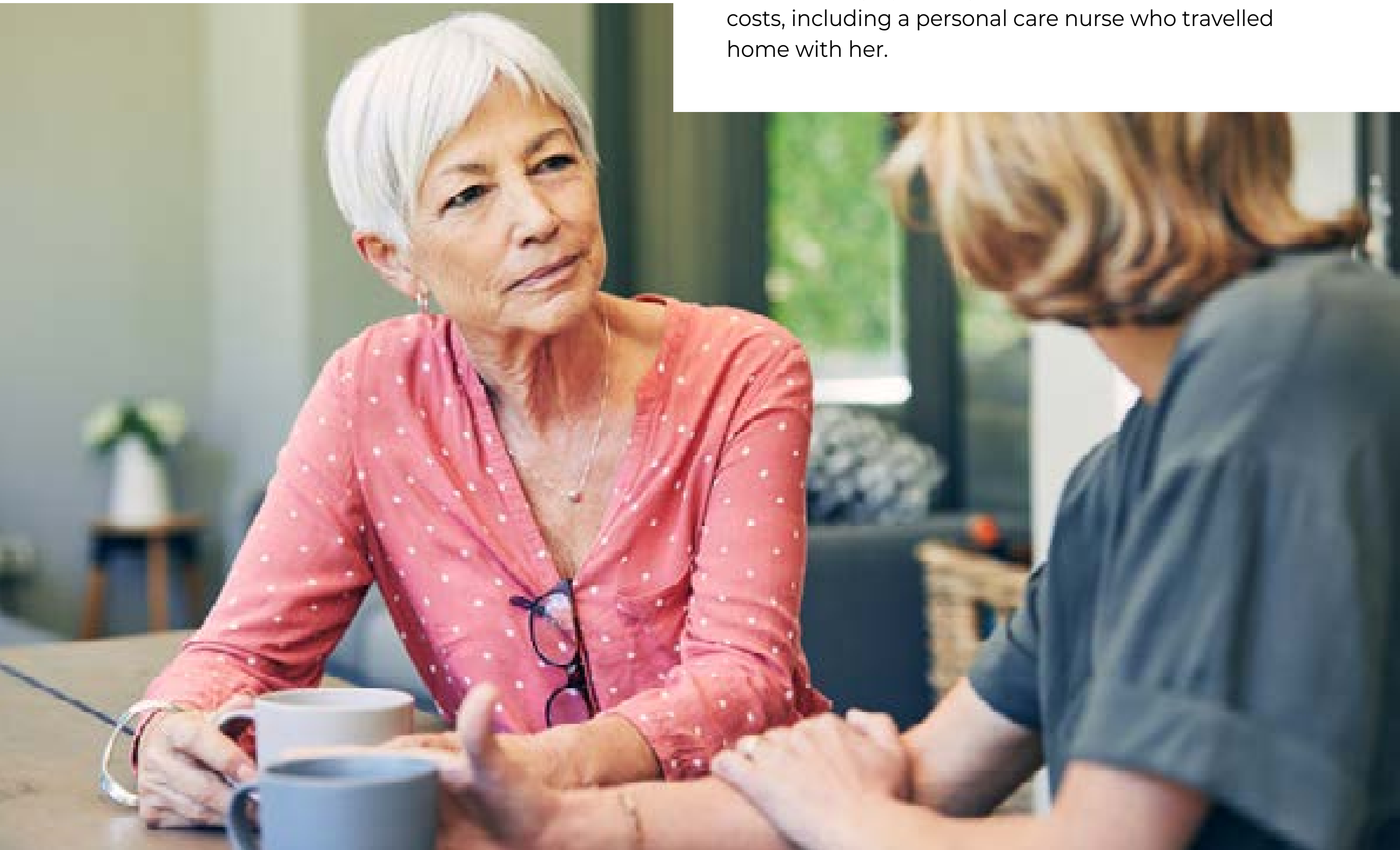
Things were moving fast. After an x-ray and CT scan, Margaret went directly into surgery. “They put a piece of paper in front of me and asked me to sign it, but it was all in Greek and there was no one to translate,” says Margaret.

As she was wheeled into a tiny theatre, the anesthetist and his assistant tried to tell her what they were going to do using sign language. Then, Margaret started vomiting. The situation had quickly become life-threatening.

“The Greek surgeon saved my life,” says Margaret. “I woke up with a stoma and a bag on both sides of my abdomen and tubes everywhere, but I was alive.”

Margaret’s daughter flew to be at her side from Australia. She helped Margaret negotiate the hospital and language differences. In preparation for her flight home, she practiced climbing stairs daily with her daughter as she would need this skill to board the airplane. She was finally sent home to Australia after ten days, accompanied by a critical care nurse. “I didn’t cry once until the plane started coming in over Brisbane airport. It was sheer relief. I did everything I had to do to get through but when that plane flew over Brisbane I just started crying and couldn’t stop.”

Margaret is full of praise for the ship and its crew, particularly the ship’s doctor. “I think the only reason I survived was because of the powerful antibiotics they gave me,” she says. “I was put onto them straight away and I think that’s the reason I pulled through.” She says she cannot recommend having travel health insurance highly enough as it covered all her medical costs, including a personal care nurse who travelled home with her.



MARGARET'S REFLECTIONS

This is a story of incredible human strength and courage, with what Margaret experienced so far from home but also in how she's managed her life since that time. While she is thankful for her opportunity to travel in Europe, she is also aware that this medical emergency could have had a very different outcome. "(Europe) was the most awesome experience because it was totally outside anything I'd experienced before," she says. "I had no idea until afterwards that with faecal peritonitis you can die up to three weeks post-surgery. My daughters say I should write down every day 'I'm alive, I'm alive, I'm alive,' but some days I don't feel so lucky," says Margaret. Whilst grateful to have survived, everyone has their down days and she says managing permanent bladder and bowel conditions comes with its challenges.

Margaret describes herself as a 'frequent flyer' to her local hospital. "I've had six major abdominal surgeries, my stoma repaired multiple times due to prolapse and obstruction and now I have adhesions (fibrous tissue that can form between organs) and persistent pelvic pain," she says. "However, my colorectal surgeon doesn't want to do any more surgeries as he is concerned about the risk of perforation to my small intestine."

Naturally, Margaret's personal experience with incontinence made her more empathetic with patients in her job as a nurse continence specialist. "Listening, asking them to describe in their own words what they were experiencing and how they felt about it and I'd be hard put ending the appointment in under two hours," she says.

"I've had a good life. I really have and I've thoroughly enjoyed being a nurse," says Margaret. She is thankful to be able to support others in need and although retired now at 70, she works as a community volunteer once a week. "My greatest joy is to sit and have a cup of tea with someone and have a nice chat. I like to listen to people's stories and hold that space for them. You can't take away their pain, but you can listen to and validate their experiences. We can learn from everyone's life stories and for me as a nurse it's been an honour and an education."

If this article has affected you in any way, please call:
Lifeline: 13 11 14 or 1800 RESPECT: 1800 737 732

WHAT IS URODYNAMICS?

Urodynamics or urodynamic testing, is a special bladder test that assesses how well the bladder fills and empties and how well the urethra is functioning. It generally involves having a catheter inserted into the bladder to monitor the pressure inside the bladder and a tube in the rectum to monitor pressure outside the bladder. These two pressure measurements help to work out what the bladder is doing as it fills with water and as the water is passed out.

WHAT IS BOWEL PERFORATION?

Bowel perforation is a hole in the lining or wall of the gastrointestinal tract. It is a potentially life-threatening complication of several diseases. Common causes of perforation may include trauma, instrumentation, inflammation, infection, malignancy, ischaemia and obstruction.

WHAT IS NEUROGENIC BOWEL AND BLADDER?

A neurogenic bowel or bladder can be the result of an injury to the spinal cord or nerve pathways to the bladder and/or bowel which can disturb communication between the brain and the nerves that control bladder and bowel function. This often results in the bladder not contracting and emptying properly, and poor awareness of the need to go to the toilet for your bladder and/or bowel resulting in incontinence.

WHAT IS SELF-CATHETERISATION?

Self-catheterisation (or intermittent self-catheterisation) is when you pass a catheter (or tube) into your bladder via your urethra to empty your bladder and remove it afterwards. This may need to be repeated several times per day depending on what your bladder function is like or how well it empties and as guided by your relevant healthcare professional.

Continence
Foundation
of Australia

Always rushing to the loo?

It doesn’t have to control your life

One in three women experience leakage from the bladder or bowel (incontinence). There is help available – you’re not alone. In many cases, incontinence can be treated, better managed or even cured.

Speak to a Nurse Continence Specialist for free, confidential advice.

Call National Continence Helpline

1800 33 00 66

Scan the code for further information or visit **continence.org.au**

The Continence Foundation is a not-for-profit organisation and peak body promoting bladder and bowel control health.