A healthy bladder and bowel play such a critical role in determining the quality of one’s life. In this edition Jane Ticehurst, a continence nurse of 14 years’ experience, reminds us of the devastating impact losing bladder or bowel control can have on someone’s life. She recalls a comment one of her patients, a woman with paraplegia, made: “If I could choose between regaining the use of my legs and having control of my bladder and bowel, I’d choose my bladder and bowel.” She also references a 2012 study that draws attention to the extraordinary impact bowel dysfunction has on people with multiple sclerosis, which is, in some cases, greater than that of immobility. We also send a day with our continence nurse consultants on the National Conti Helpline and discover just how tough a road it can be for those affected by incontinence.

In this edition we have a focus on our project for 2015, Carer’s count: support for continence management and we take a glimpse into life as an at-home carer of someone with incontinence. We speak with three carers and learn how their daily struggles with incontinence management affect their lives and the lives of those they love. I hope you enjoy this edition. Keep the feedback and ideas coming at bridge@continence.org.au

Maria

Winter 2015

Carers’ project

Overactive bladders

Tight pelvic floor muscles

A day at the Helpline

An injection of kindness

Q & A continence products

About us...

The Continence Foundation of Australia is the peak national body representing the interests of nearly one in four Australians affected by incontinence, their carers, families and health professionals. The Foundation, on behalf of the Australian Government, manages the National Conti Helpline (1800 33 00 66), a free service staffed by continence nurse advisors who can provide information, referrals and resources 8am – 8pm AEST weekdays. The Foundation, established in 1989, is a not-for-profit organisation.

References

Email bridge@continence.org.au for a list of references for any articles appearing in Bridge.

Become a member

Become an individual, student or professional member of the Continence Foundation of Australia and receive many benefits including discounted registration to the annual National Conference on Incontinence, free publications and timely information about events and courses. Email membership@continence.org.au or phone 03 9347 2522.

Diagnosis revealed:

overactive pelvic floor

The third most common reason men aged under 50 see their urologist is for unexplained and undiagnosed pelvic pain. Frequently it is accompanied by bladder, bowel and sexual dysfunction. Often these men are diagnosed with prostatect and treated with antibiotics, but in 90 per cent of cases there is no improvement in their symptoms. Investigations, blood tests and x-rays rarely throw light on the condition.

Graham Smorgon, chairman of the Smorgon Family Group, was one of these men, having suffered from mysterious, and often debilitating, pelvic pain for more than 12 years. A rheumatologist, a surgeon and several physiotherapists were unable to offer relief.

A referral to pelvic floor physiotherapist Shane Morrison revealed his condition as pelvic floor muscle pain due to an overactive pelvic floor.

Overactive pelvic floor, now officially recognised by the International Continence Society, is the name given to tight pelvic floor muscles that are “switched on” and active all the time.

Shane, director of Women’s and Men’s Health Physiotherapy based in Melbourne, was able to teach Graham therapies to relax his pelvic floor, control his muscular spasms and reduce his pelvic pain.

She provides a more comprehensive overview of overactive pelvic floor, which also occurs in women, on page 9.

ARA CRESSWELL is the CEO of Carers Australia, a partner organisation in this year’s project. Carers count: support for continence management. Prior to this, Ara held leadership roles in a number of national organisations, including Reconciliation Australia and Homelessness Australia.

What drew you to Carers Australia?

I come from a long line of carers and have always been in awe of what we humans will do for those we love most. I have watched family members struggle to balance their caring role with ordinary life, though most of them would say that caring is “ordinary life”. The more familiar I have become with the role of Australia’s 2.7 million carers and their challenges in terms of wellbeing and financial security, the more I have been inspired to play a role in securing the best outcome for them.

What are the key issues for Australia’s carers into the future?

Carers are becoming caught up in a whirlwind of major government reforms to disability care, aged care, adjustments to the social welfare system, mental health reform, proposed reforms to Medicare and the delivery of medical services, and changes to the way carer support services may be delivered. Carers Australia has a major role in ensuring that carers’ interests are protected and, to the extent possible, enhanced through these turbulent times.

In the coming year we will have a particular focus on securing a service model that acknowledges carers have their own needs over and above the needs of those they care for, and which supports carers in an integrated and equitable way regardless of the age or condition of the person they care for. We will also be launching an initiative to persuade employers of the business case for providing flexible working environments to enable carers to sustain employment while undertaking a caring role, and to assist long-time carers back into the workforce once their caring role diminishes or ceases.

Ara Cresswell will be a guest speaker at the breakfast launch of World Continence Week on June 19.
CARING
At what cost?

We speak with three women who offer a glimpse into life as an at-home carer of a family member with incontinence.

BEV COOK has been caring for her husband, Gary, ever since he suffered a stroke 15 years ago, aged 50. He has since been diagnosed with terminal bone cancer.

Pivotal to every decision Bev makes about Gary is his comfort because, she says, he has been the kindest, most loving man she has ever known.

The couple live on Gary’s disability pension, and Bev recently borrowed against their home to take him on a holiday and help make ends meet. Gary is incontinent and Bev spends between $190 and $230 every fortnight on continence products.

“It’s constant; there’s no relief, no break. We have to wash him 24 hours a day because he’s unpredictable. Sometimes he’ll wake up at 3am and will stay up until 11pm the next night,” Bev said.

Harry’s father, Damian, runs his own business and, as a result of his earnings, the family’s only government support is $50 a fortnight.

“We save the government money by keeping Harry at home,” she said.

“Harry, who now weighs 95kg, is non-verbal, has an intellectual disability and suffers from ADD, a combination that makes him difficult to manage. It’s not always easy caring for someone with incontinence, as it can be unpredictable, add dramatically to the caring workload and be costly. However, advice and support from a health professional can make it easier for the carer and car recipient.”

The project aims to raise awareness and improve support and understanding of incontinence for more than 140,000 Australians living at home who need help to manage their bladder or bowel control, including people with chronic illness, a disability, children and the elderly.

“People hear Autism and think Rainman or those who are high-functioning, but Harry slips through the cracks. He’s very low functioning.” Ms Zerafa said.

CARERS COUNT
Support for continence management

Preparations are well underway for World Continence Week, which takes place June 22-28. This year’s theme, ‘Tell someone who cares, encourages people affected by incontinence, or those caring for someone with incontinence, to seek help by phoning the National Continence Helpline (1800 33 00 66).

The theme supports this year’s special project, Carers count: support for continence management, which will be launched during World Continence Week.

There are 139,000 Australians living at home who need help to manage their bladder or bowel control, including people with chronic illness, a disability, children and the elderly. It’s not always easy caring for someone with incontinence, as it can be unpredictable, add dramatically to the caring workload and be costly. However, advice and support from a health professional can make it easier for the carer and car recipient.

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Tackling Overactive Bladder

Overactive bladder can have a profound effect on a person’s ability to participate fully in life. For many, conservative measures make a significant impact on their quality of life.

An estimated 12 per cent of the population has overactive bladder, a condition that can cause much upheaval in a person’s life. Research shows people with overactive bladders have less work productivity, lower sexual satisfaction, higher rates of depression and poorer health. About 12 per cent of Australian adults have symptoms of overactive bladder, such as waking up at night to pass urine.

Conservative treatments

After conditions such as prolapse, spinal damage, enlarged prostate and certain medications have been ruled out, symptoms of overactive bladder can be effectively alleviated with non-invasive, drug-free treatment programs, such as pelvic floor training and bladder training.

- Pelvic floor training.
  Your continence professional can teach you how to strengthen and train your pelvic floor muscles so you are better able to control urinary leakage and lessen the impact of involuntary contractions of the bladder.

- Bladder training.
  Your continence professional can teach you how to train your bladder so it holds more urine and empties less often (while maintaining necessary fluid requirements) by scheduling toileting breaks and holding on for longer periods.

Lifestyle measures

Preventing the condition may be difficult, but symptoms can be reduced by adopting a few lifestyle changes.

- Regulating your fluid intake.
  Your continence professional can help you regulate your fluid intake so you drink the correct volume for your body and level of activity, at the right times. Too much fluid can overfill the bladder and too little can concentrate the urine, which irritates the bladder. Your fluid intake should be scheduled so you drink well ahead of appointments or outings.

- Limit alcohol and caffeine-based drinks.
  Alcohol, caffeine-based drinks and fizzy drinks are known to irritate the bladder, which exacerbates symptoms of overactive bladder. Alcohol also has a diuretic effect, which can cause more frequent urination.

- Avoid constipation.
  Constipation can trigger or worsen symptoms of overactive bladder. Not only is the bladder’s physical space in the abdomen restricted as a result of constipation, straining on the toilet can also weaken the pelvic floor. Ensure you take every measure to avoid constipation, such as eating a fibre-rich diet, exercising regularly and responding immediately to your body’s signal to defecate.

- Keep your weight in the healthy range.
  There is evidence that losing weight decreases the severity and frequency of symptoms of overactive bladder.

When nothing else works

For severe cases of overactive bladder that haven’t responded to conservative treatments and medication, Botox injections and sacrocolpopexy are further options.

- Botox.
  Botox is injected via a cystoscope into about 20 sites on the bladder muscle, causing partial paralysis and stopping the bladder from contracting.

- Sacrocolpopexy.
  A pulse generator is surgically implanted into the sacral nerve, which resets the neural messages and restores normal bladder function. It is only suitable for cases where the neural connections to the bladder are intact.

Both treatments need to be recommended and administered by a specialist. Botox is PBS-funded for the treatment of severe overactive bladder, while the approximate $20,000 cost of sacrocolpopexy is PBS-funded in some public hospitals only.

More and more health professionals are coming to the realisation that overactive pelvic floor muscles may be responsible for previously unexplained chronic pelvic pain and incontinence. Specialist continence physiotherapist SHAN MORRISON explains.

What is an overactive pelvic floor?

This is when the pelvic floor muscles don’t fully relax, are held in a constant state of tension or when they contract when they should be relaxing, such as when urinating or defecating. As well as pelvic pain and pelvic floor muscle pain, overactive pelvic floor causes symptoms such as voiding problems, obstructed defecation and painful intercourse.

How do symptoms present?

In men they can present as pain or discomfort in the lower abdomen, perineum (between the testes and the anus), penis, testes, anus, lower back, buttock or tailbone. Women can experience pain in the abdomen, pelvis and legs, but symptoms can be reduced by adopting lifestyle measures, such as eating a fibre-rich diet, exercising and pelvic floor relaxation. There is evidence that losing weight decreases the severity and frequency of symptoms.

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- Keep your weight in the healthy range.
  There is evidence that losing weight decreases the severity and frequency of symptoms of overactive bladder.

What causes overactive pelvic floor?

Curiously, we also see patients with urinary urgency and overactive bladder presenting with an overactive pelvic floor, which we believe may be due to neurological sensitisation caused by the muscle overactivity.

What causes overactive pelvic floor?

It may be that some people hold their tension in their pelvic floor muscles instead of more common areas, such as the neck or shoulder muscles. Some women have done a lot of gym work with core training and hold their bellies and pelvic floor muscles in tight all the time in order to have tight pelvic floor muscles. This adds to the problem of habitual muscle tightness.

The pelvic floor muscles are not meant to be held tight all the time; they should be soft and flexible, like the muscles between your thumb and index finger.

What can be done?

A pelvic floor physiotherapist can design an individualised down-training program that needs to be practised every day at home. They can teach stretches and relaxation exercises that release and relax pelvic muscles and help overcome the pain.

Treatment may also involve desensitisation to vaginal penetration while practise pelvic muscle relaxation, with the goal of progressing to sexual intercourse. A physiotherapist may give instructions on gentle internal massage of the pelvic floor muscles, which teaches them how to relax and soften.

Where can we learn more?

You can talk to a pelvic floor physiotherapist or access some of these excellent resources:

- The Pelvic Pain Foundation of Australia: pelvipain.org.au
- Pelvic Pain e-book: pelvipain.org.au/information
- CVS, for pelvic floor muscle relaxation: thepelvicfloorclinic.com.au
- The Explain Pain Handbook: Protectors.com

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A DAY IN THE LIFE OF A HELPLINE CONTINENCE NURSE

This selection of calls to our National Continence Helpline gives some indication of the breadth and scope of inquiries our continence nurse consultants field on a daily basis.

I took a call from a woman in her 50s. She'd had an abscess in her bowel last year that had developed into an anal fistula (a tract from her bowel to the skin near the anus). This resulted in leakage and she had become faecally incontinent.

She phoned the Helpline because her application for funding through the Continence Allowance Payment Scheme (CAPS) had been rejected. She wanted advice from us because she had been told her condition was "not permanent and severe".

Her GP had filled in the form, and I wondered if a crucial box on the application hadn’t been ticked. I suggested two options; one was to contact the CAPS office to clarify the reason for their decision and the other was to go to her local continence nurse for another assessment and a new CAPS application. I told her the nurse would also be able to help her apply for the state-based scheme she was eligible for. I also suggested she keep a copy of her CAPS application – something I advise all applicants.

She had a great attitude, full of humour and persistence despite difficult circumstances. However, she was frustrated about her CAPS application’s rejection and mused over how she might try to convince the CAPS people that her condition was serious. Jokingly, she suggested sending in a photo of her anal fistula.

I told her a complete application form would be more likely to get her funding approved. In closing, I told her there was no need to send the Helpline a photo, but if she did, we’d love to see it autographed!

I spoke to a mother of a seven-month-old breast-fed baby, concerned that her baby was constipated. She told me she had already introduced an adult diet by simply chopping up whatever she and her partner ate. The baby’s faeces were now dry and pellet-shaped, she said, and she wanted to rectify the situation before her imminent return to work.

I explained that the baby’s digestive system was not sufficiently developed to handle an adult diet and advised her to cut back on some of the foods she was giving her baby, and reintroduce them gradually at later dates.

I suspected the baby was not getting sufficient liquids and suggested she increase her breastfeeding in order to add more fluid to the baby’s diet. I also suggested she puree the baby’s food and add fluid to it.

I advised her to do her utmost to restore the baby’s bowel movements to a soft consistency because administering laxatives to an infant was not in the baby’s best interests.

A woman in her 50s, herself a nurse, phoned the Helpline in a distressed state because recent failed bowel surgery had left her faecally incontinent. Her colorectal surgeon had recommended she self-administer a daily bowel wash-out, which would empty the lower bowel, thereby preventing any faecal incontinence for the remainder of the day.

She had phoned the Helpline because the concept of a bowel wash-out was upsetting and confronting. I explained how the wash-out worked and reassured her it was an effective way of maintaining her continence. I also advised her to visit the manufacturer’s website, where she could access further information, including demonstration videos. I suggested she contact the company directly because they employed continence nurses who could provide further personal support.

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Janine
A 92-year-old man phoned the Helpline for advice on preventing incontinence. He still lived at home with his wife and neither of them had any problems at the present time. They wanted it to stay that way.

They were both active, had well-balanced diets with adequate fibre intake, drank sufficient fluids and were evidently doing all the right things.

I told them they were clearly on the right track and encouraged them to maintain their good habits.

Merrill
A 94-year-old woman phoned the Helpline to reassure us that, yes, even at her age, pelvic floor exercises worked.

She’d recently been referred to a continence physiotherapist for urinary incontinence and had received instructions on doing pelvic floor exercises correctly. She told me that, even though she couldn’t “get down on the floor any more”, her urinary incontinence had been cured since starting her pelvic floor exercise regime.

I let her know it wasn’t necessary to get on the floor to do the exercises, and explained the meaning of “floor” in this context, which she appreciated.

It was a lovely call, and great to hear her obvious delight in no longer having to put up with urinary leakage.

Clare
A gentleman had phoned the Helpline to enquire about his eligibility for CAPS funding while living overseas. He also wanted to know if his family in Australia could purchase the catheters on his behalf and post them out to him.

I made enquiries with the Department of Social Services and found out that he was eligible and that his family could make the purchases.

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Steve
AN INJECTION OF KINDNESS

JANE TICHEURST, a continence clinical nurse specialist at Northern Sydney Home Nursing Service, tells us why kindness has been a potent factor in her patients’ healing.

I wasn’t one of those little girls who always knew she wanted to be a nurse. I was 18 and decided to be a nurse 10 days before our university applications were due. I wanted to travel and always be able to get a job, and nursing seemed the obvious choice. I have travelled and I’ve always had a job, but I was also incredibly lucky to choose a career I love. But it’s the community where I’ve found my niche - in the speciality of continence. It is interesting how my approach to nursing has changed in 14 years of practicing. When I started, the emphasis was on the science and physiology. These things are still important, but I’ve come to realise that it doesn’t respect the patients’ experience of ill health and treat it with compassion, my knowledge and skills have little impact on their involvement in their own wellbeing and health outcomes.

“She’d felt bitted during the first assessment.”

Being a continence nurse affords me the privilege of touching people’s lives when they are at their most vulnerable. More than 4.8 million people suffer from urinary or faecal incontinence, but despite this, incontinence still invites social stigma. I recently had a paraplegic lady tell me: “If I could choose to be not one of those little girls who always knew she wanted to be a nurse. I was 18 and decided to be a nurse 10 days before our university applications were due. I wanted to travel and always be able to get a job, and nursing seemed the obvious choice. I have travelled and I’ve always had a job, but I was also incredibly lucky to choose a career I love. But it’s the community where I’ve found my niche - in the speciality of continence. It is interesting how my approach to nursing has changed in 14 years of practicing. When I started, the emphasis was on the science and physiology. These things are still important, but I’ve come to realise that it doesn’t respect the patients’ experience of ill health and treat it with compassion, my knowledge and skills have little impact on their involvement in their own wellbeing and health outcomes.

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