Celebrating inspiring people
Welcome to our special World Continence Week edition of Bridge Magazine. In this issue, we will be celebrating inspiring stories from real people who have generously shared their moving accounts of living with incontinence. One such story comes from Melbourne writer and advocate, Greg Ryan. Greg was born 53 years ago with an imperforate anus, which means without an anal opening, a condition that back then could have killed him in his first day of life. It was a pleasure to meet Greg and his uncle, TV personality Bert Newton, at the launch of Greg’s new book A Secret Life. His is a confronting story full of anguish, anxiety and enormous courage.

Our cover story features Sydney businesswoman, wheelchair user, wife and long-distance swimmer Anne-Marie Howarth. Anne-Marie suffered a spinal cord injury in 2005 and discovered first-hand the cost of ordering single-use catheters. Across Australia, there will be hundreds of celebrations happening in the lead up to, and during, World Continence Week this year including; displays and children’s storytimes in libraries, primary schools and council facilities; healthy bladder and bowel talks with community groups, at health organisations, aged care and retirement facilities; pelvic floor exercise classes in fitness clubs; continence displays in pharmacies and performances as part of the comedy roadshow currently touring the nation.

A special thanks to all of our partners and supporters of the Laugh Without Leaking public awareness campaign, particularly our Ambassador actress/comedian Bev Killick who is documenting her personal journey from incontinence to continence which you can follow on laughwithoutleaking.com.au.

If you would like to share your own personal story, we would love to hear from you.

So stay warm this winter and enjoy a good read with this edition of Bridge Magazine.

Jodie
Jodie Harrison
Editor

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Email bridge@continence.org.au for a list of references for any articles appearing in Bridge.
Irmina Nahon is Assistant Professor, Clinical Education Coordination at the University of Canberra and works as a pelvic floor physiotherapist in private practice. She is very passionate about continence promotion, as well as research into the assessment and management of incontinence.

What sparked your area of specialty in pelvic floor and continence health?

After working as a physio for 10 years, I did a post graduate certificate in pelvic floor rehabilitation at Melbourne University because it seemed like an interesting course back in 2001. Prior to that, I had only had minimal exposure to women’s health. What really got me thinking was the opportunity to be part of a Men’s Continence Clinic, that the Canberra Government was hoping to set up. I discovered that there was no research available to support the treatment of male continence issues. We were taking evidence from female research and applying it to men. That just seemed wrong to me. There are many differences in male and female continence and it is more than the dangly bits. So, I did a Masters and then a PhD to find out how we can best assess and treat male pelvic floor dysfunction.

I treat men and women as well as children’s continence and pelvic floor dysfunction now. I am still focusing my research in the male pelvic floor but also research in the other areas.

What are the common symptoms of poor pelvic floor health?

Leaking urine, going to the toilet frequently or urgently and altered control over the back passage are some of the more common symptoms that people with poor pelvic floor health experience. However, some people also get pain in the pelvic floor, which can be really debilitating. What is most important is that we talk about this more. Most people with bladder or bowel issues keep it to themselves rather than talking about it.

Why don’t we talk about this and who should we talk too?

Embarrassment and thinking our habits are normal are our biggest barriers. “Nice people don’t talk about what they do in the bedroom or on the toilet”. If we do not talk about these things, how do we know what we do is right or wrong? Why do we see these topics as being disgusting or taboo? Many people are worried about talking to their GP. This is the first person you should talk to if you have a concern about continence or pelvic pain. Pelvic floor physiotherapists and continence nurses are specially trained to talk to people about these issues as well. You do not need a referral to see a physiotherapist, just check first that they are a pelvic floor physiotherapist.

What do you ask when you see a new patient?

When I see a patient for the first time, I will spend an hour finding out what the problems are. I will ask about when it started, how severe it is and how much it impacts on them. The questions do get very personal, and I will cover what happens in the bathroom, as well as the bedroom. There are no wrong answers, as everyone experiences pelvic floor problems differently. After working in this field for more than 15 years, there is nothing that I haven’t heard before so there is no need for embarrassment either.

Once I know what is going on, I can formulate the why and then the treatment options. Pelvic floor exercises are only a part of the large array of options I have to help manage and treat pelvic floor dysfunction and pain.

Should we all be doing pelvic floor exercises?

Pelvic floor exercises are very good when the muscles below the bladder and bowel are weak and cause leakage when pushed. However, pelvic floor exercises may not be as effective when it is the control of the bladder from the brain that is the problem, or when the pelvic floor is so tense that it causes pain. This is why completing a good assessment is key to effective treatment. Not everyone leaks urine for the same reason.

My research has also shown that how we train the pelvic floor needs to be individualized. Women who have given birth for example, have a stretched weak pelvic floor after 9 months of carrying the baby and delivering it. Men who have their prostate removed for prostate cancer do not have a weak pelvic floor muscle, but need to retrain how and when they use the muscles to compensate for the change in control due to removal of part of the continence mechanism.

Can pelvic floor exercises cause pelvic pain?

Yes, in some cases doing pelvic floor exercises can cause pain in the pelvic area. For some people their pelvic floor is too tense and working to tighten it more can and does cause pain. A careful assessment, which includes an examination of the muscles internally, can identify this. Then we use ‘down training’, relaxation and other techniques to rectify this. Pelvic floor tension can also be caused by pain caused by other conditions such as endometriosis, recurrent cystitis or severe urgency. An experienced pelvic floor physiotherapist will assess the issues and help develop a treatment program.

How long does it take for continence or pain issues to improve after starting pelvic floor conditioning?

When properly assessed and diagnosed, the pelvic floor should start to show signs of improvement within a few weeks. How long it takes will depend on how motivated someone is to work on it and how severe the issue is. Pelvic pain usually is a little slower but with careful management can also improve greatly.

The key is to have a good assessment done by an experienced pelvic floor physiotherapist or continence nurse.
World Continence Week 2018
from stigma to celebration

Incontinence has traditionally been perceived as a taboo subject, a stigma that has seen people suffer in silence instead of talking about their problems. As a result, many cases have gone unreported, preventing treatment and often a cure.

To celebrate World Continence Week, we are sharing inspiring personal stories from the determined people who have battled incontinence and emerged from their struggles with silver linings.

As the national peak body in Australia, we see World Continence Week as a great motivator to encourage people to take the first step to improve their bladder and bowel problems—which is to talk about them. Incontinence affects 1 in 4 Australians and the first step to improving bladder, bowel and pelvic health problems is to ask for help.

“IT is a massive problem affecting over 5 million adult Australians and costing the Australian economy more than $67 billion a year,” says Continence Foundation of Australia CEO Rowan Cockerell.

“We know that many people dismiss their leaking as a normal part of getting older or after having a baby. But it is not normal and has a serious negative impact on daily life for millions of women, men and children.”

“Don’t put up with it! The good news is that you can quickly change your life for the better. Most bladder and bowel problems can be better managed, better treated and, in many cases, even cured says Mrs Cockerell.

Incontinence is an issue that affects people worldwide. From 18 to 24 June this year, there are World Continence Week celebrations happening across the globe; in Canada, USA, China, Denmark, Brazil, Singapore, New Zealand, Italy, Poland, Uganda, Greece and Germany, to name just a few.

Here in Australia, we have partnered with health and arts organisations, schools, libraries, government and the continence industry to promote events, talks, performances and displays Australia-wide such as children’s story times, healthy bladder and bowel talks with community groups, and pelvic floor exercise classes in fitness clubs.

To find what is happening near you, search our What’s On directory http://www.laughwithoutleaking.com.au/blogs/events/

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Thanks

The Continence Foundation of Australia thanks our wonderful partners and supporters of Laugh Without Leaking and World Continence Week 2018, helping to spread the good news that the majority of bladder and bowel problems can be better treated, better managed and even cured!
We are leading the World Continence Week celebrations with our Laugh Without Leaking campaign featuring comedian, actress and mother-of-two Bev Killick, who has struggled with incontinence for most of her life. Laugh Without Leaking has been rolling out across TV, newspapers, radio and across the Internet using humour to encourage people to talk about their bladder, bowel and pelvic floor issues, as the first step to seeking help. It has heralded the discussion of personal stories of resilience and inspiration, and facilitated the message that the majority of bladder and bowel problems can be better managed or even cured.

“I remember in primary school that I had a weak bladder and the teacher would reprimand me for asking to go to the toilet during class,” says Bev. “My Mum eventually intervened, but I think my body became confused about the impulses to go to the bathroom. Because of my concerns, I became out of tune with my body’s needs.”

“Years later, after I had my children, I was naughty and didn’t do my pelvic floor exercises. This meant my floor was weak and I leaked - especially when I laughed. That’s a very dangerous situation for a comedian!” But Bev turned her continence trials into a comedic triumph, writing her experiences into her stand up routine.

“Whenever I’m on stage, I get the audience to do pelvic floor exercises and I actually do them too – I’m not just pretending. When I did a show called Busting Out I used to put a pad on to catch leakage. I would be onstage for 40 minutes at a time, so I didn’t have a chance to go to the toilet and it involved a lot of jumping around. It happens to a lot of singers, you’d be surprised. Especially when you’re singing and you’re really using your diaphragm to belt out the songs … oops I did it again!”

By becoming the ‘face’ of continence, Bev is now on the road to improving her own bladder control issues.

“You don’t have to endure this problem. You can get better!” That was the greatest news I could hope to hear after my first consultation with a pelvic physiotherapist.”

“I thought I might feel embarrassed or awkward, but I actually felt very comfortable. Surprisingly, there was nothing difficult about it. At last I feel hopeful for the for-wee-able future,” she smiles.
Greg’s Secret Life

Greg Ryan was born without an anal opening, a congenital abnormality known as Imperforate Anus which affects 30,000 babies around the world each year. Without surgical intervention at birth, Greg would have died within 24 hours. Two Australian surgeons saved him, but the outcome ushered him into a life of shame, secrecy, social stigma and intense mental health difficulties. After years of surgical intervention and counselling, Greg found a pathway out of his despair. He shares his journey of courage, loneliness, and enlightenment with us.

At various times, most of us have had that uncomfortable feeling knowing something is not right with your stomach and we have to race to the toilet. But for me it takes on a different meaning, as I was born with a birth defect called Imperforate Anus (IA), which is also known as Anorectal Malformation (ARM). Unknown by 99.9% of the general population, this congenital anomaly occurs at an incidence rate of ONE in 5000 births in western countries and about double that in other parts of the world.

In lay terms, I was born without an anal opening or any sphincter muscles or nerve control in my rectum/anal area. Coupled with that I have associated major urological issues and that combination means I have had many surgeries as well as intrusive procedures (Rectal Enemas, Bowel Washouts etc.) from the day I was born to as recently as 18 months ago. Unfortunately, due to my dysfunctional bowel and rectum/anal area, it means I must deal with the uncertainty of what may occur with my bowels every single day of my life.

I learnt to cope with being known as the smelly kid at school; on the football field with my best-mates by using the strategy of rubbing dirt onto the back of my shorts, so no-one would notice the inevitable soiling patch; at high school I wore my school pants. Worst, when all my friends had the weather, to camouflage the stain on my jumper tightly around my waist, no matter how evident. On occasions, I have to treat the nappy rash created by the acidic nature of the mucous leakage by using cream.

The ARM collection of anomalies is rare and because of its affects it was something that I could not discuss due to the stigma attached to toilet habits and hygiene issues. Even though we can’t live without our bowels the last thing anyone wants to talk about, or listen to, is someone’s bowel habits. It was certainly one thing I didn’t want in any conversation. So, I chose to keep my condition as ‘my secret’ to anyone other than my parents and my doctors and, not surprisingly, I thought I was the only person with this condition.

The thought that anyone would know I had an issue which was so embarrassing, and humiliating was too much for me to bear so I learnt to live my life doing everything I could to protect “my secret” from being revealed.

The secret however eventually came at a cost physically and emotionally. I lived in a state of constant anxiety. I was petrified that someone could smell me because I had had an involuntary bowel accident due to faecal incontinence or had flatulence over which I had no control. More dramatically, I sometimes felt a stool in my rectum which I had no idea was coming because I had no muscle control or feeling in my rectum.

The only place I felt safe was on a toilet. Here I don’t need to be on guard, to feel scared or anxious, to feel ashamed or embarrassed. I can be myself and not worry about ‘my secret’. But after I leave the toilet, the battle continues because I must contend with anal leakage due to not having any muscle control to prevent the normal bodily function of mucous. The mucous causes leakage which in turn causes soiling. So, I wear a female panty liner to protect myself from any soiling patch being evident. On occasions, I have to treat the nappy rash created by the acidic nature of the mucous leakage by using cream.

Everyone born with IA/ARM - and there are about two million of us alive today, along with our parents who did not have a choice about our fate - have to adapt and deal with the physical and mental consequences of this life-long condition every day. This is primarily in silence. In 2014, I was incredibly fortunate to find small online support groups catering for individuals born with IA/ARM and their families and after 50 years I realised that I wasn’t alone anymore.

Last year I decided to ‘come out’ publicly by writing a book which I naturally called A Secret Life – Surviving a Rare Congenital Condition. My purpose was to alert everyone to the condition, encourage a dialogue and arrange better support for all IA/ARM sufferers across the world.

I am now talking to thousands of others carrying this burden, along with supporting parents and educating the medical fraternity of the physical and mental issues connected to the condition, which for so long has been viewed as a ‘Paediatric only’ medical issue. I don’t have to live with the burden of ‘my secret’ now, but still must contend with living with the physical and mental health challenges of my condition. Revealing ‘my secret’ has become a truly wonderful feeling. Now I feel free to talk openly and contribute to spreading awareness without that fear of being exposed.

The proceeds from the sale of Greg’s book ‘A Secret Life’ will be distributed to his non-profit organisation ONE in 5000 Foundation, onein5000foundation.com.au
MEDIA SPOTLIGHT

We have been busy working with media outlets around Australia to help bring bowel and bladder health into the public spotlight. Here are some of them.

Comedian Bev Killick
Our Ambassador, comedian Bev Killick has been promoting our Laugh Without Leaking campaign on ABC Radio, the Herald Sun and HIT Central Queensland Radio. You may have also seen Bev in action on our TV commercial. If you’ve missed it, you can view it on our campaign website: www.laughwithoutleaking.com.au

Go 55s
Go 55s has published features in their past two issues on Incontinence – What It Is And How To Cure It and Men Have Pelvic Floors Too. Go 55s have also been promoting the National Continence Helpline.
Anne-Marie Howarth was 31 years old when she suffered a motorbike accident which left her with a spinal cord injury, restricting her bladder and bowel control. Not to be outdone by her injury, instead it opened a world of new opportunities.

When was your motorbike accident?
It happened in 2005. I was on my learner’s licence and I’d only had the bike and my licence for four weeks when I took a corner too fast and slid out and hit a guard rail in the Blue Mountains. I sustained a T7 incomplete paraplegia as a result of that which resulted in a loss of bladder and bowel control. Because it’s incomplete, I have some control over my bladder and bowel but not enough to be particularly helpful.

Directly after the accident I spent the better part of five months in hospital, which is pretty standard for an injury like that. In hospital, they just put you on a Foley indwelling catheter and a bag, and while I was taught to use the intermittent catheters in hospital, I wasn’t really strong enough or fit enough to get on and off a toilet very easily to get my pants on and off.

How did you manage after you got out of hospital?
When I left hospital, probably somewhat prematurely, I had with me a Foley catheter and a bag and continued to use that for several months. Until I was fit enough and strong enough to change back to intermittent catheters which a lot of people with paraplegia use, but they were very, very expensive and I did the maths and realised if I keep using these for the next 50 years I’d be spending about $100,000 on catheters. I thought that was insane! It wasn’t until three years after my injury that I actually started ocean swimming about two years after my injury – I’ve always been a swimmer, but I never thought I was fit or strong enough prior to my accident (which turns out to be ridiculous, but I didn’t know that then). Up until recently I would swim around three times a week. The distance would vary depending on what, if any, events I was training for – somewhere between 1-Skm. This last summer I slacked off due to persistent shoulder problems, though I’m hopeful that I will get back to it in future.

What inspired you to start your own business?
I looked around at other countries and I could see that catheters were available more cheaply in the US for example. But there are restrictions on purchasing catheters over there because you have to have a prescription. And also if you import catheters there’s a cap on how much you can import – there’s an Australian Government restriction that you can only get three months supply. And it’s a personal supply so that meant you couldn’t buy in bulk from overseas so there was just no cost-effective way of getting anything more cheaply. And then I read if you registered and had a company then you could import them and I thought maybe I’m not the only one with this problem. So that’s where it started and I crossed my fingers and gave it a go. That was in 2010 – five years on from the accident.

What difficulties did you have to overcome?
When I set up the business I was working two jobs at the time, looking after websites. My husband was extremely supportive, but it was basically me running it so I’d basically have a bunch of catheters in a bedroom in the house, I’d grab some to go to work in the morning and go and deal with everything in the afternoon. A lot of people didn’t know at the time but I’d go to work with a big sack on my wheelchair which was loaded up and I’d take it to the post office each afternoon. I’d sneak into the conference room at work and return customer’s phone calls. So I actually did that for the first three years in business, and then it just got out of hand. At some point I got eParcel to come and pick up the parcels from my house so I didn’t have to drag them up to the post office because there were just too many of them. But the business has grown a lot since those early years – I now have staff packing and answering the phone. It’s a full time business for me now.

What’s your message of inspiration to anyone struggling through incontinence issues?
With incontinence I would say you can be surprised by what you get used to. Things become normal very quickly, and after a while you won’t even give it a second thought. I’ve changed my catheter something like 25,000 times now. Although it is very shocking to start with, you will be surprised by what you can get used to.
Q: Jack is a 92-year-old man who reported he was having a very poor urine stream to the point of not passing urine for many hours at a time. Jack’s son asked what could he do for his dad?

A: Jack definitely needs to go to see his local doctor immediately. Jack has probably ignored his poor bladder habits for many years but it is time to have a chat with the GP. The GP can do some tests and if necessary refer Jack to a specialist to check and see if the bladder is emptying properly.

Q: Rose is a 24-year-old woman and was having trouble with her bowels with persistent diarrhoea. She works in a job where it’s not easy to go to the toilet. When she gets the diarrhoea she uses medicine so she can do her work without interruption. Then she gets blocked up again. She asked for our help.

A: Having a bowel pattern of diarrhoea and constipation is a problem and you need to be assessed by your GP as soon as possible. He may ask you to have some tests including a bowel X-ray to see what your bowel is doing. Conditions like constipation can be diagnosed this way. Once the GP knows what the problem is he can then help you to work out strategies to manage your bowel so you can go to work and be confident everything will be alright. Healthy bowel habits are really important – look on page 11 to help you get into a good routine.

Q: I work in a supported accommodation in Victoria, caring for a 35-year-old male with severe disabilities. He is requiring continence pull ups daily, related to adverse behaviours. We have worked with both the psychologist and occupational therapist with no change in his behaviour. Is he eligible for any financial assistance?

A: This young man is eligible for funding as his adverse behaviours have failed treatment and his incontinence will probably not improve. He can apply for the Continence Aids Payment Scheme (CAPS) and the Victorian State Wide Equipment Program (SWEP).

To access the CAPS scheme you can download the forms at www.bladderbowel.gov.au The SWEP program requires a Continence Nurse.
Advisor assessment and subsequent prescription. This program only provides washable products and urinary catheters. When your client goes over to the National Disability Insurance Scheme (NDIS) ensure these products and the Continence Nurse Advisor yearly assessment are added into the plan, as all federal and state funding will roll over into the NDIS plan. For more information on NDIS please go to www.ndis.gov.au

**FIVE HEALTHY HABITS FOR YOUR BLADDER AND BOWEL**

Good healthy bladder and bowel habits can have a significant impact on our lives, and small changes in our daily habits can help prevent, or at least improve, urinary incontinence and faecal incontinence.

1. **Eat a well-balanced diet with at least 30g of fibre daily.**
   Two of the big risk factors for incontinence are obesity and constipation. Both can stretch and weaken the pelvic floor muscles – either through carrying excess weight or straining on the toilet.

2. **Drink about 1.5 - 2 litres of fluid daily**
   Drink to satisfy your thirst, not to meet an arbitrary volume. Your urine should be pale lemon in colour, and darker urine indicates insufficient fluid intake.
   Overfilling your bladder can cause accidental leakage, or if overstretched regularly, make the bladder floppy and unable to empty properly.

3. **Exercise regularly**
   Aim for about 30 minutes a day and remember, if you’re not the sporty type, walking is perfectly adequate. General exercise helps to: keep the pelvic floor toned, prevent constipation and keep the weight down.

4. **Keep your pelvic floor toned**
   Everyone needs to do pelvic floor exercises every day. Strong pelvic floor muscles are critical for holding up our abdominal organs, controlling our urinary and anal sphincters, and sexual function.

5. **Practise good toilet habits**
   Sit on the toilet leaning forward with your elbows on your knees, and your knees higher than your hips (use a footstool if necessary).
   Empty your bowel when you get a strong urge, and avoid holding on. If you hold on too long, you risk the faeces hardening, which can lead to constipation.
   Empty your bladder when it’s full, and don’t get into the habit of going ‘just in case’. Take the time to empty your bladder completely every time.

For further information speak to your doctor or a continence nurse advisor on the free and confidential National Continence Helpline on 1800 33 00 66 or visit continence.org.au

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1 in 4 Aussies are incontinent
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