Note from the editor

Many people believe the myth that incontinence is a normal part of life, particularly for those who have had a baby, are disabled or are in their twilight years. This is NOT true.

In fact, the majority of people who report bladder and bowel issues are under the age of 50 years and it may surprise you to know that there are between 20,000 to 60,000 teenagers with incontinence in Australia today. We also found there was very little information out there specifically for this vulnerable younger age group.

In this issue of Bridge, we introduce you to an exciting new website that the Foundation has developed for young people with bladder and bowel concerns. It is called Incontinence in Confidence and is packed full of great tips for getting help, handling tricky social occasions and managing incontinence problems.

We also meet young Queensland model, Anja Christoffersen who shares her story about being incontinent since birth and why she is now standing up as a role model for other young people with health issues.

We talk to Continence Foundation of Australia President, Michael Murray who, after a distinguished career as a continence health professional, recently found himself on the other side of the doctor-patient continence divide. He shares his very personal insights following the diagnosis of a serious illness.

Finally, we are looking forward to a touch of spring in Tasmania as the continence industry gathers in Hobart for the annual National Conference on Incontinence. There will also be a Community Forum on Continence on 23 October (see page 12).

Jodie Harrison
Editor
Dr Ong works as a geriatrician at the Royal Melbourne Hospital - consulting in the Continence Clinic and conducting urodynamic studies and research. His work centres on the management of incontinence presenting alongside other medical issues.

What interested you in pursuing a geriatric medicine and continence career?

I am forever grateful for my seniors who mentored me. They inspired me in the way they cared for the most frail and vulnerable patients - holistically and compassionately. Through the geriatric medicine registrar training program, I had an opportunity to take up a fellowship to train in the continence area. I was humbled by how immensely I could impact a patient’s and carer’s quality of life.

Describe your typical work week.

The week starts with clinical discussions of complex cases within our multidisciplinary team of doctors, continence nurses and pelvic floor physiotherapists. Later, I consult in the outpatient clinic and carry out video urodynamic studies. I conduct tutorials to medical students and junior doctors rotating through our department. I participate in Journal Club within our clinic and with other clinicians interested in urodynamics. There is an annual meeting with clinicians at the Royal Children’s Hospital to assist with children transitioning to adult services. I also visit residential aged care facilities to carry out comprehensive geriatric assessments which support the resident, family, general practitioners and facility staff in managing some of their frail and complex residents.

What kind of impact can continence issues have on major decisions like relocation to a residential home?

It is recognised that the three major reasons for a person having to relocate into a residential aged care facility are dementia, immobility and incontinence. I think the biggest challenge is that we have to address all of these simultaneously, because they frequently occur together. To enable people to live in their homes for longer, we firstly need to improve the recognition of these conditions so that the person can be offered treatment to improve and manage them. Too often people think it is part of ‘getting old’. Treatment is usually well-tolerated, practical, specifically-tailored to the person’s situation and widely available. They can also be linked in with numerous support programs, access to equipment, as well as carer support. Should a person relocate to residential care, I advocate that these conditions continue to be reviewed to maximise a person’s quality of life.

Do you have recent research that you’d like to share?

Our clinic has active research in the area of nocturia, spearheaded by Professor Wendy Bower. Nocturia is waking up at night to pass urine and has been associated with worsened health outcomes. It interrupts sleep and impacts a person’s quality of life.

Nocturia depends on the ability of the bladder to store urine at night. It also depends on the amount of urine the kidney produces at night, which is then dependent on heart, lung and hormone function. Sometimes, people have nocturia for factors completely unrelated to urine, such as sleep, pain or mood issues. Each person’s nocturia might be due to a different cause or causes. Understanding and identifying these causes allows for better targeted interventions to improve outcomes.

What single action could make a real difference to continence sufferers?

You are not alone. There is assistance available and experts in the field who can help. Frequently, it is something simple and practical that could potentially make a world of difference. So seek help. Contact the National Continence Helpline on 1800 33 00 66 or see your local doctor.
From catwalk model to role model

Brisbane-born model Anja Christoffersen was only 17 when she first walked in Amsterdam Fashion Week. Three years later, she’s also focusing on another kind of modelling—being a role model for young people with chronic bladder and bowel conditions. Anja was born with VACTERL Association, a disorder that affects many body systems. While she’s been incontinent her entire life, she hasn’t let it get in the way of pursing her dreams. Anja speaks to Kasia Kosidlo about her challenges and ambition to help others.

Could you tell us a little bit about yourself?

To look at me you would think I am a normal, ambitious 20-year-old without a worry in the world. Behind the scenes, I have daily struggles with chronic health issues. I am affected by vertebral abnormalities, a single kidney and a ‘plumbing problem’. When I was born, I couldn’t get food into my body or get it out. At the top end, I had esophageal atresia, and a fistula with my trachea – meaning there was no join from my mouth to my stomach; food and water would be channelled directly into my lungs. This was repaired at birth. On the bottom end, I had cloaca where my intestine, urethra and duplicated reproductive organs came out in one channel. At birth, I first had a colostomy and vesicostomy, then a full reconstruction at seven months old where they created the three separate openings.

In terms of bowel function, my diagnosis meant that I didn’t have an anal sphincter, muscles, rectum or nerves, so I’ve been incontinent my whole life.

What has this diagnosis meant for your day-to-day life?

When I was younger, I was in and out of hospital with chest and urinary infections, chronic constipation and VACTERL监察, further medical imaging, treatment and surgeries. At one year of age, I began doing daily rectal washouts [enemas] to induce bowel contractions and give me social continence. Otherwise, my bowel was like a tap that was turned on and would flow constantly or totally off and blocked up. Even with these washouts I would still have accidents in day-to-day life. I also face some chronic pain and other ongoing issues related to my bowels, reproductive and urinary systems.

How do people react when you share your story?

Ever since I was very young, I’ve been open about my story with lots of my friends and family. Thankfully, people have been really understanding and I haven’t faced any bullying when I have been open about it.

I also believe it is important to help raise awareness, especially with the growth of social media where everyone seems so perfect. It creates an unrealistic expectation for young people. I think being open about my health challenges educates others about the silent battles young people like me face. It also provides a space where others do not feel so alone in the fact that they too have struggles.

Have you met other people with similar health issues as you?

When I was growing up, the survival rate of VACTERL wasn’t as high and incontinence was something that was considered a taboo subject. It wasn’t discussed as openly as it’s beginning to be now. I used to wish for a positive role model talking openly in the media.

Last year, I decided to reach out in some of the online Facebook communities and share a bit of my story. I received an overwhelming, positive response and I realised that my story was helpful to others with similar conditions. And there was a lot of people out there. Social media is a great communication tool for people all over the world, particularly those who live in countries that may not have access to the medical care we do in Australia or the support networks. Connecting online gives people hope and the knowledge that they are not alone.

How important is a positive and confident attitude?

I was lucky to have the support of my family and my friends, especially my mother and my godmother as I was growing up. They didn’t smother me in sympathy nor let me feel sorry for myself for long. When we would discuss my condition, they always said, “it doesn’t matter”, “it doesn’t have to define who you are” and “it doesn’t have to have an impact on your quality of life and the dreams that you can achieve”. I grew up with the belief that I could do whatever I set my mind to, despite my congenital condition.

Of your career so far, what has been a highlight?

My biggest highlight would be walking in Amsterdam Fashion Week the day before my 18th birthday. It was something that I really wanted to do. So I set it as my goal of 2016.

My goal now is to model more overseas and keep working in Australia. I am also focused on using that platform to become a role model for others who suffer from chronic health conditions such as VACTERL Association, imperforate anus, incontinence and many more.

What would you like to say to other young people growing up with incontinence issues?

I’d say to them that as difficult as it may at times seem, stay positive and be confident. If you feel comfortable, be open about your condition so other people are aware and can support you when needed. Don’t let incontinence define you. Don’t let it stop you from doing what you want to do. Don’t let it cause you to isolate yourself and not leave the house. Be brave. There is always a way to better manage incontinence. Seek help to find that way!

A NEW WEBSITE FOR TEENAGERS WITH INCONTINENCE

The Continence Foundation is excited to launch a world-leading website designed to provide information, advice and support to young people.

Incontinence in Confidence was developed with the support of a group of continence experts, specifically for teenagers wanting to know more about daytime urinary incontinence, bedwetting and faecal incontinence.

Incontinence is commonly dismissed as an issue that affects older people, but research tells us that between 20,000 and 60,000 Australians aged 13 to 18 experience some form of incontinence. This can have a debilitating effect on quality of life and mental health, especially as they go through a period of significant social and physical development.

“We are proud to launch this website which is a game-changer for adolescents seeking answers about their continence concerns. Incontinence in Confidence means they no longer have to search through the misinformation out there. It is a safe and supportive online space for young people to get the answers they are looking for,” said CEO of the Continence Foundation of Australia, Mrs Rowan Cockerell.

Incontinence in Confidence supports teenagers at all stages – from those who have never seen a doctor for continence concerns, through to people who have been diagnosed.

It provides information on the different types of incontinence, who it affects, treatments, where to get help, tips on socialising, staying motivated, tricky conversations, dating, relationships and how to confidentially get on with life.

Find out more by visiting inconfidence.org.au
When the continence expert becomes the patient

Ever wondered if your doctor or health specialist truly understands the debilitating effect incontinence has on your life? Associate Professor Michael Murray does. We spoke with him about his own compelling, very personal post-surgery story.

Michael Murray is the Medical Director of Continuing Care and Head of Geriatric Medicine at Austin Health. He is also a clinical educator at Melbourne and La Trobe universities, President of the National Ageing Research Institute (NARI) and serves on several boards including as President of the Continence Foundation of Australia. He regularly works 70 plus hours per week; seeing patients, teaching medical students and voluntarily sharing his expertise in the interests of public service.

Today, Michael is discussing his recent learnings from the ‘other’ side. He is battling the biggest health challenge of his life after being diagnosed with incurable cancer.

“Back in January, I was told I possibly only had months to live. I had a tumour in my bowel and metastases in my liver and lymph nodes. It came as somewhat of a shock as I suppose it inevitably does. The drive that evening with my wife to see my specialist was very difficult,” said Michael.

“But I wasn’t going to take that lying down. I knew I still had a lot of living and work to do. I was going to make sure that I had the best chance I could to get a few more years out of life.”

Michael sought the advice of the best medical specialists he could find. Fortunately, subsequent tests revealed a much slower growing type of cancer than was first thought and it was hoped that extensive surgery with removal of half of his large bowel, some small bowel and part of the liver would give him the best opportunity and longest survival.

“I was very lucky in the sense that I had a high level of health literacy and a wide circle of friends and colleagues who work in this field to whom I am greatly indebted. I spoke with surgeons, physios, dieticians ... Most people are hard pressed to see one dietician, let alone four as I did.”

Post-surgery, Michael has had to overcome many obstacles to reach his goal to return to work.

“I tackled my rehabilitation like a full-time job. Every day, I would push my tolerance levels a little bit further, walking farther, exercising more ... I had a great physio who was an old colleague who worked me hard. I was incredibly motivated to return to work.”

Among the more distressing challenges Michael faced, was severe faecal urgency and episodic incontinence.

“Having worked most of my life in the field of continence did not lessen the shock and horror of now living with the reality of daily diarrhoea. If you had to choose about the type of incontinence you suffer from, faecal incontinence would not be your first choice. It is very difficult to contain. A well-formed poo is containable but a huge amount of liquid that comes out with ferocity, is not a great option.”

“I experienced reluctance and anxiety to leave the house. It is very difficult to prepare yourself adequately. Whilst I understood the theory and was well supported with lots of medication initially, not much works in that difficult situation.”

“I had to carefully plan my life around the availability of a toilet, taking ‘pre-emptive’ opportunity in terms of using the toilet before leaving home or indeed planning before I went anywhere a toilet wasn’t available. I quickly learnt what cafes or shopping centres had good facilities and ensured I used them at every opportunity. I needed to always carry a backpack of continence supplies; disposable pull ups, wipes, medicated cream, spare underwear ... I never left home without it.”

“I think I became more difficult to live with, more irritable and grumpy and my sense of self took a bit of a nose dive. I was extremely fortunate to have great friends and colleagues. I was given a huge box of gifts; puzzle books, DVDs, books and all sorts of distractions. I had people come to take me for short walks initially up and down my street, me on my frame with my emergency supplies. I enrolled in a cancer rehabilitation program at St Georges Hospital which was brilliant and covered sleep, exercise, diet, psychological support and no doubt contributed to my regaining my resilience.”

Six months post-surgery, the cancer is still there but Michael’s incontinence is dramatically better. His rehabilitation enabled him to regain much energy and, together with 25kg weight loss, fitter than he has ever been in his adult life. He is delighted to be back at work helping others with their health issues.

“Since my cancer diagnosis, I have realised I do not want to waste any time. I do not have time to waste. I have become more focused on achieving the most I can in the time I have,” he said.

Michael hopes that by sharing his recent experience, others will feel empowered to seek help.

“Continence Australia is there to help. They give people, who don’t have the access to knowledge and resources like I do, the assistance they need to do something about their incontinence. I urge others to take that first step toward a better life.”
What causes diarrhoea?

Diarrhoea has many possible causes including:

• bowel or stomach infection
• food allergies or intolerances such as lactose intolerance
• alcohol
• the use of stimulant laxatives, especially if overused or used incorrectly
• bowel diseases including diverticulitis, Crohn’s disease, ulcerative colitis, or irritable bowel syndrome
• some medicines, such as antibiotics
• long lasting constipation
• a shortened bowel as a result of surgery to remove some of the bowel, and
• radiotherapy.

If you experience severe diarrhoea it is important to seek medical advice. For more information, call the National Continence Helpline 1800 33 00 66

Continence videos for the Deaf

Deaf Services Queensland have released a series of short online videos on bladder and bowel health thanks to a community grant from the Continence Foundation of Australia.

They have produced an informative video series for those who communicate using Auslan. It covers essential information like bladder and bowel control, how to sit on the toilet properly, and healthy habits and exercises with a preventative focus.

Deaf Services Queensland identified poor communication and health literacy as key barriers for hard of hearing and deaf seniors accessing the support they need - and the organisation has set out to combat this.

The Continence Foundation’s Queensland Health Promotion Officer, Rae Plush - together with an Auslan interpreter and captioning - present four short video clips, which have been distributed online and via DVD or USB sticks on request.

“Congratulations to those involved for finding innovative ways of turning face-to-face workshops into accessible content that can be easily shared and referred back to,” said Continence Foundation CEO, Rowan Cockerell.

The continence video series is available on Youtube and the Deaf Services Queensland website at: www.deafservices.org.au/services/Ageing-Well/Video-resources

If your community group is interested in applying for a grant for an initiative to promote healthy bladder, bowel or pelvic floor habits, head to www.continence.org.au/pages/community-health-promotions-grants-program.html or email grants@continence.org.au
Women’s health nurse and Continence Foundation member Julie Tucker, realised the consequences of not having appropriate disposal bins and brought the matter to the attention of Gawler Mayor, Karen Redman, who also has a background in health.

“Talking to family, friends and colleagues, I was made aware that women’s and disabled toilets were covered but men didn’t even have rubbish bins, let alone continence bins. There are a lot of myths in the community around men’s sneaky leakage. Many thought that it didn’t happen to men and was only a woman’s problem,” said Julie.

Continence issues can affect anyone, no matter the demographic. The prevalence of incontinence is estimated at 10 to 15 per cent in Australian men, which increases up to 20 to 30 per cent in men over 70.

Inadequate methods of disposing continence products can mean a constant worry of public embarrassment and demotivate men from doing everyday things like venturing from the house. Having to carry around disposal bags and waste can be resolved with discrete sanitary bins in toilets.

Gawler Council has recognised the immense impact a small step like installing bins will have for the community.

“When the Council was considering the motion, I gave each councillor a little pack with a pad, disposable bag, wipes etc. so they could see what a person may need to dispose. I think it helped to conceptualise what people with incontinence have to contend with,” said Julie.

Councillor Redman said that the compelling continence proposal earned a positive reaction from both the council and community.

“There was unanimous support from councillors to install the bins. Members of the community I have spoken to were surprised it wasn’t already in place,” Cr Redman said.

The Continence Foundation congratulates Gawler Council on this initiative and hopes other local governments will soon follow.

“It’s clear that the lack of sanitary disposal bins in men’s toilets is a widespread problem across Australia, but immediate change can happen when communities work together,” said CEO of the Continence Foundation, Rowan Cockerell.

“What’s really exciting is that men’s groups within the community are already aware and offering to support the rollout of bins. I have now started conversations with other councils to set the seed to raise the profile of this issue in more communities,” said Julie.
Since launching our public awareness campaign, *Laugh Without Leaking*, continence has very much been in the media spotlight, with 492 media stories across Australia to an audience of over 134 million.

Our media spokespeople were in high demand on TV, radio, in print and online media outlets. We would like to specially thank our ambassador, comedian Bev Killick, along with continence health professionals Annabelle Citreon, Annelize Prinsloo, Marg Sherburn, Irmina Nahon, Shan Morrison, Janine Armocida and Continence Foundation of Australia patron, Bethia Wilson, for their media interviews.

We also thank Health Minister, The Hon. Greg Hunt MP, and Minister for Senior Australians and Aged Care, The Hon. Ken Wyatt AM, MP, for launching World Continence Week at Parliament House.
My fit and healthy 16-year-old daughter continues to wet the bed at night and has occasional loss of urine in small amounts during the day. She has been seen by her GP many times and has been told she will grow out of it. She is getting very frustrated with everything. How can I help her?

A

At 16 years of age, she may grow out of it, but not without help. She needs immediate help with ensuring her occasional damp daytime episodes are corrected. I would recommend your daughter see a specialist to help her. There are many choices: from urologists, pelvic floor physiotherapists, to continence nurse advisors. Please call the National Continence Helpline to obtain a list of appropriate health practitioners that can help and support your daughter. Your daughter may find our new website for teenagers and young people with bladder and bowel incontinence helpful. She can check it out at inconfidence.org.au

I have been a very active person all my life and now at the age of 92 years old I am worried that my current training at the gym with a personal trainer may have a negative impact on my pelvic floor muscles. Is it possible to hurt my pelvic floor muscles at the gym?

A

Wow! Firstly, continue with the gym exercises for your overall wellbeing. Anyone has the potential to damage their pelvic floor muscles if they do not properly engage these muscles while doing exercise. You can modify your exercises so that they will be safe on your pelvic floor muscles. On our website Pelvic Floor First, it explains how to protect your pelvic floor while doing exercises. www.pelvicfloorfirst.org.au/pages/pelvic-floor-safe-core-exercises-.html

I would also recommend that you show your fitness instructor this website, so you can both work together to ensure all the activity and exercises you are doing are not causing any damage to your pelvic floor muscles. The National Continence Helpline can also refer you to a pelvic floor physiotherapist.

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Spring 2018 continence.org.au
Q: If I layer continence pads on top of one another will it provide me with extra protection?

A: Pads have a plastic backing to prevent leakage. When the pad on top is wet, it overflows to the next pad. This usually causes leakage on the sides of the pad and the pad on the bottom is not used to its full capacity. Many people think that there is nothing they can do for their incontinence, except to buy pads. This is incorrect. The majority of incontinence cases can be better managed or cured with the intervention of a health professional that specialises in continence management. At the very least, the person can save money by receiving advice on the most suitable product to contain their incontinence.
COMMUNITY FORUM ON CONTINENCE IN HOBART

The Continence Foundation of Australia is hosting a free forum for adults affected by bladder and bowel issues, their carers, family and friends. This is a great opportunity for residents of Tassie to learn about pelvic floor muscle health, continence and associated issues, plus management options.

Speaking at the Community Continence Forum will be Clinical Nurse Consultant, Alyson Sweeney and Senior Physiotherapist, Sarah O’Loughlin - both from Tasmanian Health’s Community Continence Service.

The Community Continence Forum will be held on Tuesday 23 October, and include a light supper from 6.00pm, at the Hotel Grand Chancellor Hobart. This is a free public event but due to limited spaces, bookings are essential.

The free Community Continence Forum will coincide with the annual gathering of Australian and international continence experts at the National Conference on Incontinence that week.

Register (online) http://ow.ly/X85J30lpq71 or by calling 1800 33 00 66 to secure your place.

27th National Conference on Incontinence - thank you for your support

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