The adult experience of bedwetting
Welcome to the first edition of Bridge for 2020!

Our cover story is a reminder that incontinence affects people of all life stages. No more believing the common myth that bedwetting is a children’s issue! Matt* is a young man who has shared his story of living with bedwetting (nocturnal enuresis) since he was 15. Incontinence can complicate many young adult experiences like dating and living in share houses, but he continues with an attitude of positivity and resilience.

On page 4, we’re making sure you stay updated with the news of the Royal Commission into Aged Care Quality and Safety, and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Did you know there are new standards in place for aged care services? The Aged Care Quality Standards mean aged care services will be assessed with new checks that put the person receiving care at the centre. Find out more on page 5.

As always, we encourage you to write to us and share thoughts, feedback or your own story. Email in to bridge@continence.org.au.

Rowan Cockerell
CEO, Continence Foundation of Australia

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About us...

The Continence Foundation of Australia is the peak national body representing the interests of one in four Australians affected by incontinence, their carers, families and health professionals. The Foundation, on behalf of the Australian Government, manages the National Continence 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.

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 education courses.

Email membership@continence.org.au or phone 03 8692 8400.

References
Email bridge@continence.org.au for a list of references for any articles appearing in Bridge.
**What does a day in your work week look like?**

I have two different types of days! My role as a nurse practitioner involves going beyond standard nursing work. I am part of a team which aims to provide complete primary health care within the person's home – be that in residential aged care or their own home. I prescribe (or deprescribe) medications, order tests and refer to specialists. My role involves physical exams, treating minor illnesses and of course, always looking at what is happening with the person's bladder and bowel function.

As the clinical lead with the Continence Foundation of Australia, my role covers projects like reviewing publications to make sure that information is supported by evidence, providing clinical support to National Continence Helpline staff and supporting education.

**What are some of the unique challenges that come with managing continence in residential aged care?**

People living in residential aged care have very complex health care needs. Often, they have multiple illnesses, are on many different medications and need a lot of help and care from other people.

Like anyone else with continence issues, people in aged care should have access to a thorough assessment and suitable management options. It should always be remembered that incontinence can be improved, or even cured, for many people.

“We should focus on expecting continence rather than expecting incontinence.”

Sometimes there is an expectation from family, carers and the person themselves, that the only way to manage incontinence is by wearing pads. Never assume that pads are the only option.

Sometimes it can be as simple as looking at what medications may affect the bladder or bowel and making adjustments. For example, someone taking sedative medication may be drowsy and is less likely to safely walk to the toilet. This means they may be slower to recognise their need for the toilet and not be able to get there on time and without falling. All of this could increase the risk of incontinence. I’d like to note that most people’s distress can be helped in ways other than sedation.

**Most people wouldn’t think falling or mobility is related to incontinence. Can you explain the relationship?**

Managing the risk of falls is an important consideration in aged care. Keeping people as mobile (moving) as possible in residential care is very important. This isn’t just for their general wellbeing but also so they can fulfil basic human functions, like toileting, with independence. Evidence has shown that a lack of mobility can increase a person’s chances of incontinence in aged care.

Another issue I find often comes up is when people are given medication to help them sleep at night. Many older people still wake up at night with a full bladder and may fall trying to get to the toilet.

Why is it more difficult to manage faecal incontinence (accidental leakage from the bowel) in people in aged care?

The reasons why it happens are complex. Studies have estimated the rate can be as high as half of all residents experiencing faecal incontinence. There are many things that increase someone's chances of developing faecal incontinence (risk factors):

- age
- loose stools
- prior bowel surgery
- reduced mobility
- constipation
- inability to toilet independently
- neurological conditions e.g. Parkinson’s disease, dementia
- chronic medical conditions e.g. diabetes, depression.

Other factors which can contribute to constipation and faecal incontinence include:

- dehydration (may occur when the person is unable to get themselves a drink)
- reduced food intake (meaning a lack of fibre which is important for normal bowel function)
- medication side-effects.

People living in the community also experience many of these problems. However, most people living in residential aged care have a high degree of dependence on carers for help with their daily life.

If someone thinks or knows their family member or friend isn’t receiving quality continence care, what should they do?

If you have concerns about the care received it is important to speak to the staff, if you feel comfortable doing this. Often, families have a good knowledge of what helped the person to manage their toileting needs at home and can work together with staff to achieve quality care. Staff in residential aged care should include the person (or their representative) in any care planning to ensure that their personal preferences are met.

If this does not resolve concerns, the facility manager or the GP would be appropriate to speak to.

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**Joanne Dean** is a nurse practitioner working in aged care and continence in Canberra, ACT. She has over 25 years’ experience in continence assessment and management of adults and children with bladder and bowel dysfunction. She has worked across multiple areas of practice and was recently appointed the Continence Foundation of Australia’s Clinical Lead.
The inquiry has reached its final months, since starting in January 2019. The Commission released an interim report in October 2019, sharing their progress and findings so far.

What they found:
“The Royal Commission into Aged Care Quality and Safety’s Interim Report has found the aged care system fails to meet the needs of its older, vulnerable, citizens.”

Poor continence care was one of the major issues brought to the attention of the Commissioners. The report described the mistreatment of residents in aged care facilities. Some facilities rationed pads or didn’t encourage residents to go to the toilet, which meant residents were often left upset and sitting in urine or faeces.

The Commission’s final report will be released by 12 November 2020.

HAVE YOUR SAY ON AGED CARE AND DISABILITY

The Royal Commission into Aged Care Quality and Safety has been looking at the quality of aged care in Australia and ways of improving services into the future.

RESIDENTS WITH INCONTINENCE

| Autumn 2020 | continence.org.au

75% - 81%

Analysis of Aged Care Funding Instrument data

NOT MAKING HEADLINES

Do you think the media should be reporting more on aged care?

ABC investigative reporter Anne Connolly highlighted that the Banking Royal Commission received a staggering three times more media coverage than the Aged Care Royal Commission. Based on same reporting period and analysis of metro from media monitoring service Stream.

The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is currently underway and scheduled to continue for three years.

The Commission is looking at what governments, institutions and the community should do to better protect people with disability from experiencing violence, abuse, neglect and exploitation. It will also explore how to promote a more inclusive society and related matters.

The Commission is holding hearings around Australia where witnesses will be appearing to provide evidence.

Support and legal advisory services are available if you are affected by or interested in taking part in the Royal Commission.

Anybody can make a submission of information or experiences to the Commission. This can be done:
- Online – disability.royalcommission.gov.au
- By phone on 1800 517 199
NEW STANDARDS FOR AGED CARE

Know your rights under the new Aged Care Quality Standards, in place from 1 July 2019.

There are new standards that must be met by all aged care services receiving funding from the Australian Government. These standards were created to ensure that people are receiving good care.

**What should you expect?**

The new standards place importance on the person receiving care having choice and maintaining dignity. The first standard describes how the person being cared for should feel:

“I am treated with dignity and respect, and can maintain my identity. I can make informed choices about my care and services, and live the life I choose.”

More information about the standards is available from the Aged Care Quality and Safety Commission (not to be confused with the Royal Commission).

Visit [agedcarequality.gov.au](http://agedcarequality.gov.au) or call 1800 951 822

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**Are you entering the NDIS or renewing your plan?**

BrightSky Australia supports people with disability and their NDIS needs by providing healthcare products and claiming directly with the portal or working with plan managers so you are not out-of-pocket or over budget.

We offer a comprehensive range in:

- Continence
- Nutrition
- Mobility Equipment
- Wound Care, Skin Care and other specialist healthcare products

*All proceeds from BrightSky go towards helping people with physical disability and their support network*

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- ndis@brightsky.com.au
- www.brightsky.com.au

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A urinary tract infection (UTI) is a bacterial infection in the urinary system. Most UTIs are caused by E. coli bacteria, usually from the bowel. These bacteria are perfectly normal in the bowel but when they move across to the urinary system can result in an infection.

**SYMPTOMS TO LOOK OUT FOR:**
- Pain, discomfort or a ‘burning’ feeling when urinating (weeing)
- Needing to urinate more often, or urgently
- Pain in the lower abdomen or back
- Urine that looks cloudy or has an unpleasant smell
- Only being able to urinate a few drops at a time
- Fever, feeling like vomiting, vomiting, feeling shaky (in serious cases).

**WHAT TO DO**
If you think you have a UTI go straight to your doctor. They will be able to rule out other causes and prescribe treatment. The treatment for UTIs often involves antibiotics, but these are only recommended if you are having symptoms.

**ARE UTIs SERIOUS?**
It is important to get the right medical advice and treatment for a UTI. In some cases, the infection can spread to the kidneys or cause other serious problems.

**HOW COMMON ARE UTIs?**
UTIs are very common. About one in two women will develop at least one UTI in their lifetime. Women are eight times more likely to have a UTI than men. In women, the urethra is shorter and is closer to the anus. This means the bacteria can spread more easily. However, UTIs in men are classified as complicated. Frequent UTIs in men could be a sign of other problems. It is important to have a GP make sure the bladder is emptying properly.

**INCONTINENCE AND UTIs**
Wearing incontinence products that have been soiled with faecal matter (poo) makes it easier for the normal bacteria in faeces to enter the urinary system and potentially cause a UTI. It is important to change soiled pads, pants and underwear as soon as possible.

**LIFESTYLE CHANGES TO TRY**
- Drink enough fluid. Your urine should be a pale yellow colour. This is especially important if you have a urinary catheter.
- Practice good toilet hygiene. Wash your hands and always wipe your bottom from front to back after emptying your bowel.
- Empty the bladder after sexual intercourse if you find this has triggered UTIs in the past.
- Take steps to avoid constipation. Constipation can prevent your bladder from emptying properly. You have a greater risk of developing a UTI if your bladder does not empty properly.

**WILL THESE TIPS WORK FOR EVERYONE?**
No, there are some people who are simply more likely to have UTIs. It is not fully understood why this may be.

Some people experience repeated UTIs. These cases are called recurrent UTIs and are diagnosed by a medical practitioner. Lifestyle changes such as those listed above may be useful for some people but not others.

Some people will have bacteria in their urine if it is tested but experience no symptoms of an infection. This is called asymptomatic bacteriuria and is a common finding, particularly in older people. It does not usually need antibiotic treatment.
“Unfortunately, a UTI is one of my first memories. I was sitting on the toilet feeling like I was busting to go, only to find I hardly had anything there, and of course that awful burning feeling that left me in tears. It is still such a vivid memory for me,” Caitlin says.

The UTIs continued throughout her childhood and only became less common in adulthood. She is now 26 and estimates she’s had about three cases over the last five years.

“The worst of the three was when I was hiking for four days in New Zealand. We were completely isolated, mid-way through our hike and the symptoms started.

“I managed to ward it off until we were on a train ride home. I arrived home and immediately called the doctor. I was feverish and very, very unhappy!”

Caitlin says there is a lot of anxiety around pain and feeling like the symptoms of another UTI are starting. Unexpectedly, she has managed to turn these negative experiences of UTIs into fuel for a career she’s passionate about.

“I don’t let UTIs stop me from doing what I love. I suppose the main thing it led me towards was my career choice in becoming a pelvic floor physio,” she says.

“My whole life, I’ve understood what it’s like to be impacted by my bladder. I find I can really empathise with the women I work with.”

Some factors that make it more likely for women to have recurrent UTIs include:
- sexual intercourse
- use of spermicidal products for contraception
- maternal history, for example having a mum with a history of UTIs
- having their first UTI at a young age.
I used to consider my bedwetting the most shameful secret I had to carry. I’m 32 years old now, and in my 20s I did everything I could to make sure no one else worked it out. There were definitely giveaways. For one, I was a young guy living in a share house and washing my bed linens twice a week…

Years later, anybody who knows me well is aware that I still wet the bed. Keeping my incontinence a secret is a ship that sailed a long time ago.

The fact is that some people wet the bed while others don’t. Some people grow out of it, and others don’t. I just happen to be one of the ones that didn’t. It goes without saying that I’ve tried everything I can to stop wetting the bed.

For a long time, I thought it was normal and that most people had occasional bedwetting problems. It only happened about four times a year, so as a young teen, I didn’t really think about it. I tried to ignore it and continued with the ‘bury my head in the sand’ approach until a girlfriend brought it to my attention. By then, it was getting more and more frequent.

I didn’t see anybody for my issue until I was 18. I had treatment for a suspected infection but it didn’t stop the bedwetting. Afterwards, I didn’t go back to the doctor until age 21. That time, I really wanted to get help. The doctor referred me to a urologist, but I will never forget how silly and small I felt when I called to make an appointment. “We only deal with children,” they said. As though I needed more reminding that this was something I was supposed to have ‘grown out of’.

Growing up, I obeyed the unwritten rule in my household that this wasn’t something to discuss. I just wish the approach had been different. If my kid was wetting the bed, I wouldn’t try and ignore it. At night, I transformed into a mouse that changed the sheets silently at 3am or stayed awake during sleepovers with friends so that I wouldn’t fall asleep and have an accident.

My biggest fear was my friends finding out. Eventually when I was 17, they did, and the taunts and bullying started. That period of my life damaged me for good. I was so hurt that people were having a laugh at my expense. It made me stronger though. I often think that if I could cop that and come through relatively unscathed, I don’t need to worry.

Incontinence is certainly something that makes people uncomfortable. I have anxiety and depression and I speak freely about my mental health. But when you mention wetting the bed, people get this ‘look’ – almost like they must react that way so everybody can see they don’t have incontinence.

I have experienced incredibly cruel actions from people who just don’t understand incontinence or think it’s something to laugh about. A few years ago, my housemate’s partner took a photo of me after I had wet the bed and posted it to Facebook. It made me feel incredibly vulnerable and never want to live in a share house again. What gave me a little bit of comfort – and hope – was that people who I didn’t even know were defending me online and saying what she did wasn’t cool.

My condition makes dating and relationships difficult. In fairness, it really is a lot to ask of anybody. These days I’m very upfront and tell a new partner that I may wet the bed but have prepared adequately with continence products like plastic sheets and a pull-up.

Yes, I’m a 32-year-old man and wear a pull-up to bed. Deal with it.

I’ve found that telling others about my incontinence can make a difference. I was working with a woman and after I was honest with her about my bedwetting, she actually told me that she had the same issue. I was one of the first people that she told. I really want to be a person that people can trust to confide in. That’s a good way to see yourself.

I’m choosing to share my story with anybody who wants to read it. Anyone who is going through the same thing will understand on a totally different level. My message to you is to keep calm and carry on. You’re a soldier. The people who judge have no idea what you go through daily.

If you’re experiencing incontinence, you’re not alone. Call the free National Continence Helpline on 1800 33 00 66 to speak with an experienced team for information, advice and support.
SHARE YOUR STORY
with Bridge readers

Email bridge@continence.org.au
Incontinence is expensive. We’re talking the kind of expensive that totals 67 billion Australian dollars. That’s the estimated total cost of incontinence in Australia, based on a 2010 Deloitte report.

The estimate includes money spent on health systems, productivity loss in workplaces and employment, aged care and carer costs. For individuals, the personal cost all adds up. This could include laundry costs, pads, other incontinence products, and unexpected costs like replacing clothes and having to head home to change after leaking.

The Deloitte report estimated a week’s worth of incontinence products in Australia. We’ve updated these prices to show the change in cost (inflation) from 2010 to 2019.

<table>
<thead>
<tr>
<th>Number used per week</th>
<th>Cost per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liners</td>
<td>$3.30</td>
</tr>
<tr>
<td>Incontinence pads</td>
<td>$11.31</td>
</tr>
<tr>
<td>Incontinence pants/protective underwear</td>
<td>$32.66</td>
</tr>
</tbody>
</table>

The good news is you can access help to pay for continence products.

**TAKE THE PRESSURE OFF**

Financial help is available through the Continence Aids Payment Scheme (CAPS) offered by the Australian Government, and other state and territory schemes.

**ELIGIBILITY**

An applicant is eligible for CAPS if the applicant is five years of age or older and meets one of the following requirements:

- permanent and severe loss of bladder and/or bowel function (incontinence) due directly to an eligible neurological condition; or

- permanent and severe loss of bladder and/or bowel function (incontinence) caused by an eligible other condition, provided the applicant has a Centrelink or Department of Veterans’ Affairs (DVA) Pensioner Concession Card entitlement.

CAPS is just one of the funding schemes available to Australians who need support for their incontinence products. Because the funding system is complex, the National Continence Helpline can help make sense of it for you.

Our Continence Nurse Advisors are standing by to take your calls on funding, or any other questions you have relating to incontinence.

**PHONE NOW ON 1800 33 00 66**

- More information
- Request an application form
- Help completing the form
**What does having regular bowel habits mean?**

Regular bowel habits are very individual. Opening your bowels anywhere from three times a day to three times a week is considered normal. This is as long as the bowel motions (poo) are easily passed and a thin sausage shape.

Search for the Bristol Stool Chart on the Continence Foundation website [continence.org.au](http://continence.org.au) to see what the ideal poo (type four) looks like.

**I’ve noticed my poo has been dark, almost black. Is this something I need to worry about?**

It is worth going to see your doctor. Dark poo can sometimes be related to your diet or iron supplements you’re taking, though it could also mean you have blood in your stool. Dark stool or blood in stool definitely warrants a visit to your doctor!

**I’ve heard that some cases of faecal incontinence and diarrhoea are caused by food allergies or intolerances. Is this true? How do I check if mine is caused by food?**

Diet does affect your bowel motions and a healthy, well-balanced diet can help keep your bowels regular. Some foods can cause constipation and others can cause diarrhoea. The two most common food allergies causing bowel problems are gluten and dairy allergies. Gluten is found in wheat products and people with this allergy may have coeliac disease.

Some people can have bowel symptoms caused by food intolerances and often these are also from gluten and dairy. An intolerance is not as serious as an allergy. It is important not to take yourself or family off these foods without being tested as you can’t test for something which isn’t in your system.

Gluten can be tested through a simple blood test and then if further investigation is needed, a gastroscopy (examination of the upper digestive tract) may be done. Dairy allergies can also be tested through a blood or skin test and lactose can be tested in a blood test or a breath test after drinking a special lactose drink. Talk to your doctor if you think you need to be tested.

**Why do I always have a strong urge to poo after drinking coffee?**

Coffee can be a stimulant. Studies have found that coffee stimulates colonic motor activity, which means it can make people want to poo. Some people find a coffee in the morning gives them the urge to poo and other people will say it doesn’t affect them at all. It just shows how we are all individuals and can respond differently to what we eat and drink.
SIGNS OF A HEALTHY BLADDER

EMPTIES 4-6 times each day

CAN HOLD up to 400–600ml of urine (wee)
   The feeling of needing to empty occurs at 200–300 ml.

MAY WAKE YOU UP once at night to pass urine or twice if you are over 65

TELLS YOU when it is full but gives you ENOUGH TIME to find a toilet

CONTINENCE HELPLINE
1800 33 00 66
continence.org.au

8am-8pm (AEST)
Monday - Friday