

Bridge

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SUMMER

The Family Edition

Continence Carer of the Year

Meet Robert

What genes tell us

Healthy taco recipe



Continence Foundation of Australia

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National Contenance Helpline 1800 33 00 66

A free service staffed by Nurse Contenance Specialists who can provide information, referrals and resources 8am - 8pm AEST weekdays. The Foundation, established in 1989, is a not-for-profit organisation.

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Become an individual, student or professional member of the Contenance 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@contenance.org.au or phone **03 8692 8400**.

Note from the CEO

In the issue we celebrate all things family. The feeling of family can be hard to describe - what does it mean to you? Maybe you thought of your love for kids, partner, parents or friends that feel like family.

In our National Consumer Survey 2020, we asked people about their lives. One in three people with incontinence say it affects their relationship with family and friends. Inside this issue, you'll read about having those important conversations with friends, family

carers, and what research tells us about genes and prolapse.

If you have holidays or travel coming up, make sure to check out the National Public Toilet Map toiletmap.gov.au. As always, the National Continence Helpline 1800 33 00 66 is there to help you every weekday and is only closed on national public holidays.

You can always get in touch by emailing bridge@continence.org.au

Best wishes,



Rowan Cockerell
CEO, Continence Foundation of Australia



1 in 3
(35%) Australians with incontinence say it affects their relationship with family and friends.



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Water bill relief for Western Australians with incontinence

Are you spending more on water and laundry costs because of incontinence?



Thousands of people receiving the Continence Aids Payment Scheme (CAPS) in Western Australia can now save on their water bill. CAPS is an Australian Government program that helps people with permanent and severe incontinence pay for some of their continence products.

The cost of managing incontinence doesn't stop at products. Extra laundry, cleaning and showering means water bills are usually higher than other households.

Under the Medical Assist allowance of the Water Corporation, households with a CAPS recipient

can use up to 180,000 litres of water per year at no cost. The average person will save over \$380 each year.

However, many National Disability Insurance Scheme (NDIS) participants do not receive CAPS. A Water Corporation spokesperson says it is looking at expanding the Medical Assist program.

“The Water Corporation are investigating the possibility of including NDIS recipients with permanent and severe incontinence in the Medical Assist program.”

Apply online for the WA Medical Assist program: watercorporation.com.au/medicalassist. Find out more about the Continence Aids Payment Scheme from the **National Continence Helpline 1800 33 00 66**.

Supporting your loved ones living in aged care

2020 has been especially heartbreaking for aged care residents, their family and friends, and staff. Australia saw aged care homes record thousands of COVID-19 cases and the majority of deaths around the nation.



The timing of the COVID crisis came after findings from the Royal Commission on Aged Care Quality and Safety's Interim Report in October 2019. The Commission described the aged care system as a “shocking tale of neglect,” saying it failed to meet the needs of its older, vulnerable, citizens.

Push for quality continence care as we wait for the final findings of the Commission in February 2021.

How continence care should be

Safe and effective continence care puts the dignity, wellbeing and choices of the person receiving care first. The Continence Foundation of Australia has information for aged care workers and management. You can encourage your aged care provider to check in with the Foundation for more help.

Encourage open conversation

A recent study for the Royal Commission on Aged Care Quality and Safety showed almost 50 per cent of residents' top concerns were never shared with anyone. Some of the reasons that residents didn't share their concerns were feeling they were 'too minor' or that 'nothing

will change' even if reported. Speaking up can improve quality of care for you, your loved ones and other people in the future.

Do you know where to complain?

The Aged Care Quality and Safety Commission (different to the Royal Commission) is responsible for checking providers and working through complaints. They encourage you to try and raise the issue with the staff and aged care provider first, if you can. Then, there are many ways you can make a complaint:

Online: agedcarequality.gov.au
Phone: 1800 951 822 (free call)
Letter: GPO Box 9819,
 in your capital city



TRADING IN THE TOOLS: Carer of the Year 2020

A fitter and turner by trade, **Robert Sykes'** switch to full-time carer was unexpected. Almost 20 years later there's no doubt that his kind and supportive nature makes him an amazing carer to his daughter Olivia.



Every year, the Continence Foundation of Australia celebrates the role of carers with the Continence Carer of the Year Award. In 2020, we are proud to recognise **Robert Sykes** of Coffs Harbour, NSW, with the Award.



I was lost for words. I don't consider myself any different to anybody else, just doing my job and looking after my family. My daughter is family. – **Robert Sykes**

The 2020 Continence Carer of the Year Award is proudly sponsored by

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In 2001, Rob and wife Sharron were expecting their first child, Olivia.

“One minute we were just a couple waiting for their first daughter to be born and suddenly, we got this whole new world to look into.”

Olivia was diagnosed with the rare WAGR syndrome a few months after being born. The syndrome can include complex health needs like global developmental delay, and eye problems like cataracts.

For Rob and Sharron, this didn't change anything.

“When they gave us the diagnosis, we said ‘you know, nobody's flicked a switch in her’. She's still the same little girl we've had for three months. They've just told us something about it. Let's just work with that, Rob says.”

They had to get used to a lot of “worst-case scenario talk” when being told what to expect.

“They said that she'd have trouble walking and things like that. And it turned out she didn't really have trouble walking,” Rob says.

Together, Rob and Sharron made the “purely practical” decision for Rob to

stop work and become Olivia's primary carer.

Dropping Olivia off at her first day at kinder, Rob had all the usual emotions and worries of any parent. He remembers gripping the steering wheel and crying, worried that tiny Olivia “would get eaten up”.

Olivia was happy at school and there was suddenly some spare time during the day to squeeze in new interests. Rob was inspired by the support services he accessed for Olivia and started a Diploma of Community Welfare, later working in disability support and aged care.

During school hours, he volunteered at a carers centre. He used his counselling skills to phone carers to check in, and organised days out for other male carers to talk about what was on their minds – or simply enjoy the footy.

“It also helped me. You're seeing other people and how they're dealing with it. The counselling aspect involves a lot of self-examination.

“I thought it put me in a better mind state than if I just sat there and thought ‘oh, this is a load of rubbish’. You always look for the good side.”

Rob brings this cheerful energy into everything he does. Together, their family celebrates the wins and every step Olivia takes towards independence.

Olivia is non-verbal, and Rob is always looking for signs and cues to better understand her needs. He noticed that Olivia was waking up unhappy some mornings. Trying some new things in the toileting routine ended up making a huge difference to her wellbeing and mood.

"So she has a dry night's sleep. And when she wakes up, she's far more happier," Rob says.

He understands how important his own mental health is too, especially with his background in supporting other carers.

“ Burnout ... it happened to me a couple of times. I just have a little fuel gauge ... I can see it pictured in my head. ”

"I can tell when it's getting down and know when I've got to take a day off or something. You have a little release mechanism. I listen to music or muck around in the garage."

Olivia shares his love of music and together they spend time mixing and cooking, going on road trips and socialising.

It's clear that Olivia will always have a special Dad, advocate and carer in Rob.

WHO CAN BE A CARER?

Carers can be of any age, who provide unpaid care and support to family members or friends with a disability, mental illness, chronic condition, terminal illness, drug issue or who are frail aged.

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WHEN FAMILY MATTERS IN PELVIC HEALTH

We know that some women have a bigger chance of getting a pelvic organ prolapse. What is the link between your family history and your chance of getting a prolapse?

What is pelvic organ prolapse?

Pelvic organs include the bladder, uterus (womb) and rectum (back passage). These organs are held in place by support tissues called 'fascia' and 'ligaments'.

The pelvic floor muscles support your pelvic organs from below. If the support tissues are torn or stretched for any reason, and if your pelvic floor muscles are weak, then the pelvic organs may not be held in their right place. They may bulge or sag down into the vagina (birth canal). This is known as a pelvic organ prolapse (POP).

There is excellent help available

There are many ways you can help prevent, manage and treat prolapse. Make sure to speak with your doctor or continence health professional about your situation and if you think you have a prolapse.



Prolapse tends to run in families

A 2012 review looked at different studies on prolapse and family history. Researchers found that compared to women who did not have any prolapse, women with a prolapse were much more likely to have family members with the same problem or condition. They said that this made for a stronger hypothesis (scientific guess or prediction) that a person's genes play a role in their chance of getting a prolapse.

Researchers have also been looking at whether certain genes could be linked or related to the prolapse happening.

Genetics and support tissue

Genetics is the study of genes. Your genes make you, you and are passed on in your family. They affect things like your eye colour and height, as well as many health conditions.

Some genetic disorders such as Ehlers-Danlos syndromes and Marfan syndrome are heritable. This means they can be inherited or passed on from family. These disorders

affect support or connective tissues (including fascia and ligaments) found all around the body.

Support tissues are very important in pelvic health because they attach the pelvic organs to the pelvic wall. Women with the heritable Ehlers-Danlos syndromes have been found to more often have a prolapse.

Other factors

Family history is just one part of the puzzle. There are other risk factors that increase the chance of having a pelvic organ prolapse:

- **Childbirth.** Giving birth to a baby can cause the vagina to stretch and cause tears to the supporting tissues and pelvic floor muscles.
- **Persistent (long-term) coughs** like those linked to smoking, bronchitis, asthma and cystic fibrosis
- **Lifting heavy weights**
- **Constipation** because over the long term, straining and pushing to open your bowels can affect the pelvic floor

PREVENTION

Learn more about preventing (avoiding) prolapse and incontinence with lifestyle changes. Scan this QR code in your camera app to find out more or visit [continence.org.au/prevention](https://www.continence.org.au/prevention)





Jules Robinson wasn't afraid to share a huge life experience - **marriage** - with *Married at First Sight* TV viewers across the nation. The 37-year-old business owner and *Always Discreet* ambassador has continued this trend in 2020, this time opening up about her pregnancy and urinary incontinence.

“ I can't really pin-point an exact moment when I experienced my first accident. Like the one in three women in Australia, I've definitely experienced this a few times in the past. It was only until my pregnancy I started properly researching incontinence. ”

'Why aren't women talking about this more?'

Jules Robinson on family, friends and empowering conversations.

► What does family mean to you?

Family really is everything. We're feeling this now more than ever after the birth of our baby boy, Oliver, in October. There's no doubt this year has only brought to light the importance of family. They are the people that are there after a bad day, my support network cheering me along on the sidelines, or just a familiar face to have a laugh with.

► Do you have advice for people wanting to discuss incontinence with their own family and friends?

My experience got me thinking - why aren't women talking about this more? I think there's a strong perception that it only affects older women, and the women who experience it feel unattractive or unfeminine or that there is something wrong with them. But it's actually quite common.

Out of curiosity, I did a bit of my own research with a group of my girlfriends. Out of the 17 that I asked, only two of them had never experienced bladder leaks. Only two! I'd really encourage you to open up with your family or friends. Just start the conversation (even if it may feel a bit uncomfortable to start with) and I guarantee you will feel relieved and empowered afterwards.

► What positives have come out of those conversations?

One of the biggest things is that I can take comfort in knowing I'm not alone. There truly is something empowering about sharing your own experience. If anything, it's helped keep the conversation open across other topics we typically keep to ourselves.



Finding yourself needing to go to the toilet a lot? Men's health physiotherapist **Travis Monk** answers common questions around frequent urination (emptying the bladder often).

“ Many stories have been told by men about near misses with leakages and falls. Also, being in the bad books with their wife as a result of nightly wakings. ”

Men: check the plumbing to sleep and live better

As a physiotherapist, I often hear from men who've noticed they need to urinate more than normal. They may also experience their bladder not feeling fully empty afterwards. It's normal for men to be urinating 4-6 times in the day and once during the night.

Usually, having to get up and head to the toilet many times throughout the night is the most upsetting issue. This has an obvious effect on sleep quality, mental health, thinking and relationships.

► Why does it happen?

Frequent urination in men can commonly be caused by prostate enlargement, an overactive bladder, or treatment for tumours in the bladder or prostate (like prostate

surgery). Something unavoidable - getting older - is also linked to prostate enlargement and a weaker stream of urine.

It is important you see a medical professional for a check and to rule out other conditions such as diabetes. Seek urgent medical care if you have any sudden changes.

► Is there help available?

Absolutely, lifestyle changes and pelvic floor muscle exercises can make a real difference. I recommend you see a health professional who will look at your lifestyle and medications to find what's right for you. You can phone the **National Continence Helpline on 1800 33 00 66** to find services in your area.

Helpline Q&A

Getting help for your bladder and bowel health

“ I would encourage anyone with incontinence to get help no matter how long you have had it



Janie Thompson is the Continenence Foundation of Australia's new Clinical Services Manager, leading the National Continenence Helpline.

For confidential information and advice, you can phone the **National Continenence Helpline on 1800 33 00 66** (Monday to Friday, 8am to 8pm AEST).

What is a continence service? How can I get a referral or know if I need one?

A continence service or clinic often has a team with different health professionals such as Nurse Continenence Specialists, Pelvic Floor Physiotherapists, Geriatricians and Urologists. Some services may have one or two health professionals, especially in more rural and remote areas.

These professionals can do a continence assessment to look into why and how you need help. They will work with you to make a management or treatment plan based on your goals (for example, to be able to go out and visit friends and family, to get out of bed less at night).

Some continence services need a referral letter and your GP or specialist can organise this if you need one. Other services let you refer yourself. The National Continenence Helpline (1800 33 00 66) can help you find continence services in your area.

What can I expect?

You will be asked to share your story. This will be used to work out what type of bladder, bowel or continence problem you have.

Questions may cover:

- continence symptoms like how often you go to the toilet
- if you need to rush to get to the toilet or leak on the way
- if you leak when you cough or sneeze etc.
- any health issues, operations, medications
- pregnancy and childbirth experiences
- what care you are getting or need help with
- bathroom and toilet equipment

Physical checks, urine tests, and ultrasounds are often part of a continence assessment.

The assessments are detailed, but very important information is collected to help improve or cure your continence concerns.


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Need inspiration for a fun family dinner? Check out this healthy taco recipe from **Milly Smith**, Accredited Practising Dietitian. It's a great chance for kids and the entire family to get involved in making food together.

Tacos aren't always seen as a healthy option.

When made at home, we can pack a taco shell with lots of healthy goodies.

MIX AND MATCH TACOS

This recipe uses black beans as its protein. Beans are packed with fibre and are great for our gut health! They help to soften and keep our bowel motions regular. Don't forget to make sure you're having extra water when you are increasing fibre in your diet.

The recipe also adds other gut-loving ingredients like vegetables, herbs and yoghurt. You can mix and match to suit family tastes.

Ingredients

8x taco shells (toasted as per packet instructions)

Filling options

(place each into separate bowls):

1/2 an iceberg lettuce (shredded)

1x punnet cherry tomatoes (diced)

1x tin corn kernels (drained)

1x avocado (sliced, mashed or made into guacamole)

Grated tasty cheese (for serving)

Greek yoghurt (for serving)

Lime wedges (for serving)

Coriander (for serving)

Method

1. In a pan, add drained black beans, tinned tomatoes, paprika, cumin and salt/pepper. Bring to a simmer and cook until tomatoes have reduced by half (around 15 minutes). If you would like a thicker sauce, add cornflour.
2. Once the beans are ready, pour them into a bowl ready to serve.
3. Prepare taco shells and have the other filling options ready in bowls. Place the fillings you would like in your taco shell and enjoy!



Bean filling

1x tin black beans

1x tin diced tomatoes

1/2 tsp smoked paprika

1/2 tsp ground cumin

Salt and pepper to taste

1 tsp cornflour (to thicken if required)



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STAYING HYDRATED IN SUMMER

Why is it important to stay hydrated in the heat?

When it's hot or you're exercising, your body will react to the heat by sweating. Sweat makes your skin moist or wet and then helps you cool down when it evaporates (changes from liquid to gas). This also means you're losing water from your body.



1. Get enough fluids throughout the day

Drinking less won't help with incontinence or bladder control issues.

In fact, drinking less may make your urine more concentrated (stronger) and could irritate your bladder.

Your doctor can help you find out how much fluid is right for you, as you also don't want to drink too much either.



2. Choose water

Alcohol, fizzy drinks and caffeinated drinks like coffee can irritate the bladder, so having mostly water is the best choice.



3. Check the colour of your urine

Pale yellow coloured urine is a good sign of being hydrated. Medications, food and health conditions can change the colour of your urine so talk to your doctor if you are worried.



4. Try creative ways of getting more fluid

There's a reason watermelon is so popular in summer! Some foods have naturally high water content, so why not add strawberries, celery, melon and lettuce as options.



5. Don't wait until you feel thirsty

Some people, especially older people, don't feel thirsty but may still be dehydrated.

6. Bring a water bottle with you

Keys, wallet and water! This will make sure you're not stuck without access to water. Sip slowly throughout the day to stay hydrated. You might need to drink a bit faster if you are exercising or feeling hot.

What is fluid?

Fluid is everything you drink. It is also in a lot of what you eat, such as fruit and vegetables.



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