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From the editor

One of the lead articles in this issue is a touching story on page 6 about an old man and his outdated views about incontinence, and the profound impact this had on his quality of life. Women, it seems, are much better at managing their health, many of them engaging with the health services as the result of pregnancies and childbirth.

Pregnancy and childbirth also make women three times more likely to suffer from incontinence than women who haven’t had babies, and expectant women are the target of the Continence Foundation’s next major project, which we introduce on page 3.

Here at the Continence Foundation, we find that sometimes our key messages are challenged by TV ads or social media postings that burst into our collective consciousness. A recent TV ad that managed to annoy, not only health professionals, but the average woman and bloke on the street, was one promoting the use of sport panty liners for “crotch sweat”, which was ridiculed by media commentators and health professionals across the country.

Another was a YouTube clip Crossfit – Do you pee during workouts? which seemed to normalise, even commend, exercise-induced urinary leakage. It attracted angry protests from continence health professionals the world over.

These flawed populist notions make the promotion of the Continence Foundation’s message – that incontinence is, in most cases, preventable and treatable – more critical than ever.

I hope the stories in this issue go some way to furthering the Foundation’s good work. There is even a story on page 4 about similar claims promoted by certain commercial interests that may not be doing us as much good as they would have us believe.

Happy reading.

Maria

Maria Whitmore
Editor
An app-titude for kids with special needs

Getting toilet training right for a child with special needs can mean the difference between a lifetime of independent toileting and one further incapacitated by incontinence. This is why the Victorian Continence Resource Centre developed a phone app to guide parents of special needs children through toilet training.

Victorian Continence Resource Centre executive officer Lisa Wragg said the smart phone and tablet platform was a perfect fit for children with special needs.

“They don’t need fine motor skills to use them, and they’re visual, and they don’t have to be able to read,” Ms Wragg said. The app contains a full sequence of toileting images, each with a simple, easy-to-explain instruction. Parents can customise the picture sequences to accommodate their child’s progress and ability, and even record their own instructions.

“The app can be used for a wide population; the voice-over capacity means you don’t have to speak English, and people with low literacy skills can use it too,” Ms Wragg said. The app also instructs parents on guiding their children through five fundamental toileting steps (such as bottom wiping, pulling pants up and down, hand washing) using techniques such as role play.

Download Toilet Training for children with special needs from the iTunes store and One Step at a time Toilet Tips from Google.

Phase two of the CALD project

The Foundation’s most recent project – Incontinence Outreach in CALD Communities – continues to extend its reach into Australia’s non-English speaking communities.

The 20 foreign language web pages (view them at continence.org.au/other-languages) are still being promoted on ethnic radio, and a pilot study on their use and accessibility in clinical settings is underway at three Victorian hospitals.

The project is now at phase two and the Continence Foundation, in partnership with key multicultural organisations and ethn-specific associations, is piloting information forums featuring qualified presenters and accredited interpreters to Chinese and Arabic communities in three states. Fact sheets and web pages will also be translated into a further seven languages, including Dari and Hindi.

5 minutes with Caroline Gargett

Associate Professor Caroline Gargett is a senior research fellow of the National Health and Medical Research Council of Australia, and deputy director of the Ritchie Centre at Monash Institute of Medical Research, heading up the Women’s Health Theme.

What research are you doing related to pelvic organ prolapse?

My research group, along with the CSIRO, are investigating a cell-based therapy to treat pelvic organ prolapse. Mesh used for vaginal repair surgery has caused problems in the past due to its poor integration into the prolapsed area. We are developing patient-friendly mesh materials that better match the properties of vaginal tissue, and combining it with stem cells taken from the lining of the uterus. We are implanting this tissue engineering construct into animals to see if the mesh compatibility improves.

What led to this research?

Soon after we discovered adult stem cells in the uterine lining (endometrium), I heard a leading urogynaecologist speak on the problems of mesh used in pelvic organ prolapse surgery. I was astounded by the large numbers of women needing prolapse surgery and on the poor outcomes. I thought we could combine a woman’s own endometrial stem cells with a mesh to promote healing of the vaginal wall.

What do you hope to achieve?

We hope to develop a cell-based therapy that is strong enough to support prolapsed vaginal walls, with sufficient flexibility, but without the current side effects such as mesh erosion or pain. We hope the stem cells will promote better integration of the foreign mesh material into the vaginal region.

How has your research progressed?

We have had promising results using a rat model of skin wound repair and human endometrial stem cells combined with our new mesh. We found the mechanical properties of the mesh improved, the stem cells promoted the growth of new blood vessels around the implanted mesh, and new healthy collagen was laid down through the mesh. We are now working to test our cell-based therapy in a large animal model of vaginal surgery.

Delivering the maternal message

Blame it on the children.

No, seriously, it’s their fault more women than men are affected by urinary incontinence.

Having a baby makes a woman three times more likely to leak than a woman who hasn’t had one. In fact, one in three women who’ve ever had a baby will wet themselves.

In the majority of cases, however, urinary incontinence as a result of pregnancy and childbirth is preventable and treatable. The importance of reaching out to pregnant women and the health professionals who work with them cannot be underestimated, and the Continence Foundation’s next project aims to do exactly that.

Project manager Samantha Scoble is working with a number of health professionals and stakeholder organisations to address the project’s three main areas of focus: advocacy at a midwifery level; awareness raising among pre and postnatal women; and educating health professionals.

Advocacy: Midwives are critical not only for delivering babies, but also delivering best possible outcomes for mothers before, during and after childbirth. The project will advocate to address the amount of continence and pelvic floor-related information in antenatal guidelines and midwifery core competencies.

Awareness: The project will also develop a pregnancy and continence guide resource, along with a smart phone app to raise awareness of incontinence and pelvic floor muscle exercises among pre and postnatal women.

Education: Using an online course as well as face-to-face education, the project will provide education about the impact of pregnancy on pelvic floor dysfunction to health professionals working with pre and postnatal women.

The maternity project will be launched during World Continence Week in 2014. For more information, contact the Continence Foundation’s Health Promotion Officer Samantha Scoble s.scoble@continence.org.au
The error of our ways

So you thought wearing high heels was bad for you? Research by a stiletto-wearing urologist from Milan suggests they may be quietly working our pelvic floor as we totter along on them. While the scientific jury is still out on the merits of heels, there’s plenty it agrees on, including the inadvertent harm some of us may be doing to our bodies in our quest for a great one.

THE DRINK BOTTLE ACCESSORY

Claims abound that drinking at least two litres of water a day is great for our skin, weight loss and general wellbeing. But more and more health professionals, including women’s health physiotherapist Dr Patricia Neumann, say we should only drink to satisfy our thirst, not to meet some arbitrary target set by a marketing executive.

“On a normal day we need to pass between 24 and 30ml of urine per kilogram of body weight. So if you weigh 60kg, that’s between 1.5 and 1.8 litres. What we drink is what we pass, and there’s water in the food we eat,” Dr Neumann said.

Her advice is backed by continence health physiotherapist Jill Nyman, who said an overloaded bladder could cause dribble-type leakage due to overflow incontinence, and even exacerbate stress incontinence with coughing, sneezing or sudden movements.

“And persistent overfilling can potentially cause overstretch of the bladder, which in turn leads to inability of the bladder to contract and empty effectively,” Ms Nyman said.

EXERCISING FOR HIGH IMPACT

Before launching into the latest fitness craze, make sure your pelvic floor is up to it. PPF ambassador and international Gymstick program coordinator Marietta Mehanni said high-impact exercises, such as cross-fit, put extra strain on the pelvic floor and increased the risk of incontinence.

“Firstly, there is nothing wrong with high-impact exercise if your pelvic floor is strong enough to tolerate it. But men and women also need to exercise their pelvic floor muscles just as they would any other muscle group,” Ms Mehanni said.

She warned about weight-bearing exercises such as deep squats with weights, which could strain the pelvic floor if done without the accompanying pelvic floor training.

Continence and women’s health physiotherapist Jill Chenoweth said stress incontinence was often a first sign the pelvic floor was under excessive strain and potentially impacting on other core functions.

“The pelvic floor muscles are one of the major core muscles that help support the back, and pushing down on them rather than contracting them when lifting can cause weakness, and the discs to prolapse,” Ms Chenoweth said.

A SWEET SUBSTITUTE

Diet soft drinks may not be the healthy alternative to sugary drinks we think they are.

Accredited practising dietician and diabetes educator Natasha Murray said some research suggested they may actually increase appetite, thereby leading to increased food intake and weight gain.

Her statement is backed by a 2008 study at the University of Texas that revealed a “diet soda paradox”, where drink consumption was associated with increased weight gain.

Being overweight increased the risk of urinary incontinence, and the best way to achieve a healthy weight was to eat fewer kilojoules and to be more physically active, Ms Murray said.

“The Australian Dietary Guidelines recommend limiting foods high in added sugar and low in nutrition, such as carbonated soft drinks, confectionery, cakes and biscuits,” she said.

WHEN MORE IS LESS

Having a well-balanced diet with plenty of fibre is good for us. It’s also vital for helping stay continent, with constipation one of the biggest contributors to urinary and faecal incontinence.

Some people, however, believe vitamins can be substitutes for real foods.

“If people rely on supplements for their vitamins and minerals, it is unlikely they will be having enough fibre to help keep them regular.

“Adults should aim to include 20 to 30g of fibre each day, children should aim for 14 to 24g depending on their age.”

LEFT HIGH AND DRY

Wearing panty liners every day is another widely promoted practice. Dr Margaret Sherburn from the Melbourne Royal Women’s Hospital is concerned women who wear them every day “just in case” of accidental leakage adopt an attitude of acceptance.

“They have the mindset that ‘I’m a woman, so that means I can’t do anything without wearing a pad because I might leak’,” she said.

Dr Sherburn said clinical advice gave women the confidence to stop wearing pads.

“They do the work and strengthen their pelvic floor, and then have the confidence not to wear pads anymore,” she said.

Mercy Hospital women’s continence nurse Christine Murray said some women obsessed about normal body odours and wore panty liners to soak up normal vaginal discharge.

“Vaginal secretions are healthy and we have them for a reason,” Ms Murray said.

The continual wearing of panty liners can cause skin irritation in the delicate vulval skin.

“It’s much healthier if these pads are not worn. The healthiest option is to wear cotton underpants,” she said.

1. Dr Maria Cerruto, the University of Verona
Pelvic Floor Exercises

WHO: They’re not only for women. Men, too, need strong pelvic floor muscles. They hold up our pelvic organs (intestines, bladder, uterus), help close our urinary and anal sphincters, and are important for sexual function.

WHAT: You have to identify the muscles first so you know which ones to exercise. A good way to do this is to stop the flow of urine while on the toilet (but don’t do this as a regular exercise). Feel the sensation of squeezing and lifting. Another way is to pretend you’re trying to stop breaking wind. Again, feel the sensation of the muscles being activated.

WHEN: Do them any time of day – just as long as you do them.

WHERE: Anywhere – standing, lying down or sitting (with good spinal posture). No one will know.

WHY: So you stay in control of your bladder and bowel, can bear the weight of the organs in your pelvis, and exercise safely.

HOW: Get yourself comfortable and:
1. Squeeze and ‘draw up’ the muscles around your front and back passages and hold as strong as you can for a couple of seconds while breathing normally.
2. Relax. You should have a distinct sensation of ‘letting go’.
3. Repeat the above two steps about eight times, relaxing for about the same amount of time in between each squeeze.
4. Over time you can gradually build up the squeeze (and relax) time to about eight seconds.
5. Do this two or three times each day.

App wrap-up

Physiotherapist and fitness professional Lisa Westlake introduces the Continence Foundation’s newly-launched Pelvic Floor Safe app.

Without doubt, one of my most exciting roles as an ambassador for Pelvic Floor First has been to assist the Continence Foundation of Australia in the production of the new Pelvic Floor Safe app, which is now available for smart phones and tablets across the iOS and Android platforms.

We know that certain exercises may cause or exacerbate incontinence, especially in women (or men) who are suffering, or at risk of, compromised bladder or bowel control or prolapse.

While it’s well understood that those with vulnerable pelvic floor function should avoid high-impact and heavy resistance exercises that cause straining, it may come as a surprise that even wide squats and abdominal curls can be problematic.

But the last thing we want is people to avoid exercise and miss out on the many physical and psychological benefits of being active. This free app outlines a range of pelvic floor-safe fitness options.

The physiotherapy-designed routines provide safe, sensible guidelines to help people who want to boost their fitness without straining their pelvic floor.

As well as instructions on how to do pelvic floor muscle exercises, users can choose from three customised exercise programs, dependant on their pelvic floor function. Each level includes a range of exercises for total body fitness and is accompanied by an instructional video.

While particularly appropriate for new mums, this app is a fabulous option for post-menopausal and menopausal women, anyone suffering from incontinence and pelvic floor issues related to chronic coughing, being overweight or low back pain, providing an effective low-load, low-impact fitness routine they can do anywhere, any time.

>> Download the app now from iTunes. The app will be available on Google Play from December 7.

Abena Premium Range

Choose the Abena Premium range for the very best comfort and security. Genuinely breathable material ensures that the skin is protected to the highest possible standard.
When Harry met Gary

Harry* was a man of simple pleasures. He enjoyed camping, the odd fishing trip with his mates and the daily walk into town to buy the paper and chew the fat with some of the other old coppers.

A widower in his early 80s, Harry had moved in with his son after his wife’s death a few years earlier. Over the past few years, however, Harry had gradually abandoned many of his favourite pastimes, these days venturing only to the Orbost Men’s Shed once a week.

Community health nurse Gary Green, who had been part of setting up the shed, remembers a conversation with Harry about four years after he’d started coming. “He was telling me about his inability to get out and about because of his incontinence …” Gary said.

“So many men become isolated because of their incontinence … they don’t want to be seen as dirty old men.”

— Glenys Quick

“His said he could come along because he wrapped a towel around himself like a nappy and pulled his tracky daks over the top. “He really enjoyed being with the other blokes, and said it was the only thing he was prepared to go to that much effort to get to,” Gary said.

Gary suggested that district nurse Glenys Quick call around to his house for a home visit. “I knew he knew Glenys because of some other health issues he’d had – he was diabetic and he took me up on the offer,” Gary said.

One week later, Harry surprised everyone, including Gary, by announcing to the 30-plus men assembled at the Men’s Shed that he “no longer pissed himself”.

“And then he dropped his daks in front of everyone and proudly showed them what he had,” Gary said.

Harry displayed his external catheter, essentially a condom drainage system that emptied his urine into a bag strapped onto his leg. “Now I can come along with you on the fishing trips, the Blokes’ Fridays, to the shops,” Harry told the men.

Over the next couple of weeks, as Harry resumed many of his old pastimes, four more old blokes at the men’s shed approached Gary. “They quietly came up to me and asked if I could put them in touch with ‘that nurse’,” he said.

Glenys Quick, who introduced the men to the condom drainage system, said their attitude had been a hinderance to their finding help. “So many men become isolated because of their incontinence. They feel as though they’re not acceptable in the community; they don’t want to be seen as dirty old men,” Glenys said.

She said Harry was reserved and cautious when she visited him. “Mind you, it was fun and games. I asked him to take off his pants and he was so shocked to do that – in front of a woman!” she said.

“And it was quite strange for him to look at a condom – and then to put it on! It was very personal; so personal.”

Harry’s public revelation made it easier for the others to seek help. “Because of Harry, the men didn’t even have to acknowledge the problem with anyone. They just rang up and made the appointment,” Glenys said.

The incident highlighted the deeply held shame and embarrassment many in the community, particularly older men, associated with incontinence. “They think, ‘I’m getting old therefore I have to expect these things’. Some isolated men don’t even know about continent pads,” Glenys said.

“Thats why community links are so important. Because of community, there was a flow-on effect in Orbost.”

Gary, who is now the community engagement manager for the Australian Men’s Shed Association, said peer education was vital for reaching men, particularly older men. “That was a great example of how blokes get their information from peers,” he said. “When it comes from a peer, it’s much more valuable and much more effective. “The thing about blokes is that they want information that’s blunt, to the point, and down to earth. We health professionals can learn a lot from these sorts of blokes.”

* Not his real name.

Risky business

You are at risk of urinary incontinence if you:

- are overweight
- lift heavy weights regularly
- have a history of back pain
- have had trauma or injury in the pelvic area
- have had bladder or bowel surgery
- have prostate problem or have had prostate surgery

The continence nurse consultants at the National Continence Helpline (1800 33 00 66) can offer confidential advice or refer you to a nearby continence health professional.

For more information about men’s continence issues, visit theshedonline.org.au and follow the Health and Lifestyle tab to reach the Bladder and Bowel Health page, a collaborative initiative between the Australian Men’s Shed Association and the Continence Foundation of Australia.
Six years ago Tim Settle was in excellent health. He was happily married and had a well-paying job that financed his adventure lifestyle, which included flying planes, scuba diving and jet skiing.

But two years later, Tim found himself at the darkest point of his life when he felt “as close to suicide as you can get without doing something about it”.

At the age of 42, Tim had become incontinent.

His surgeon’s reassurance that he’d be “right in a couple of weeks” after his radical robotic prostatectomy rang hollow.

Tim’s incontinence was so severe six months later, he had to plan his activities around his fluid intake, which was timed down to the minute because “it took 20 minutes for a glass of water to come out the other end”.

“I had zero control of my bladder. I had to be flat on my back because if I stood up I leaked,” he said.

Tim had no erectile function, which figured low in his priorities, anyway.

“When you have continuous leakage and have to wear a nappy at night, and your penis is so sore at the tip because it’s constantly wet, your potency doesn’t even come into the equation,” he said.

Tim was diagnosed with “fairly advanced” prostate cancer at 42 years of age. After considering all the options, a radical prostatectomy with nerve-sparing surgery offered the best chances of survival at his age.

A few months after the surgery, he was advised he might end up with a substantial degree of urinary incontinence for the rest of his life.

“I was heading down the suicide path. I couldn’t work properly because of the incontinence, so it was difficult to support my family. I’d lost my potency. What use was I? I was a mental wreck,” he said.

A few months after the surgery, he was advised he might end up with a substantial degree of urinary incontinence for the rest of his life.

It was only after hearing about a physiotherapist, Peter Dornan, who’d also had a prostatectomy and was now fully continent, that things changed.

He contacted Peter, who immediately put him on an intensive exercise program that involved crunches and pelvic floor exercises. This exercise regime, Peter told him, would retrain the neuromuscular and vascular systems that controlled everything in the abdominal cavity, including the pelvic floor muscles.

“One day, about two weeks after starting the exercises, I realised I was upright and wasn’t leaking anymore. I’d gone from zero to about 80 per cent control in two weeks. I couldn’t believe the improvement,” Tim said.

Peter, who’d had a radical prostatectomy about 10 years earlier at age 52, had been through a remarkably similar situation.

“The procedure left me severely incontinent to the extent that it seriously impacted on my lifestyle as well as my professional career, emotional health, exercise activity and sex life. I became fairly despondent, indeed depressed,” Peter said.

Over the next few years he devoted himself to investigating the physiological cause of his dysfunction, and developed an exercise program that was ultimately successful in treating his incontinence.

He also wrote a book about it and now specialises exclusively in helping men restore their continence post-operatively at his Brisbane clinic.

Five years after seeing Peter, Tim says he is now 95 per cent continent and no longer requires continence aid products.

His erectile function is also restored, returning gradually over a period of two to three years. He and his wife are now the proud parents of two-year-old Amy.

But Tim believes the supports for men like him are severely lacking.

“Patients don’t get enough counselling before or after surgery,” he said.

“The discussions I had with the urologist and doctors were completely insignificant. I didn’t even hear about the National Continence Helpline, so it’s up to governments and organisations like the Continence Foundation to fill the gaps, because there still is a massive gap.”
Lighten up on bedwetting

In most cases, making a few changes to your child’s drinking and eating habits will make a huge difference to their bedwetting.

If your five-year-old is still wetting the bed occasionally, don’t worry too much. One in five children will have the odd bedwetting incident, and it’s perfectly OK. Clare Fyfield, a children’s continence nurse working with disabled and able-bodied children in Gippsland, Victoria, said there were some simple and practical steps parents could take to address bedwetting concerns.

As a first step, she encouraged parents to regulate their children’s fluid intake so it was at its highest in the morning and decreased as the day went on.

“Give them a big drink with breakfast, as well as milk on their cereal, and send them off to pre-school or school with a drink bottle. Have them drink plenty during the day so they don’t need to drink at night, and always go to the toilet before going to bed,” Ms Fyfield said.

Most children eventually grow out of bedwetting, which often runs in families with a history of misbehaving (or overactive) bladders.

“And some children are such deep sleepers they don’t wake up to the signals,” Ms Fyfield said.

One in 10 children will still wet the bed occasionally at the age of seven.

“If this is happening regularly at age seven, and if the child really wants to be dry at night, then you can take them to a children’s continence specialist,” she said.

A continence nurse or physiotherapist will ask the parent to chart the child’s fluid intake, bowel habits and diet as part of a preliminary continence assessment.

“From that information we make a care plan for management. One child I saw had been having milo, tea and coffee before bed, just like mum and dad. He had caffeine withdrawal,” she said.

“And many parents are unaware that constipation contributes to incontinence. A full bowel can take up so much space in the pelvic region it compresses the bladder and can cause other bladder issues.”

Ms Fyfield said that in the majority of cases, when children changed their drinking patterns and adopted regular bowel habits, their bedwetting improved or stopped.

“We check if it’s something acute like a urinary tract infection – when children rush to the toilet and have smelly wee – or a sudden onset of a temperature,” she said.

Ms Fyfield also acknowledged the role stressful or disruptive situations could play, such as access weekends.

For the small minority of children who still regularly wet the bed after all the preventative measures had been taken, treatments such as bedwetting alarms worked well.

“If everything is fine – their drinking, bowels and able-bodied children are all normal – then we go for the alarm, which has about an 85 per cent success rate,” she said.

Parents with concerns about their child’s bladder or bowel habits should contact the National Continence Helpline (1800 33 00 66).

The Continence Foundation of Australia website continence.org.au also has fact sheets on toilet training, bedwetting and good bladder and bowel habits.

Did you know?

- Bedwetting is common, often running in families. More than 100,000 Australian children will wet the bed tonight.
- Constipation is the biggest cause of urinary and faecal incontinence in children, and about 30 per cent of Australian children are constipated.
- If your child experiences at least two of these within an eight-week period, they are constipated:
  - Fewer than three bowel motions a week
  - At least one episode of faecal incontinence
  - Their stool blocks the toilet plumbing
  - Withholding behaviour
  - Painful defecation

Just like the grown-ups

Continence nurse Clare Fyfield said the ideal time for parents to instil good bladder and bowel habits in children was at toilet-training stage, when they instinctively mimic their parents and siblings.

“Children can sit on an adult toilet with insert and footstool or step-up frame from about the age of 18 months. This encourages the ideal position for toileting,” Ms Fyfield said.

“It doesn’t matter if they’re not interested in doing anything; the idea is that they become familiar with sitting on a toilet, that it’s not strange.

“Get boys to sit down to do a wee, right up until they’re fully toilet trained and fine doing a poo on the toilet.”

Ms Fyfield said toilet training was occurring later in Australian families as the use of pull-ups became more prevalent.

“They’re convenient for mum but the child becomes used to the pull-ups, feels comfortable and doesn’t become aware of the wetness,” she said.

“If they don’t want to get out of pull ups, I suggest parents put knickers on under them so they ‘feel it’ when they get wet.”
When a child needs assessing

We asked children’s continence nurse and National Continence Helpline consultant Janine Armocida what parents and children can expect in a continence assessment.

Q: When should a child have a continence assessment?
A: If a child is having regular daytime wetting or soiling accidents at the age of four, or has been successfully toilet trained but starts soiling or wetting at a later stage, they should have a continence assessment.

If a child is still wetting the bed regularly at the age of six or seven, they should also have a continence assessment. We know 20 per cent of five-year-olds and 10 per cent of seven-year-olds still wet the bed and the sooner the child has treatment the better the outcomes. It is a myth to believe that all children will grow out of bedwetting. Anyone – parents, GPs or specialists such as paediatricians – can make a referral.

Q: What do you look for?
A: We check for neurological conditions such as spina bifida occult by observing the child’s gait, checking their muscle tone and lower limb strength, and their spine, particularly the lower spine.

We also check for urinary tract infections with a simple stick test. We look at the colour of the urine; if it’s dark the child may not be drinking enough, which can make their urine too acidic and the bladder more unstable.

We also palpate the child’s abdomen to check for constipation.

Q: What is a bladder and bowel diary?
A: A bladder and bowel diary provides important information about the possible cause of the incontinence and the best way to treat the problem. We ask parents to record their child’s fluid intake, each occasion the child empties their bladder (and the volumes) for three days, and their bowels for one to two weeks using the Bristol stool chart. It’s also important to record any accidents and if the child initiated toileting or needed prompting.

Q: Describe a uroflow test?
A: We use a flow toilet, which provides a printout of the urine flow rate as the child empties their bladder. It should be like a bell curve – starting off slowly, strongest in the middle and tapering off at the end. This helps identify any voiding dysfunction.

Q: What is a bladder scan?
A: It’s an ultrasound that checks whether or not the bladder is emptying fully. If a child doesn’t empty their bladder fully it puts them at risk of developing urinary tract infections or other problems.

Q: What tips do you give them about going?
A: It is important to teach children to relax on the toilet for both bowels and bladder. We teach them how to sit properly – with their back straight, bending from the hips with their hands or elbows on their knees. If a child has a wetting problem we might ask them to count to 10 once they have finished to encourage the bladder to empty properly.

To encourage children to empty their bowels properly we encourage them to sit on the toilet for five minutes, about 30 minutes after a meal, to take advantage of the gastro-colic reflex, which is a mass movement of contents through the bowel.

When toilet training boys it’s a good idea to get them to sit. They will be able to stand when they’re older, and it’s much easier to ignore the call to do a poo if they’re standing up, which could lead to constipation.

Sleepover stress-buster

Chris Hardwick, a clinical psychologist at Sydney’s Westmead Children’s Hospital, works daily with children and families affected by bedwetting. He offers some practical tips to help prepare a child for an overnight sleepover.

Talk about possible scenarios

Talk and think through with your child what may happen, and problem-solve and plan what they would do if the worst scenario took place. Give them a strategy, a plan.

For example, will they need a change of underpants, pyjamas, pull-ups? Where can they go to get changed? Where can they put their wet clothes?

When children have a well thought-out plan, they will be much less anxious about what might happen and confident they can manage it.

Organise a support person

If there’s an adult in the other setting who can be made aware of the situation, and the child is OK with their knowing, then organise that support person.

If the child knows there will be a grown-up there – a teacher, an auntie or a friend’s mum – who they can quietly go to if they need help, that will make them feel less anxious.

If the child is fairly confident about coping, that’s OK. But if they’re not sure they can handle certain scenarios, then it’s best to recruit a support person.
Just like breathing

Carer of the Year

Having a Down Syndrome baby at the age of 21 was never in the life plan of the Continence Foundation’s 2013 Carer of the Year, Jane McCartan. But her baby’s birth had a life-changing impact on her life and the lives of at least 70 other young people.

In 1976, when Jane McCartan was 21 and pregnant with her first baby, she could never have imagined her life ahead as foster carer of more than 70 children and babies over the course of the next 38 years.

Nor could she have predicted that she and husband Tony would adopt two Down Syndrome babies, Megan and Joseph, now aged 29 and 25 respectively, who still live with them at their South Sydney home.

Or cerebral palsy baby Michael, who survived just five years after his adoption.

She would certainly never have foreseen falling in love with severely disabled twin baby boys Will and Codye, that she and Tony would agree to take on their permanent care about nine years ago.

The birth of their first child, David, with Down Syndrome in 1976, turned out to be the catalyst for Jane’s dramatic turn of events – from self-described “yuppie” adventure traveller to stay-at-home mother of a disabled baby boy.

Originally from Northern Ireland, Jane and her husband had been living and working in Sydney for two years and had been intending to embark on the next leg of their global travels, when David was born.

“I didn’t even know about Down Syndrome. Back then it was hidden. They were either put in institutions or hidden at home,” Jane said.

But in Jane’s eyes, David was beautiful.

“He was normal to me. I didn’t see David’s disability,” she said.

Within four years, Jane and Tony had had two more of their own children, both of whom are now married with children of their own.

“I have had paediatricians tell me I need to be certified.”

– Jane McCartan

Had David been born a few years later, surgeons wouldn’t have hesitated to operate on his ventricular septal defect (VSD), or hole in the heart.

“It was such a simple case of VSD, but in those days they didn’t operate on Down Syndrome babies.”

David died in 2000, aged just 23, from his heart condition.

Jane’s “vocation” began while she was a young mum at home caring for her three young children. Anglicare called her one day to ask if she might help integrate a non-English-speaking Down Syndrome girl with her own children a few days each week.

“And that’s how it all started. It led to fostering. It was just a normal thing for me. Children came and went – pre-adoptions and foster children,” Jane said.

Their charges were invariably disabled children or drug-affected infants and every now and then, one of them stole their hearts.

They adopted Down Syndrome babies Megan and Joseph within a few years of each other in the ‘80s, while severely disabled cerebral palsy baby, Michael, came into their lives in 1996.

He died in 2000, the same year they lost David.

Most recently, in 2004, they took on the care of twin babies, Codey and Will. Severely disabled, the twins were epileptic, immobile, incontinent, blind and deaf. The also suffered a lung condition which required regular suctioning.

“They weren’t expected to live beyond 12 months, but they thrived,” she said.

Her care extended to home schooling them via distance education, because taking the twins anywhere was so logistically fraught.

“I needed someone to push the other wheelchair. And I needed to make four phone calls just to go anywhere. It was just so hard to take them anywhere, so I didn’t go anywhere.”

Her husband has been an integral part of the partnership, Jane said, steadfastly supporting her throughout the years.

“With the twins, Tony would do all the shopping. He did everything for me; if I didn’t have Tony I couldn’t have done all that I have,” she said.

Matters took a dramatic turn for the worse in September last year, when the twins contracted pneumonia – the same time Tony was rushed to hospital with a life-threatening brain haemorrhage.

After 16 days in ICU, Tony recovered sufficiently to come home. He then took extended sick leave to help Jane care for the twins, who were also out of hospital.

But in August this year, the twins’ health suddenly deteriorated and, within two days of each other, they died of influenza. They were just nine years old.

Jane, who is still grieving the twins’ death, said she would not change a thing if she had had her time over.

“I have had paediatricians tell me I need to be certified,” she laughed.

Jane’s care extended beyond the reach of her home when David started school, and she became a vocal advocate for the rights of children with disabilities.

In fact, it was as a result of her challenging the New South Wales education system that David started school at age four.

“If most of a child’s learning is done before the age of five, why did Down Syndrome children not start school till the age of six or eight? It didn’t make sense,” she said.

Jane was a school council committee member for many years and president for 10 at Megan and Joseph’s school, the Caroline Chisholm Special School.

She has been a thorn in the side of politicians and bureaucrats for decades, fighting for the rights of disabled children.

“I have a placid nature until I see something that’s not fair for our children; then I go for the jugular,” Jane said.

“Since Jane was nominated for Carer of the Year by Bankstown Hospital’s Claire Dobson, a continence nurse advisor who was referred to the family when they took on the twins.

Claire’s first impression of Jane’s home, she said, was like entering a spotless mini-hospital, but “most of all there was a sense of overwhelming love, compassion and calm.”

Jane said winning the award came as a shock, because her work is “second nature, like breathing”.

“I’m really chuffed. It’s lovely to think that people value what I do,” she said.

Jane’s value to the community is indeed substantial. If Megan and Joseph were in state care they would each cost the government an estimated $280,000 a year, and the twins $300,000 each.

As she reflects on the significance of the award, her thoughts turn to the twins – and to all the children she’s loved and cared for.

“Codey and Will were beautiful, really beautiful. I hope this award makes them important,” she said.
Q: I am six months pregnant with my second child and have noticed that I leak urine sometimes when I cough or pick up my 18-month-old son. I didn’t experience this when pregnant with my first child. Is this likely to stop after my baby is born, or should I see a doctor? I am wearing pads to avoid mishaps, but don’t want to rely on them forever.

A: Any unwanted leakage of urine is incontinence, no matter how small the leak, and it is likely to get worse if left untreated. Incontinence can be due to many factors (including family history and constipation), but unfortunately, pregnancy is one of the major contributors. This is most commonly due to the pregnancy hormone relaxin and the strain on pelvic floor muscles during pregnancy and/or birth. One in three women who have ever had a baby will wet themselves. Many continence issues during pregnancy do resolve, although women who experience problems are at greater risk with subsequent pregnancies and post-menopause.

The good news is that incontinence can often be treated successfully with simple pelvic floor muscle exercises. If you strengthen your pelvic floor now, you can negate a lot of these issues.

We know that 50 per cent of women don’t perform their pelvic floor exercises correctly, so it’s advisable to see a continence nurse or physiotherapist specialising in women’s continence if you’re still having problems. The continence nurse consultants at the National Continence Helpline (1800 33 00 66) can refer you to one in your local area.

Q: I am four months pregnant with my first child and am worried I will put on a lot of weight and not be able to lose it after the baby is born. Before I fell pregnant, I ran about four times a week and I would like to continue some form of exercise, but a friend told me I could damage my pelvic floor and suffer incontinence if I do.

A: During pregnancy it is normal to have a healthy weight gain of approximately 12-14kg. Many women have a good exercise program prior to, during and after pregnancy, and there is no reason to change your exercise regime. However, you may need to monitor it and possibly be less rigorous towards the latter stage of pregnancy. Be sure to keep up your pelvic floor exercises so your pelvic floor can tolerate the strain from the extra weight you are carrying.

The Foundation has just released the Pelvic Floor First app, which features a wide range of pelvic floor safe exercises designed by a physiotherapist. The free app has three levels of intensity, which is great for expectant mums and those wanting to resume exercise post birth. It is available from iTunes and suitable for smart phones and tablets across the iOS and Android platforms.

For further advice, contact a pelvic floor physiotherapist. Phone the National Continence Helpline (1800 33 00 66) for a referral to a physiotherapist in your local area or for further information.

Q: I have just recovered from my fourth cold this year, which means I’ve been housebound for the fourth time. Many years ago I saw a urologist who gave me Vesicare tablets, which only worked for a couple of years. Until now I’ve only been incontinent with a cold or cough, but since my last cold I am leaking every time I stand up, bend over, carry the washing basket, sneeze or laugh, and am wearing a pad full time. What should I do?

A: If you are leaking when coughing it means you are suffering from stress incontinence. Your urologist would have given you Vesicare tablets for urinary urgency, not stress incontinence.

Even if, in the past, the incontinence has resolved after your cough improved, you are showing signs of a weak pelvic floor. If you do nothing the muscles will only become weaker and the incontinence will become worse. The best advice I can give you is to see a continence physiotherapist for pelvic floor muscle rehabilitation. It would also be worth talking to your GP about your colds (four colds in one year is a lot!) to find out if a cough suppressant would be appropriate.
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