Bridge

BLADDER & BOWEL CONTROL HEALTH

SUMMER
2024

Continence Foundation of Australia

From housebound to hopeful - Melissa's story

Healthy toileting habits in schools

Amanda Carmody - helping families thrive

Children's bowel health with Dr Janet Chase

National Continence Helpline 1800 33 00 66
A free service staffed by Nurse Continence 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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References For a list of references for any articles appearing in *Bridge*, please **email** bridge@continence.org.au

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Email membership@continence.org.au or **Phone** 03 8692 8400.

The Continence Foundation of Australia greatly values the stories people share of living with or caring for someone with incontinence. Reading the experience and advice of others can make a huge difference to someone in a similar situation. If you would like to share your story with us, please register on our website.
Go to www.continence.org.au/life-incontinence/personal-stories#sharestory

Unless otherwise indicated, the photographs used in Bridge are those of models and bear no resemblance to the story.

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NOTE FROM THE CEO

Welcome to the Summer 2024 edition of Bridge magazine. This edition has a special focus on toilet training, with plenty of information and tips to ensure a positive experience for your child. Summer offers an excellent opportunity to start toilet training and we have a page full of online toilet training resources for you on page 18.

Schools are increasingly responding to the support needs of children who are managing incontinence. In this edition we share advice from educator Bronwyn Robinson regarding the support of children at school. We share a personal story from a parent about caring for a child with incontinence and articles by nurses and paediatric specialists about the best ways to respond to the challenges and nurture family relationships at the same time.

We offer support to many parents with toilet training on our National Continence Helpline on 1800 33 00 66. This is a free and confidential service, staffed by nurse continence specialists who offer information, advice and support. They also provide a wide range of continence-related resources and referrals to local services.

The Foundation encourages schools to implement Toilet Tactics, an educational resource for primary schools. Toilet Tactics promotes healthy bladder and bowel habits in children and aims to improve or maintain the standard of school toilets across Australia.

The National Public Toilet Map is another helpful resource for parents. It lists over 23,000 public toilets across Australia, including adult change and baby change facilities. This map is invaluable for the parents of young children who are travelling during the summer holidays. The National Public Toilet Map is proudly managed and supported by the Continence Foundation of Australia.

Rowan Cockerell,
CEO,
Continence Foundation of Australia

IN THIS ISSUE

ABOUT THE FOUNDATION

The Continence Foundation of Australia is the national peak body promoting bladder and bowel control health. Our goal is to eliminate the stigma and restrictions of all aspects of incontinence through research, advocacy, consumer education and professional development.

This includes providing high quality continence resources, education and services. The Foundation advocates for policies and programs that consider the needs of people affected by incontinence and supports research and professional education in incontinence.

Continence is the ability to control your bladder and bowel. Incontinence is the involuntary loss of urine and faeces. In many cases incontinence can be prevented, better managed and even cured.

Who we support: We support people of every age, gender and cultural background. Incontinence affects women, men and children of all ages, physical abilities and social and cultural backgrounds.

How we can help: We have resources for individuals and for health professionals.

- If you need support for yourself or a family member, the Continence Foundation of Australia's National Continence Helpline (1800 33 00 66) is staffed by nurse continence specialists who offer free and confidential information, advice and support. It operates 8am to 8pm AEDT, Monday to Friday
- Our website includes a wide range of helpful information, self-help guides and tips on getting support. You can also download or order paper copies of resources.

Health Promotion Initiatives: We lead initiatives aimed at improving both public health and community accessibility, such as Pelvic Floor First, promoting pelvic floor exercises and BINS4Blokes, encouraging the installation of incontinence product disposal bins in male toilets.

NATIONAL PUBLIC TOILET MAP

PLAN YOUR SUMMER HOLIDAYS WITH THE NATIONAL PUBLIC TOILET MAP

Need to take the children to the toilet, change a baby's nappy or find an accessible facility?

The National Public Toilet Map (NPTM) shows the location of more than 23,000 public toilets across Australia, including adult change and baby change facilities. It has proven to be a vital resource for all Australians, especially those with incontinence, travellers and young families.

More than just a directory, the NPTM allows individuals to filter and search for specific toilet features, including opening hours, wheelchair accessibility and adult change facilities.

The map includes

- The location of the nearest public toilet
- Details of opening hours, accessibility, parking and many other features
- An option for you to add and update public toilets to further expand the map
- The ability to create and share your own specialty maps. Specialty maps can be shared as a URL or QR Code, so you can email, print or share it on social media
- Distance by route, which shows the quickest route to a facility, on foot or by car. This ensures that distances include factors such as one-way roads and building access.

WHERE TO FIND THE NATIONAL PUBLIC TOILET MAP

Access the map via toiletmap.gov.au

SCAN HERE
TO GO TO THE MAP

You can also download the app from Google Play or the Apple App Store.

The icon looks like this.

"The National Public Toilet Map is a useful website and app for everyone. It is especially helpful for those who experience incontinence and would otherwise restrict their activity for fear of not having access to a toilet."

Rowan Cockerell, CEO
Continence Foundation of Australia

The National Public Toilet Map is proudly managed by the Continence Foundation of Australia and funded by the Australian Government Department of Health and Aged Care as part of the National Continence Program.

HELPING FAMILIES THRIVE

Amanda Carmody is a registered nurse, child and family health nurse, midwife and paediatric continence nurse. She is based in Queensland, and she uses attachment-based strategies to help families and children with both sleep and continence issues. These strategies put attachment and connection between parents and children as a top priority when making any change.

Amanda states that children will typically toilet train themselves with a little help and encouragement, so if toilet training is delayed, not progressing or the child is struggling; getting professional help sooner rather than 'waiting and seeing' is always better.

Children are never incontinent on purpose; it is not laziness nor bad behaviour. Children want to fit into their community and they want to feel normal, so when things go wrong, they feel different and it can affect their self-esteem.

It can alter parents' self-esteem as well. Parents will often compare themselves to others. When their child is not achieving toileting skills they may feel ashamed. Amanda's role is to help parents understand what's going on in their child's body, normalise the frustration they feel, and explain that there are strategies and support available. "I'm trying to build up both the parents and the child's self-esteem. There has been no failure, this is a problem that we need to get on top of."

Attachment refers to the emotional bond between a child and their parent, this is crucial for healthy development. When the attachment is secure, children feel safe and supported, and are likely to cooperate. This is why working with attachment strategies is important in addressing incontinence in children. When families understand any underlying medical reasons and obtain a treatment plan, they can then support their child to take actions that will address the incontinence, with open communication, understanding and empathy.

These new habits are often about helping the child to strengthen their mind-body connection. For some of the children Amanda works with, this can pose extra challenges.

Amanda Carmody, Thriving Families

WHAT IS ATTACHMENT THEORY?

Attachment theory is a body of thought about the relationships and bonds between people, especially those between a parent and child. Caregivers who are responsive and nurturing to a child allow the child to develop a sense of security. This is relevant to toilet training because that trust and security can help a lot when you're trying to achieve something new.

GETTING EMOTIONAL SUPPORT

Remember it is completely normal for parents to experience negative feelings, just as it is for children. Children usually express their feelings as behaviours, but as an adult you have a few more options.

Some helpful strategies:

- Talk to someone. Call a friend or call the Foundation's National Continence Helpline for free and confidential advice on 1800 33 00 66
- If you are very stressed in the moment, put your child in a safe place and leave the room, go outside or to a window and breathe deeply
- Connect with other parents who you can share your tips, concerns and successes with
- Learn about child development so you know what to expect. To find reliable resources, look for websites that are published by government health organisations, peak bodies or hospitals. Your local library can be a great place to find books on child development and your maternal and child health service may also offer resources or recommendations.

> *In almost all cases, with the right professional help, your child can have a successful toilet training journey."*

Children with neurodiverse conditions such as Autism Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD) will have sensory difficulties along with planning and cognitive issues. To successfully get to the toilet when they need to, a child needs sensory skills (a strong mind-body connection) and planning skills (an ability to think and plan ahead).

Learning how the body works can help. Amanda uses lots of visual aids to help families, including pictures and even playdough, to make models and to demonstrate how our parts move. The more families understand the easier therapy becomes. Parents and children can then problem solve together and the child gains more control over their own body. “Once you explain to parents how systems interact and work they can then understand and follow through with therapy. If they don't understand why they are doing things or where you are going with therapy, they may stop it, just when things are about to improve.”

Amanda explains to parents how the body can miscue the child, and how that can be changed so that the child’s brain, body and nervous system all start to work together. Amanda recommends always seeing a healthcare professional with relevant qualifications and/or experience, that you feel comfortable with and who has a positive approach that nurtures family relationships. “When things go wrong, or toilet training is delayed my tip is to ask for help sooner than later.”

Incontinence in children is not a failure, it is a common condition that can be treated. Any underlying medical cause should always be identified and treated first. The bonds between family members can be strengthened and the family’s connection can be repaired. In almost all cases, with the right professional help, your child can have a successful toilet training journey.

NEURODIVERSITY AND TOILET TRAINING

All children can experience extra challenges with toilet training, but some of these challenges are more commonly experienced by neurodiverse children (children with ASD and children with ADHD).

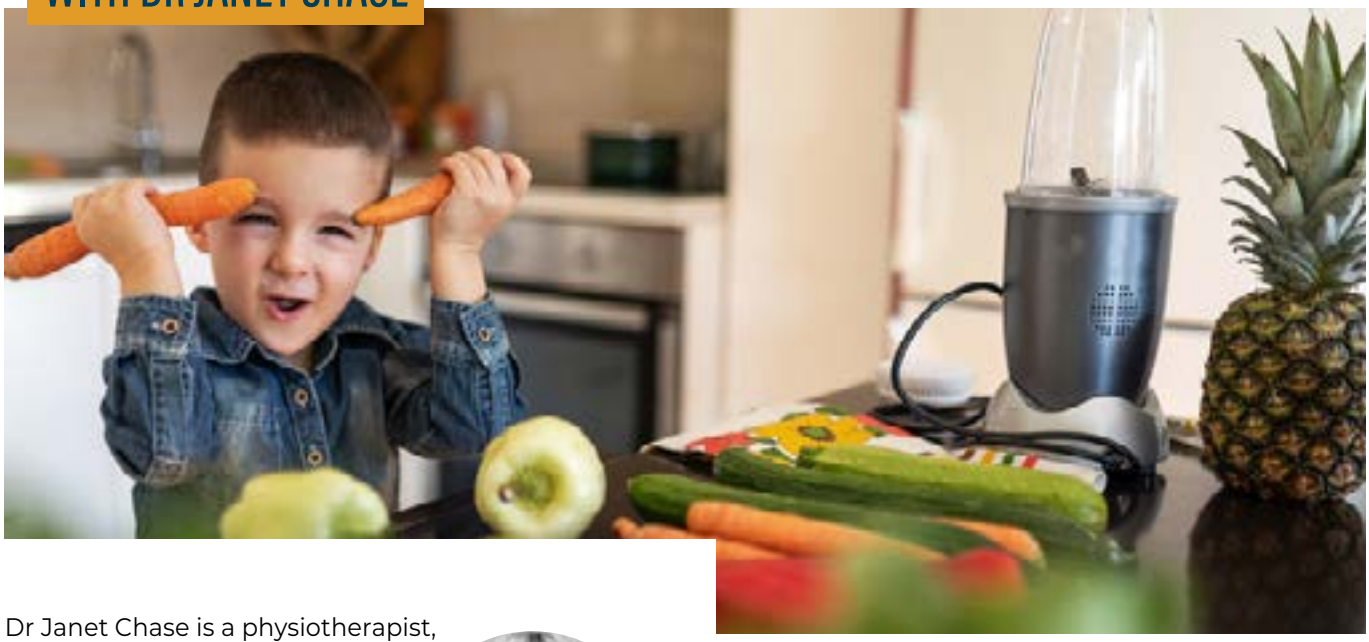
Neurodiverse children may attain toilet training independence a bit later than their peers. Even though they may take a little longer, it might be reassuring to know that most children can be toilet trained eventually and that the positive reinforcement and the help with forming habits that are suggested for neurotypical children will also assist children with ASD and/or ADHD.

Two skills a child needs for toileting independence:

1. A reliable mind-body connection. The first skill that’s needed for independent toileting is an awareness of what is happening in your body and the ability to respond to these feelings. Children with ASD often experience nervous system overload, making it harder for them to be aware of feelings in their body.
2. Planning skills. These are the skills to independently plan a trip to the potty or toilet in response to the body feelings. Neurodiverse children might need some extra help to plan ahead to ensure they get to the toilet in time.

CHILDHOOD BOWEL HEALTH

WITH DR JANET CHASE



Dr Janet Chase is a physiotherapist, academic and a founding member of the Continence Foundation of Australia. She started her career in women's health and has been a clinician in continence care for the past 35 years. “So many of the adults I was seeing said to me, ‘you know, this has always been a problem for me since I was a child’. So, I thought, why aren’t we treating the children?”

Dr Janet Chase

Constipation and faecal incontinence are common in children, but these symptoms are important to address from an early age because they are a risk factor for other conditions such as urinary incontinence, prolapse and pelvic pain in adulthood. It is best to seek help early.

WHAT CAUSES THESE DIFFICULTIES IN CHILDREN?

Janet explains that the most common reason for constipation in children is functional. This means that there is no underlying disease, but there is an underlying cause. Most commonly it is a natural response to previous painful experiences. Children with constipation may have had a distressing experience, such as nappy rash or a painful bowel evacuation and the result is that they instinctively avoid going. This then causes constipation and bowel dysfunction. It can happen without parents realising.

“Children are really incredibly sensible. If something happened once and they didn't like it or it hurt, they don't want to do it again” states Janet. Some of the less common reasons for childhood bowel conditions are coeliac disease, inflammatory bowel disease and food sensitivity. These kinds of conditions account for less than 5% of children with constipation.

WHAT SHOULD I LOOK OUT FOR?

Signs of constipation in children from three years old include

- Infrequent emptying of bowel or difficulty emptying the bowel
- Abdominal pain, ‘a sore tummy’ or flatulence
- A decreased appetite: they may become really picky eaters
- Children may be unhappy, bad-tempered, tired or withdrawn, because they do not feel well
- When they need to empty the bowel these children may go off and hide, or disappear behind the couch, they might stand up and hold on to furniture. They may appear to be straining to have a bowel action, but they are really straining not to have a bowel action
- They might have separation anxiety and just want to stay with mum or dad
- Toilet trained children may have faecal incontinence, which can be mistaken for diarrhoea.

> *Children are really incredibly sensible. If something happened once and they didn't like it or it hurt, they don't want to do it again"*

WHO CAN I GO TO FOR HELP?

The first thing to do is get an examination and assessment by someone who is trained to do so. This includes medical practitioners, nurse continence specialists with paediatric experience and pelvic health physiotherapists with paediatric experience.

With the help of a trained health care professional, most of these difficulties can be resolved and initial improvements can happen very quickly.

HOW IS IT TREATED?

Different treatment is required for constipation in children than in adults.

For a loaded bowel, treatment usually involves laxatives. Not treating constipation can harm the bowel, however treating constipation with laxatives designed for children is very safe and these laxatives can be used long term.

The condition may improve in just a few weeks, but difficulties can reoccur if treatment stops. It is usually best to continue for a few months, because there are big changes happening for the child, for example the child may need to

- Develop more understanding of how their body works
- Learn to respond to the feelings in their body (there may be no sensation from their bowel and that takes time to redevelop)
- Change their day-to-day actions in response to those feelings.

All of this takes time. Sometimes symptoms may reappear, but as the child grows and learns to understand their body better, they and their parents will be able to detect the symptoms of relapse and intervene earlier. If there is no progress over six months, then the child should see a paediatric gastroenterologist. There are some children who will have difficulties and need treatment for years.

WHAT IS HAPPENING IN CHILDREN'S DIGESTIVE SYSTEMS?

Children generally have very strong pelvic muscles, so they are quite successful at holding on. Unfortunately, holding on and not having a bowel movement makes the condition worse. "They're holding on for dear life and children, on the whole, have very efficient pelvic muscles, so they are quite successful at doing this. This, however, slows the gut down and then it's likely that the discomfort will be repeated, which reinforces the behaviour" states Janet.

Understanding some of the ways the digestive system works can help us to respond. For example, children may have the urge to go to the toilet at about the same time each day. About 15 to 30 minutes after eating a child will have a gastrocolic reflex; this causes a big squeeze to happen in the bowel or colon, that moves the contents down the bowel towards the rectum (the last part of the bowel). A child is likely to get the urge to go at around this time.

"If that reflex is happening after breakfast and the child is in the car being taken to childcare, the feeling might go away and the child misses out on going to the toilet after breakfast. It can help to be aware of that and make sure that at that time the child does have access to a toilet," mentions Janet.

PREVENTATIVE STRATEGIES

We can all experience constipation from time to time when something in our lives affects our bowel function. Travelling, a change in diet, a change in routine, an emotional upset or stress can affect all of us. Janet says that children are no different. "One of the things that parents can do early on is teach their child to go when they feel like they need to go to the toilet. Stop what you are doing and go to the toilet, don't put it off. Because the feeling of needing to go might go away but the bowel content doesn't go away."

Good nutrition, including plenty of fruit and vegetables, and timely toilet training can also help. Late toilet training has been associated with a higher rate of childhood constipation. Janet assures parents that these difficulties can be addressed and that treatments are well established and very effective as "hundreds of times, parents and their sad little child will come in to see you. And then you assess them and set them on the right path and at the next appointment the child comes bouncing in with a smile on their face. It can change within one session; once the underlying issues are worked out and everyone understands."

CHILDHOOD BLADDER HEALTH
WITH A/PROF PATRINA CALDWELL

Associate Professor Patrina Caldwell is a paediatrician who specialises in incontinence in children. She began working in childhood incontinence when she was researching recurrent (or reoccurring) urinary tract infections in children. “That research made me realise that a lot of children had problems with urinary incontinence and that was the beginning of a lifelong interest in this space.”

There are two main concerns when it comes to childhood urinary incontinence, bedwetting and daytime wetting. Bedwetting is the most common condition that parents seek help with.

BEDWETTING OR NOCTURNAL ENURESIS

Bedwetting, also known as nocturnal enuresis, may happen because a child is a very deep sleeper and they can't wake up to go to the toilet when their bladder is full. “People may think it's psychological or it's the bladder, but sleep is the biggest component of bedwetting.” Patrina explains.

There are other components that are involved in bedwetting, but deep sleep is the factor that is often present. Other components include

- Can you wake up when your bladder is full?
- How big is your bladder?
- How much urine do you make overnight?

“If you are someone who has sleep problems and you cannot wake up when your bladder is full, then irrespective of the size of your bladder, or the amount of urine you make, you will wet when your bladder is too full” states Patrina.

There can also be a genetic tendency. If one or both parents were bedwetters, then their children have an increased likelihood of experiencing bedwetting.

Treating bedwetting often involves treating the sleep difficulty. As each child is different, it is important to get an individual assessment from a health care professional. Common causes of deep sleep include not getting enough hours of sleep, finding it hard to fall asleep, disturbed sleep due to watching screens until too late at night and sleep disorders such as Obstructive Sleep Apnoea.

About one in two children who have Obstructive Sleep Apnoea will stop bedwetting when their sleep apnoea is treated, without anything else changing.

A/Prof Patrina Caldwell

There are other sleep conditions such as restless leg syndrome that can result in poor sleep and cause bedwetting.

Sometimes a child is just a very deep sleeper, who has perhaps become too practiced at holding on during the day. “If you are a child who is used to holding on when you need to go to the toilet during the day, then at night the little signal from your bladder to your brain to wake it up might not be recognised.”

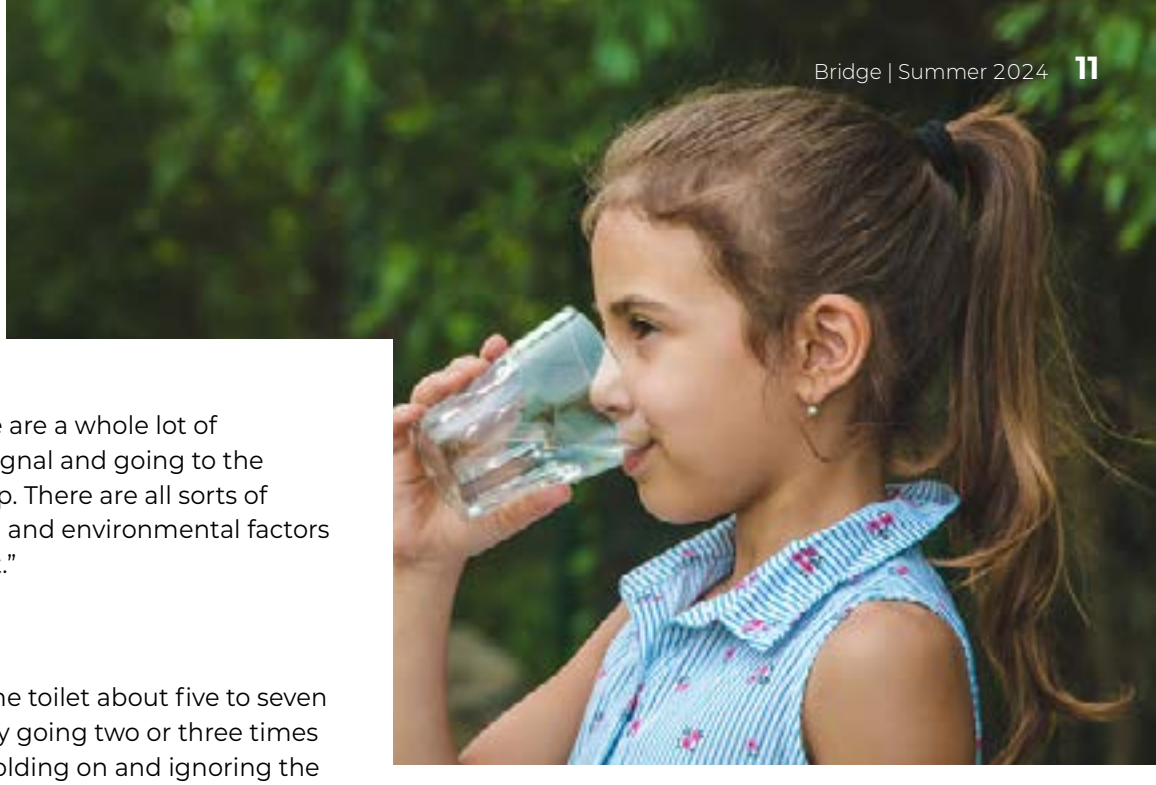
Along with seeing a health care professional to address sleep difficulties, some of the other things you can do to help children with bedwetting are to make sure they are drinking adequate fluids and check that they are not constipated. Constipation in the lower bowel can affect the bladder.

DAYTIME WETTING

Daytime wetting has quite a few possible causes. Children may have an underlying bladder condition such as a small bladder, so Associate Professor Caldwell advises parents that it is important to see a health care professional to diagnose and treat these underlying causes.

Children are also in the middle of developing their mind-body connection. There are many elements to this connection that must work before a child can be independent. These elements include

- Feeling the signal to go to the toilet
- Recognising that the signal means that they need to go to the toilet
- The ability to walk or physically get themselves to the toilet
- The ability to undress themselves.



Patrina reflects that “there are a whole lot of things about feeling the signal and going to the toilet in that one small step. There are all sorts of psychological, behavioural and environmental factors involved in using the toilet.”

HOLDING ON

Normally a child goes to the toilet about five to seven times a day. If they are only going two or three times a day, they are probably holding on and ignoring the cues to go.

Some children will avoid school toilets. Avoidance of school toilets can be a significant obstacle because children will hold on and not empty their bladder and they might avoid drinking fluids so they do not need to go. This can result in dehydration. “The Foundation has a program called Toilet Tactics, which addresses toileting issues at school. I encourage all parents, if their child has an issue with the toilets at school, to request that their school implements Toilet Tactics.”

DRINKING ENOUGH FLUID

It is important that children drink adequate fluids and do not avoid drinking. Children under the age of 12 should not be given drinks that contain caffeine, this includes many energy drinks, coffee and tea, as well as soft drinks such as coca cola.

HELP IS AVAILABLE

“Your GP is the first place to go. It is important to get help because in a very small number of children, these problems can persist into adulthood” states Patrina. For some children, one visit can resolve the condition. When there are more complex causes it can take longer but it’s always worth addressing. “I want people to feel that they can get help because they most certainly can. If you’re told there’s nothing more you can do, well, usually that’s not true, there is more. A lot of GPs are now wanting to learn what else they can do besides the first line or initial treatment, which is really an excellent sign. If you need support and help call the Foundation’s National Continence Helpline on 1800 33 00 66 and they will help you work out the next steps.”

THE NATIONAL CONTINENCE HELPLINE

The National Continence Helpline **1800 33 00 66** is staffed by nurse continence specialists who offer free and confidential information, advice and support to people affected by incontinence. They also provide a wide range of continence resources and information on local continence services.

The helpline is available to anyone living in Australia and is funded by the Australian Government Department of Health. It operates 8am to 8pm (AEST) Monday to Friday excluding national public holidays.

You can also book a callback at a time that suits you on our website.

OBSTRUCTIVE SLEEP APNEA

Obstructive Sleep Apnoea is when your throat muscles relax too much while you are asleep and your airway is blocked or narrowed and your breathing is temporarily cut off. In children, this may be caused by adenoids or tonsils blocking the upper airway.

RESTLESS LEGS SYNDROME

Restless Legs Syndrome is the urge to move your legs particularly when sitting or lying and especially at night and can be relieved by moving. Children with restless legs syndrome have an increased risk of experiencing bedwetting.

FROM HOUSEBOUND TO HOPEFUL - MELISSA'S STORY

Melissa is 31, married with two children and she is an early childhood educator. Her eldest child, Bella, has encopresis, a condition she did not know existed before her child was diagnosed with it. "I didn't even know incontinence was a thing for people who didn't have severe disabilities. Toilet training went really well, as expected. You know, there were accidents here and there and then about a month in, she stopped doing poo in the toilet and it was just accidents, accidents, accidents."

Melissa and her husband tried all the usual tips and tricks, rewards and sticker charts, but it just kept happening. They went to the family doctor. Melissa reflects that "the doctor said that three-year-olds have accidents and so I thought, okay, this is normal. Then Bella turned four and then we got told that four year olds have accidents."

Finally, they were referred to a paediatrician, a doctor who specialises in children's health, and he prescribed a three-month course of laxatives.

Bella has been on laxatives ever since. The paediatrician wrote encopresis on the file, but he did not explain to Melissa that this was a medical condition and not a delay in toilet training.

It took four years after Bella's symptoms began for the family to find effective treatment. She is now seven years old. Those four years of seeking help were difficult and lonely. The family stopped going out as much, which disrupted friendships and added to the pressure. "I thought that she was the only child in all of existence to ever experience it. I didn't know of anyone else."

It was hard to get the right help. Blood tests did not pick up any underlying disease, so Melissa engaged an Occupational Therapist (OT). The OT started helping Bella with her interoception (the ability to feel what's happening in her body).

They were prescribed washouts by the paediatrician to do at home. A washout is a treatment to clear a full bowel and help it return to a normal size. While ultrasounds showed Bella's bowel did get smaller, it was still not within the normal range of measurement and the measurement would go up and down and up again.

In March this year, Bella became very ill because of the condition and was admitted to hospital. She was there for two weeks. The treatment was a medically supervised washout. Since this treatment, her condition has improved, although it has not been resolved.

Melissa had to fight for the hospital admission and to work hard to be heard about her child's medical condition. The family sought help from a new health care professional, who was concerned that Bella's maintenance dose of laxatives was very high. Because of this, they prescribed a lower dose, but the lower dose led to Bella experiencing further constipation. Bella continues to need a high dose of laxatives to maintain her health.

Following the hospital treatment and with careful management, Bella can now go to her soccer and swimming sessions. Her parents must monitor her water intake because the laxatives she takes require her to increase her water consumption so that she stays hydrated.

Bella was diagnosed with Autism Spectrum Disorder (ASD) and Attention-Deficit/Hyperactivity Disorder (ADHD) a few months ago. Melissa says that these diagnoses may help explain some of the reasons for the encopresis. "At the start of toilet training we didn't know that she had sensory difficulties around the toilet, the smells for example. We didn't know she had issues around being able to focus on her body or difficulty sitting on the toilet for very long."

Melissa's advice to other parents is to be persistent with health care professionals. Get help early and seek a second opinion; especially if you receive advice that suggests incontinence is normal.

> ***Don't wait to be referred to a continence specialist. Just call them up and say I'm having concerns about my child's toileting; I think I need to see someone."***

Melissa says that you may need to see multiple specialists, and that this may include a continence physiotherapist or a continence occupational therapist, and she advises parents to try to learn from all of them. One person may not have all the answers, and she says that parents should be aware that loose bowel movements can be caused by constipation and faecal impaction (very hard faeces) rather than by diarrhoea. "Don't wait to be referred to a continence specialist. Just call them up and say I'm having concerns about my child's toileting; I think I need to see someone."

Talking to other parents in the same situation can be life changing. Melissa realised that a boy in her daughter's class had the same condition. When she spoke with the boy's mother, she was shocked. "When I was talking to her and she said, 'he has encopresis, that's this thing that – ' and I said you don't have to tell me, I already know. She was in tears. 'What do you mean, you know what this is?' And I said my daughter has encopresis as well."

Creating positive associations around the toilet is important. "Make the toilet nice, make it smell nice, never yell at children around the toilet. You don't want them to develop any negative feelings around the toilet." Says Melissa.

Her advice to families is to be kind to each other and to remember it is not the child's fault. Melissa explains that it is important to make sure children in this situation know that they are not alone and it is not their fault. Let them know they need medicine because right now their body needs a bit of help.

WHAT IS ENCOPRESIS?

Encopresis is also known as soiling or faecal incontinence. This is when a child has bowel accidents without awareness. It is often associated with constipation or faecal impaction and occurs when the lower bowel or rectum (the last part of the bowel) becomes full of faeces and liquid faeces or stool leaks out around this. The rectum can become stretched or distended and a child can lose awareness or sensation and not know if it is full or empty.

HELPLINE Q&A TOILET TRAINING AND AUTISM SPECTRUM DISORDER

BY JANIE THOMPSON

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that begins in early childhood. A child with ASD can experience challenges in social communication and social interaction and restricted, repetitive patterns of behaviour, interests or activities as described in the DSM-V (Diagnostic and Statistical Manual of Mental Disorders). There are three levels of ASD. A child or person with Level 1 ASD requires support, Level 2 requires substantial support and Level 3 requires very substantial support. These requirements for support are reflected in their communication and behaviours.

A child with ASD has an increased chance of experiencing nocturnal enuresis (or bedwetting), daytime incontinence, faecal incontinence and constipation or bowel emptying conditions. As a result, a child with ASD needs more time, more support and a more structured approached to toilet training. There are great benefits to the child and their family and carers to offering that support.

When supporting a child with ASD to achieve toilet training, consider the following[1]

SOCIAL COMMUNICATION

For children who struggle to communicate when they need to go to the toilet.

- Use a structured time schedule with your child that includes toileting times, to remind or take your child to the toilet based around how frequently they need to pass urine or when they most commonly use their bowels
- Use visual prompts or pictures in the toilet area to show the steps to toileting such as the Continence Foundation of Australia's Girls and Boys Toileting Sequence Pictures
- Make learning about the steps to toileting and trying to use the toilet part of your child's routine as early as possible
- Keep an eye on your child's bowel pattern and try to avoid any constipation.

SOCIAL-EMOTIONAL COMMUNICATION

For children who struggle to understand where it is socially acceptable to pass urine or use their bowels, the social impact of incontinence and the need for privacy with toileting.

- All toileting related activities involving your child should be done in the toilet environment, for example, changing pull ups, any cleaning up needed. This is to reinforce the relationship of urinating or having a bowel movement to the toilet
- Use positive feedback with any steps to toileting your child has attempted or achieved, including toilet flushing, handwashing, pulling their underwear down and up
- Use the particular interests of your child to encourage them to spend time on the toilet and develop a positive relationship with the toilet without being distracted.

RESTRICTED, REPETITIVE BEHAVIOURS

For children who want to use the toilet continually as a repetitive behaviour but do not have an overactive bladder.

- Rule out overactive bladder. Speak to your child's GP to start with
- Offer positive reinforcement for the first or initial urination only
- Offer your child activities of interest to them, to minimise repeat trips to the toilet.

RESTRICTED DIET

For children with food textural issues resulting in a low fibre diet which may contribute to constipation.

- Introduce new foods to your child slowly and steadily
- Give positive reinforcement to your child for trying new foods
- Offer food in your child's preferred style, for example mashed or mixed with other foods that are accepted by them.

SENSORY ISSUES

For children who find the toilet environment distressing (bright lights, sound of flushing toilet, cold toilet seat).

- Adjust the toilet environment to suit your child's sensory preferences
- Ensure your child can sit on the toilet with their feet well supported and in a comfortable position
- Dress the child in clothing that is easy for your child to get on and off.

MOTOR ISSUES

For children with coordination and fine motor skills challenges.

- Use visual cues to help your child follow the steps to toileting, such as pictures of the steps
- Use aids or equipment to suit your child to maximise their independence. An Occupational Therapist may be able to help with these
- Try having your child focus on the last step in using the toilet and work backwards from there, such as starting with handwashing first.

[1] von Gontard, A et al. Neurodevelopment disorders and incontinence in children and adolescents: Attention-deficit/hyperactivity disorder, autism spectrum disorder and intellectual disability – A consensus document of the International Children's Continence Society. Neurourol Urody 1-13; 2021.

The Foundation has resources to support parents and carers of a child living with a disability such as One Step at a Time – A parents guide to toilet skills for children with disability

For general information on toilet training, please see the Foundation's webpage

HEALTHY TOILETING HABITS IN SCHOOLS

BY JO EARP, EDITOR OF TEACHER

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Bronwyn Robinson is the former Education Manager (now retired) at the Continence Foundation of Australia. The Foundation's work includes supporting and providing education for leaders and classroom practitioners in mainstream and specialist schools. Bronwyn states "it's one of those things that people don't feel comfortable talking about. Why is it so difficult to have that conversation when it is absolutely critical for our social wellbeing as well as our health?"

Bronwyn explains that there are a few reasons why children attending school are not toilet trained or have difficulties maintaining either urinary or faecal continence. "There's a group of children who have trouble with their continence and this can be caused by physiological reasons, or problems with the messaging that goes from the brain down to the bladder and bowel."

Starting school before a child is toilet trained can be difficult. "Children are ready to toilet train between about [18 months] and three-and-a-half: it depends on the child. Yet, there's anecdotal evidence that... children are starting school without having attained continence. Parents may be unsure how to undertake toilet training or it can slip when children are moving between home and childcare." Bronwyn states.

Schools can't deny enrolment for a child who isn't toilet trained and Bronwyn says it is important to work together with the school and the parents. "It is important to have a discussion with the parents and have them understand that the child needs to be toilet trained, otherwise they're at risk of wetting or soiling themselves, they'll become isolated, find it difficult to make friends, and incontinence can have a negative impact on their self-esteem and quality of life."

There are also children who are toilet trained but may start having difficulties while they're at school. Bronwyn states "it could be anxiety, change of environment, starting or changing schools, it could be that the school toilets aren't very friendly or they're smelly or they don't [feel comfortable using the toilet.]" Bronwyn says for those children who are anxious about using toilets at school this can cause a chain of events. "If you're constipated, you're more likely to wet yourself because the loaded bowel [can push onto the bladder] and it can become a vicious cycle. In those instances, the conversation needs to be had between the school and the parent and a toileting plan developed and observed. So, things like letting the child go to the toilet at any time when they feel that urge; allowing children to go to the toilet when their bodies say they need to go, is really important."

The Foundation runs a program for primary schools called Toilet Tactics, aimed at promoting healthy bladder and bowel habits and ensuring school toilets are welcoming for children. Resources include information for teachers, parents, carers and students, a school toilet checklist, tips on how to improve and maintain the facilities and a student survey.

Bronwyn explains Toilet Tactics is a "whole of school approach" to the management and care of all children regarding toileting. The learning is designed for school nurses, classroom teachers, principals, parent groups, teachers' aides: anyone who might be working with children and trying to give them some understanding around why certain toileting behaviours are happening, how it can be addressed and the roles and responsibilities within schools and for parents as well. "There are quite a few strategies that schools might utilise for making the school toilets feel safe. It might be friendly colour schemes, maybe having older students who are sort of trustees to be around in the toilets when the little ones are there, maybe a buddy program or something along those lines for [increasing confidence]" states Bronwyn.

Bronwyn adds it's important for parents, schools and children to have a collaborative approach, so that everyone is working towards an outcome that the parent, the child, the teacher and the school are all in agreement with. It assists if school staff understand about the development of continence and how children develop the skills to be able to identify when they need to go to the toilet and giving them strategies to communicate with adults. Toilet Tactics offers schools this understanding and information.

"The Foundation runs a program for primary schools called Toilet Tactics, aimed at promoting healthy bladder and bowel habits and ensuring school toilets are welcoming for children."

TOILET TACTICS

Toilet Tactics is a set of resources for schools, to make sure Australian children have access to toilets that don't hold them back. Parents can recommend Toilet Tactics to their children's school, so that schools can improve their student's health and wellbeing.

The Toilet Tactics Kit helps children to adopt lifelong healthy bowel and bladder habits and informs teachers and parents regarding the importance of encouraging and reinforcing good practices early.

Find out more at
continence.org.au/toilet-tactics

TOILET TRAINING RESOURCES

The Continence Foundation of Australia has resources available to help your child reach those important toileting development milestones and gain greater toileting independence. All our resources are user-friendly with pictures and easy to follow steps, providing a general guide for parents and caregivers. Download your free copies today.

EASY GUIDE TO TOILET TRAINING

Go to Easy Guide to Toilet Training

Many parents find toilet training their child can be challenging. This booklet is a guide to help you teach your child to use the toilet in four logical steps.

ONE STEP AT A TIME - THE EXPERT TOILET TRAINING GUIDE

Go to One Step at a Time: Expert Toilet Training Guide

This is a more comprehensive guide to toilet training in a storybook format, which outlines key steps in helping your child learn how to go to the toilet on their own.

GIRLS AND BOYS TOILETING SEQUENCE PICTURES

Go to Girls and Boys Toileting Sequence Pictures

This fact sheet provides toileting tips with a series of pictures you can use with children to help develop their toileting skills.

ONE STEP AT A TIME - A PARENT'S GUIDE TO TOILET SKILLS FOR CHILDREN WITH DISABILITY

Go to One Step at a Time - Parents Guide

This guide provides five practical steps for parents to help children with disabilities to develop the skills of toileting.

Continence Foundation of Australia

Learning healthy habits early

Toilet Tactics is a free resource to help promote healthy bladder and bowel habits in schools.

SCAN HERE FOR MORE INFORMATION

VICTORIA State Government

Australian Government
Department of Health and Aged Care

Toilet Tactics is an initiative of the Continence Foundation of Australia and is supported by the Victorian Government and Australian Government.

Continence Foundation of Australia

Always rushing to the loo?

It doesn't have to control your life

One in three women experience leakage from the bladder or bowel (incontinence). There is help available – you're not alone. In many cases, incontinence can be treated, better managed or even cured.

Speak to a nurse continence specialist for free, confidential advice.

Call National Continence Helpline

1800 33 00 66

Scan the code for further information or visit **continence.org.au**

The Continence Foundation is a not-for-profit organisation and peak body promoting bladder and bowel control health.