

GUIDE

Transition Care and Urology Networks

Young people with urinary incontinence

Health professional guide



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INNOVATION

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The ACI would like to acknowledge the contribution of the following members of the guideline/schema working group.

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Working with Aboriginal people

The ACI is committed to improving the health of all patients across NSW, particularly those who have significantly higher rates of health problems and less access to appropriate health services. Children and young people with chronic illnesses and disabilities often fit into this category, as do young Aboriginal people.

Although data are limited, it appears that Aboriginal children and young people are as likely to experience urinary incontinence problems as the general population. However, there may be cultural sensitivities that make the problem of urinary incontinence less likely to be recognised and discussed openly.

An Aboriginal Health Impact Statement was undertaken prior to commencement of this project and consultation has occurred with senior Aboriginal health workers, focus groups and representative organisations. We would like to thank the key stakeholders whose contributions have informed the recommendations arising from this project. These stakeholders, including those who work closely with young Aboriginal people, will continue to be involved in the implementation of the recommendations.

It is important that the appropriate steps are taken to ensure that services are delivered in culturally safe and competent ways across the project lifespan. To achieve optimal health outcomes for Aboriginal children and young people with urinary incontinence, we will need to undertake a cultural audit to identify and address the barriers to access to care and ongoing management. The audit, along with the development of culturally competent and safe services, is described in detail in *Chronic care for Aboriginal people model of care*.

Glossary

Some of the following terminology is based on the International Children's Continence Society (ICCS) Update Report, 2014.¹

Key terminology and acronyms used in this document:

Bladder bowel dysfunction	Concomitant bladder and bowel disturbances of clinical significance and relevance. It can be subcategorised into lower urinary tract dysfunction and bowel dysfunction.
CHW	The Children's Hospital at Westmead (part of Sydney Children's Hospitals Network)
CUIS	The Childhood Urinary Incontinence Service at the Children's Hospital at Westmead
Decreased daytime voiding frequency	Voiding ≤ 3 times per day.
Enuresis	Intermittent urinary incontinence exclusively during sleep. This can be monosymptomatic (urinary incontinence during sleep with no daytime lower urinary tract dysfunction) or nonmonosymptomatic (urinary incontinence during sleep as well as lower urinary tract symptoms). Primary onset enuresis is when the child has never been dry at night (bedwetting since being a baby); secondary onset enuresis is when the child has had a previous dry period of at least six months.
HEET	Health Economics and Evaluation Team
Increased daytime voiding frequency	Voiding ≥ 8 times per day.
Pop up	A temporary training clinic that can be established anywhere throughout NSW at the invitation of the local team.
SCHN	Sydney Children's Hospital Network
Urgency	The sudden, unexpected compelling urge to immediately void.
Urinary incontinence	Involuntary leakage of urine. This can be subdivided into continuous (constant day and night urinary leakage) or intermittent (urinary leakage in discrete amounts).
Void	Emptying the bladder or urinating.

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Introduction

Urinary incontinence is a common problem that affects up to 10% of children and young people under the age of 18 years, impacting on health, quality of life and health costs⁽²⁻⁷⁾. Untreated, it can progress to adulthood. The problem has emerged as an increasingly significant one for young adults, but one that is rarely acknowledged. Incontinence is a hidden problem in adulthood, but particularly for young people whose main focus is on establishing independence, finding employment and fitting in with their peers.

Urinary incontinence is a symptom. It can be caused by a complex group of underlying disorders which are primarily related to dysfunction of the urinary bladder, the bowel and the sleep/arousal mechanism (or a combination of these mechanisms). Other less common mechanisms include pelvic floor abnormalities and purely psychological disorders. Hence, it is recommended that initial treatment in primary care be focussed on the identification and treatment of problems in bladder and bowel function.

A significant proportion will respond favourably to an approach focussed on correcting the bladder and bowel dysfunction. For those who are refractory to these simple measures, a multidisciplinary approach by experienced and trained clinicians may further improve outcomes.

The Agency for Clinical Innovation (ACI), in partnership with the Sydney Children's Hospitals Network (SCHN) and the Continence Foundation of Australia (CFA), took part in a project to improve the management and health outcomes of young people with urinary incontinence in NSW. The project is known as PISCES (paediatric information, schema, continence, education, support).

This guide has been developed as one component of the PISCES project.

Purpose of this guide

This document was developed to provide flexible guidance for health services to meet the needs of children, young people and their families and to support non-specialist clinicians. The guide aims to:

- assist community health practitioners in initiating effective evidence based care
- minimise delayed or ineffective care
- ensure targeted and appropriate referrals to specialised centres.

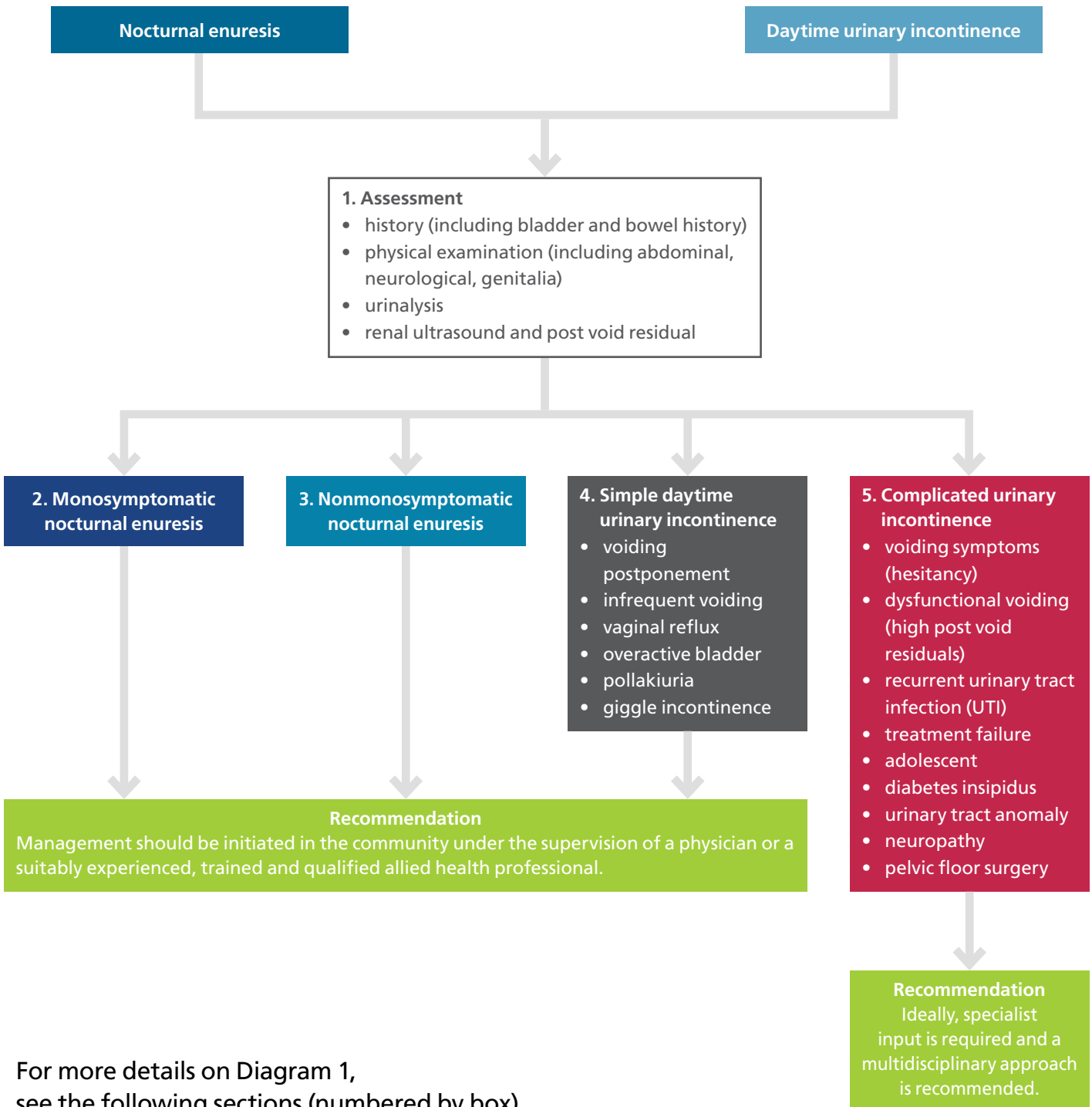
How to use this document

This document can be used by community health practitioners to provide triage advice to determine what conditions are appropriate to be managed in the community and circumstances when it would be appropriate to take a multidisciplinary approach or refer to specialist care.

- Boxes 2–4 in the diagram provide basic treatment recommendations that can be managed in the community.
- Box 5 in the diagram should ideally involve specialist input and be managed by a multidisciplinary approach.

Management of children and young people with urinary incontinence

Diagram 1: Management of children and young people with urinary incontinence



The terminology used adheres to the standards recommended by the International Children’s Continence Society¹.

Assessment (diagram box 1)

History

- Family history of enuresis or urinary incontinence
- Urinary symptoms
 - frequency and severity of wetting
 - urgency
 - voiding frequency
 - nocturia
 - dysuria or pain
 - voiding symptoms (hesitancy, straining, weak stream, intermittency, dysuria)
 - holding manoeuvres
 - urinary retention
 - urine stream
 - post micturition dribble
- Bowel history
- Fluid intake and diet
- Sleep history
- General health (including developmental delay, attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder (ODD) and other mental health history)
- Home, school and family situation

Physical examination

- Abdominal
- Spine and neurological
- Perineum/genitalia

Investigation

- Urinalysis ± urine culture
- Bladder diary
- ± Renal ultrasound and post void residual

Monosymptomatic nocturnal enuresis (diagram box 2)

Introduction

- Explain and demystify the condition to reduce blame.
- Monosymptomatic nocturnal enuresis is the most common form of enuresis: 20% of five year olds, 10% of ten year olds and 0.5–2% of adults have the condition.
- The spontaneous resolution rate is 15% per year.
- Two in three of children are not receiving treatment for enuresis.^(2–7)
- For young children not bothered by the enuresis, active treatment may not be warranted.
- If still wetting by adolescence, the young person is likely to continue to do so and the symptoms are likely to be more severe.

Urotherapy

- Drinking adequately is important to ensure optimal bladder function (fluid restriction may reduce the size of the bladder and fluid loading in the evening may increase the risk of bedwetting). Avoid caffeinated drinks as this may cause bladder spasm.
- Constipation can impact on bladder function and increase the risk for wetting. Ensure normal bowel habits through a bowel program: daily bowel movements passing normal consistency stools without straining. Some children may benefit from using laxatives and/or foot support for defecation.
- Encourage regular voiding during the day and void before bed. Voiding postponement may reduce the child's awareness of bladder sensations and their need to void.

Simple behavioural interventions

- Star charts and appropriate rewards for effort and behaviour (not continence) may assist with motivation.
- Lifting and scheduled waking to void during the night may reduce wet beds, but does not teach the child to become dry independently.
- Nappies or training pants can reduce washing, but does not help the child to become aware of when they are wet.

Alarm training

- This is a first line therapy for monosymptomatic enuresis, with a 65–80% success rate.
- Alarms condition the child to wake to void when their bladder is full and hold on when they do not need to void during the night.
- The enuresis alarm detects when the child wets, and emits a noise or vibration, alerting that the child has wet. Often children do not wake to the sound of the alarm (even if the rest of the family does).
- When the alarm sounds, the child needs to wake and try and void in the toilet (even if they do not feel they need to void). Parents should wake the child if there is difficulty with sleep arousal.
- Alarm training takes 2–3 months. The child should continue alarm therapy until they have had 14 consecutive dry nights.
- This method can be difficult for families, as a young person needs support to do alarm training.
- Overlearning (having a large drink before bed while continuing alarm training) in a child who has learnt to be dry by sleeping through the night may reinforce waking to void if they need and reduce relapse.
- If relapse occurs, repeating alarm training may help.

Desmopressin

- This is a second line therapy for enuresis.
- It is a synthetic analogue of antidiuretic hormone that works by reducing total overnight urine production.
- The response rate is 60–70%, however response is not sustained on withdrawal of medication.
- Available as melts (120mcg or 240mcg), tablets (200mcg) or nasal spray (10mcg/puff) via authority prescription (streamline). There is a higher risk of side effects with the nasal spray.
- There is a risk of hyponatraemia, which is reduced by restricting fluids from one hour before medication until eight hours after.
- It is useful for the short term, such as sleepovers.

Tricyclics

- This is a third line therapy for enuresis.
- Tricyclics are medications that are used primarily as antidepressants, but can also be used for treating enuresis.
- Use is generally not recommended because of safety concerns and poor efficacy.

Nonmonosymptomatic nocturnal enuresis (diagram box 3)

Introduction

- Explain and demystify the condition to reduce blame.
- Children with nonmonosymptomatic nocturnal enuresis have lower urinary tract symptoms, commonly caused by underlying bladder problems.
- Children with nonmonosymptomatic nocturnal enuresis are more likely to be treatment resistant.
- Treatment should target bladder function first.

Urotherapy

- Drinking adequately is important to ensure optimal bladder function (fluid restriction may reduce the size of the bladder and fluid loading in the evening may increase the risk of bedwetting). Avoid caffeinated drinks as this may cause bladder spasm.
- Constipation can impact on bladder function and increase the risk for wetting. Ensure normal bowel habits through a bowel program: daily bowel movements passing normal consistency stools without straining. Some children may benefit from using laxatives and/or foot support for defecation.
- Encourage regular voiding during the day and void before bed. Voiding postponement may reduce the child's awareness of bladder sensations and their need to void.
- Encourage or teach relaxed voiding to optimise bladder emptying.

Assess if the child has a small or overactive bladder

- Normal expected bladder capacity (EBC) can be calculated using the formula: $(\text{Age} + 1) \times 30$ up to maximum of 400mL. This is relevant for children aged 4–12.
 - If actual maximum voided volume (on the time and volume chart) is much smaller than the expected bladder capacity, the child may have a small bladder.
 - The maximum voided volume, excluding the first morning void, is considered small if $<65\%$ of EBC and large if $>150\%$ of EBC.
- The bladder may be small from inadequate fluid intake during the day, constipation or the child having an overactive bladder.
- Ensure the child is drinking adequately and not constipated. If they still have a small maximum voided volume, consider using an anticholinergic medication (such as oxybutynin) or transcutaneous electrical nerve stimulation (TENS) to treat overactive bladder
- Once the underlying bladder disorder has been addressed, the enuresis can be addressed by alarm training or desmopressin.

Oxybutynin

- This is an anticholinergic medication used to reduce bladder spasm with overactive bladder.
- Oxybutynin can help increase bladder size if the child drinks adequately while on the medication.
- This is contraindicated in urinary retention or in children with infrequent voiding who have a large bladder.

Alarm training

- Alarms condition the child to wake to void when their bladder is full and hold on when they do not need to void during the night
- The enuresis alarm detects when the child wets and emits a noise or vibration, alerting that the child has wet. Often children do not wake to the sound of the alarm (even if the rest of the family does)
- When the alarm sounds, the child needs to wake and try and void in the toilet (even if they do not feel they need to void). Parents to wake the child if there is difficulty with sleep arousal
- Alarm training takes 2–3 months. The child should continue alarm therapy until they have had 14 consecutive dry nights.
- This method can be difficult for families, as a young person needs support to do alarm training.
- Overlearning (having a large drink before bed while continuing alarm training) in a child who has learnt to be dry by sleeping through the night may further reinforce waking to void if they need and reduce relapse
- If relapse occurs, repeating alarm training may help.

Desmopressin

- This is a synthetic analogue of antidiuretic hormone that works by reducing total overnight urine production.
- Response is not sustained on withdrawal of medication.
- Available as melts (120mcg or 240mcg), tablets (200 mcg) or nasal spray (10mcg/puff) via authority prescription (streamline). There is a higher risk of side effects with nasal spray.
- There is a risk of hyponatraemia, which is reduced by restricting fluids from one hour before medication until eight hours after.

Tricyclics

- Tricyclics are medications that are used primarily as antidepressants, but can also be used for treating enuresis.
- Use is generally not recommended because of safety concerns and poor efficacy.

Simple daytime urinary incontinence (diagram box 4)

Introduction

Explain and demystify the condition to reduce blame.

Urotherapy

- Drinking adequately is important to ensure optimal bladder function (fluid restriction may reduce the size of the bladder and fluid loading in the evening may increase the risk of bedwetting). Avoid caffeinated drinks as this may cause bladder spasm.
- Constipation can impact on bladder function and increase the risk for wetting. Ensure normal bowel habits through a bowel program: daily bowel movements passing normal consistency stools without straining. Some children may benefit from using laxatives and/or foot support for defecation.
- Encourage regular voiding during the day and void before bed. Voiding postponement may reduce the child's awareness of bladder sensations and their need to void.
- Encourage or teach relaxed voiding to optimise bladder emptying.
- Children with daytime urinary incontinence and enuresis will need treatment for both.

Voiding postponement

- The young person habitually postpones micturition (particularly when distracted with play), and presents with holding manoeuvres and urinary urgency.
- The young person might fluid restrict to reduce the need to void.
- Treatment is with timed voiding (voiding every 2–3 hours whether the child feels urgency or not).
- Alarm watches are often helpful to prompt timed voiding.

Infrequent voiding

- The young person presents with ≤ 3 voids/day.
- Treatment is with timed voiding (voiding every 2–3 hours whether the child feels urgency or not).
- Alarm watches are often helpful to prompt timed voiding.
- The child should be assessed to determine if they can completely empty their bladder (by assessing the post void residual on a renal ultrasound). May need referral to a specialist if unable to empty their bladder.

Vaginal reflux

- This is characterised by urinary leakage 5–10 minutes after voiding without other lower urinary tract symptoms in girls.
- This is caused by anatomical predisposition and posture, and is common in prepubertal girls.
- Treatment is improved toilet posture.
- Educate the young woman regarding positions to improve urine clearance, such as legs widely apart or straddling the toilet backwards.

Overactive bladder

- The young person presents with urinary urgency and frequency with or without daytime wetting.
- This is the most common cause of daytime urinary incontinence in children. The child often has a small bladder capacity with a small voided volume recorded in the bladder diary.
- It can be associated with constipation.
- Treatment is with adequate fluid intake, bowel program, and a timed/regular voiding program.
- Consider using an anticholinergic medication (such as oxybutynin¹) or neuromodulation-transcutaneous electrical nerve stimulation (TENS) to treat overactive bladder symptoms.

Pollakiuria

- This is described as extraordinary daytime frequency, as the child has frequent (>20) small voids during the day.
- The symptoms disappear during sleep.
- Pollakiuria is usually associated with a recent stressor ($>50\%$ of cases).
- The condition is self-limiting; there should be reassurance that the condition is benign after excluding other causes.

Giggle incontinence

- This is characterised by voiding to completion during laughter, and is functionally related to cataplexy.
- True giggle incontinence is uncommon (most children wet when they laugh due to voiding postponement or overactive bladder).
- Treatment is methylphenidate, a stimulant to prevent spontaneous activation of pontine micturition centre in response to laughter.
- Use pelvic floor muscle training together with a timed voiding program and increase the child's awareness of potential risk situations for wetting.

¹ Oxybutynin is an anticholinergic medication used to reduce bladder spasm with overactive bladder. Oxybutynin can help increase bladder size if the child drinks adequately while on the medication. It is contraindicated in children with urinary retention or those with infrequent voiding who have a large bladder.

Complicated urinary incontinence (diagram box 5)

Presentation(s)/underlying condition(s)

- Children with refractory simple daytime incontinence (treatment failure after six months) are classified as having complicated urinary incontinence.
- Children who are at risk of profound impact on their psychosocial wellbeing due to the urinary incontinence merit fast-tracked multidisciplinary approach based care. These groups include adolescents and children with psychological issues.
- Children with voiding symptoms (hesitancy, intermittency, genital or lower urinary tract pain, straining and feeling of incomplete emptying) in addition to storage symptoms and incontinence are considered to have complicated urinary incontinence. This is because they require urine flow studies and radiological evaluation to exclude dysfunctional voiding or obstructive pathologies (although rare). Children with dysfunctional voiding resulting in high post void residuals merit specialised pelvic floor training in addition to basic treatment. Children with obstructive flow patterns may need thorough evaluation by a paediatric urologist.
- Children with recurrent urinary tract infections on the backdrop of urinary incontinence (\pm lower urinary tract symptoms) need urological evaluation to exclude predisposing urological conditions such as calculi, high grade vesicoureteric reflux or obstructive pathologies (although rare).

Evaluation

- Although the fundamental principles underpinning the evaluation of daytime urinary incontinence remain similar, it is recommended that this be done using a multidisciplinary approach in order to optimise the accuracy and thoroughness of the diagnosis and the subsequent treatment.
- Uroflowmetry and post void residual measurement are commonly performed in specialised paediatric incontinence clinics. They enable the clinician to define the possible emptying or storage abnormality and, in rare cases, indicate a possible obstructive element that needs evaluation by a paediatric urologist.
- Invasive urodynamic testing is reserved for refractory cases where specific surgical interventions are contemplated.
- Specialised imaging, such as micturating cystourethrogram, nuclear medical imaging and MRI of the urinary tract, may be ordered as part of comprehensive urological workup.

Principles of treatment in complicated urinary incontinence

- Urotherapy – Improvement/rectification of drinking, voiding and defecating habits through education remain the cornerstone of initial management.
- Multidisciplinary approach – The majority of the children with complicated urinary incontinence need a multidisciplinary approach to care. This includes concurrent provision of urotherapy education, psychological support and/or physiotherapy input as appropriate.
- Intensive therapy – Children with complicated urinary incontinence (excluding urological or neurological abnormalities) often require more intensive treatment. This can be provided for by frequent contact with a continence nurse in a hospital or community once the treatment plans are put in place.
- Specialist input – Depending on the underlying conditions, some children may need early referral to a paediatric urologist, paediatric neurologist or paediatric endocrinologist.

Treatment

Treatment of refractory overactive bladder

- Treat with urotherapy.
- Optimise anticholinergic therapy.
- Consider neuromodulation (TENS) adjunctive therapy if expertise is available, usually through a continence physiotherapist.
- Consider intravesical injection of Botulinum toxin-A for selected cases if a quick response is required. Intermittent catheterisation may be required in some cases to alleviate the side effect of urinary retention.

Treatment of dysfunctional voiding (high post void residuals with symptoms)

- Bladder emptying can be improved by teaching relaxed voiding and improving posture to optimise voiding and defaecation mechanics. A continence physiotherapist may assess and retrain muscle patterns and coordination for bladder/bowel emptying, including assessing and retraining pelvic floor muscles to normalise capabilities.
- Encourage a regular voiding program and double voiding.
- Assess and treat underlying bowel dysfunction.
- Consider neuromodulation (TENS) for overactive bladder symptoms.
- Consider clean intermittent catheterisation if large post void residual urine volumes.

Treatment of urinary incontinence in children and young people (including adolescents) with significant psychosocial impact

- Acknowledge the negative psychosocial effect and the need for prompt treatment.
- Use a fast-tracked multidisciplinary approach based care approach.
- Implement early psychological support measures.
- Counselling and therapy (as required) can be used to ensure, improve and/or maintain compliance.

Treatment of urinary incontinence with recurrent UTIs

- Confirm the validity of the diagnosis of the UTI.
- If ultrasonography normal, consider aggressive treatment of underlying dysfunctional voiding under cover of antibiotics.
- If structural anomaly of the urinary tract likely (based on ultrasonography and history), refer to paediatric urologist for workup.

Beyond the scope of this document

The following conditions are out of scope for this document:

- True anomalies of the urinary tract, including ectopic ureters, ectopic ureteroceles, cloaca and bladder exstrophy can present as urinary incontinence, which is often continuous (not intermittent). The majority of these will be obvious on clinical examination or through an abnormal urinary tract ultrasound. The treatment is led by a paediatric urologist.
- Children with subtle abnormalities of the spinal cord (spina bifida occulta) or significant neurological insults in the recent past can present with urinary incontinence as a symptom of the underlying neurogenic bladder. Often the only indications of spina bifida occulta are cutaneous lesions over the sacral region. The management of urinary incontinence due to neurogenic bladder is beyond the scope of this document.

The multidisciplinary approach

Role of the medical specialist

- Develop collaborative, family centred continence management plan
- Implement, monitor and manage appropriate interventions
- Conduct further assessment/investigations as appropriate
- Supervise and prescribe medication as appropriate.

Role of the physiotherapist

- Develop collaborative, family centred continence management plan
- Implement, monitor and manage appropriate interventions
- Teach posture and body awareness for optimal voiding and defaecation
- Retrain muscle patterns and coordination for bladder/bowel emptying
- Teach relaxed voiding to achieve pelvic floor muscle recruitment and relaxation with minimal accessory muscle activity
- Assess and retrain to normalise pelvic floor muscle capabilities if necessary
- Administer neuromodulation (TENS) for overactive bladder symptoms
- Perform uroflowmetry and ultrasonography.

Role of the continence nurse

- Develop collaborative, family centred continence management plan
- Liaise with school
- Implement, monitor and manage appropriate interventions
- Perform assessment for Enable NSW, NDIS and Continence Aids Payment Scheme (CAPS) funding (only available for permanent and severe incontinence in children older than age 5)
- Teach clean intermittent catheterisation
- Discuss appropriate continence products
- Perform uroflowmetry and ultrasonography
- Perform urodynamics.

Role of the psychologist

- Develop collaborative, family centred continence management plan
- Implement, monitor and manage appropriate interventions
- Support adherence to medical treatment plan
- Identify co-morbid psychological or behavioural problems
- Identify psychological, family and school related barriers to treatment adherence
- Help the child and family develop strategies to improve treatment adherence
- Deliver counselling and therapy (as required) for the child and address parental psychosocial issues impacting on treatment adherence and motivation.

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