Continence Advisory Service

Clinical Guideline

Assessment and provision of continence containment products for children

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**Introduction**

Incontinence is a common condition that may affect all ages with a wide range of severity and impact on the individual. Excellence in continence care (2015) supports equal access to a continence assessment promoting consistent practice providing “person centred care” and empowerment to improve health p.7. It is estimated that there are 900,000 children and young people out of a population of 8,500,000 in the UK suffering from bladder and bowel dysfunction. The aim is to improve the health and wellbeing of these children. The children’s care pathways main focus is on identifying children for toilet training readiness and thus promoting continence. Continence problems are treatable, but may take months or years to resolve so it is important to identify a diagnosis, management and toilet training pathway as early as possible, from the age of 2 years. Assessment of care needs should be integrated across health and social care and education settings with the goal of integrating care, promoting effective communication and health education ensuring the child and young person has consistent care and parents and young people do not have to keep repeating their story.

The foreword to the Guidance for provision of continence containment products for children and young people (CYP) (2016) states: “getting this right for children and young people can make a significant difference to the quality of their lives, and also those of their families”.

**Scope of guidelines**

The purpose for the guideline is to specify the service Swindon Community Health Continence Advisory Service (CAS) provide for people registered with a Swindon GP. This guideline defines the assessment, treatment and management of products and the provision of products available for children aged from 4 to19: “Guidance for the provision of continence containment products to children and young people” (2016). This document also states that there is no research base supporting toilet training “readiness signs” and therefore the longer CYP are in disposable products the more this reinforces incontinence.

This service will provide a local, accessible and cost effective service to CYP and their families and carers in line with Excellence in Continence Care Commissioning Guide (2015).

The service clinicians and admin are required to support clinical assessment and choice of products applying national and local guidelines where appropriate.

This guideline is for use by staff and those who assess for and prescribe continence management products. All clinicians accessing the service requesting washable/disposable padded product service for children must have undertaken continence assessment training and are able to provide a high quality professional assessment which promotes continence. Children between the ages of 2 and 3 with physical disabilities and learning difficulties should be assessed for their readiness to start toilet training. Assessment for readiness for toilet training can be supported with bladder and bowel diaries as this identifies bladder and bowel maturity. For example if a child has a routine time for bowel movements or has a gap of at least an hour between voids a programme can be devised to support toilet training.

In Swindon children have a continence assessment and support for toilet training provided by Health Visitors, School Nurses and Child and Adolescent Mental Health Services (CAMHS). The Paediatric Continence Nurse provides assessment and treatment for children with nocturnal enuresis.

The adult Continence Advisory Service (CAS) hosts the service providing products for children. Absorbent products are provided by Essity and are called Tena products.

Currently there are 340 children from the age of 3 to 18 in receipt of absorbent products to manage incontinence. Of these 10 are aged 3 and 30 are aged 4.

The CAS Continence Nurse Specialist reviews all assessments and product requests prior to a child accessing the product service.

**Children’s Continence Product Provision**

All children and young people should receive support to achieve their maximum continence potential, regardless of their age, culture or ability. Health education promoting diet and fluids and bladder and bowel training advice will be the first priority. Containment products should only be supplied following a full assessment and only when toilet training is found to not be achievable. Providing containment disposable products may delay toilet training as the aim of the products is to keep the skin dry and reinforces to the child that a nappy is the place where they should pass urine and defecate (Guidance for the provision of continence containment products to children and young people 2016).

Assumptions should not be made regarding the ability, or lack of ability of children & young people with additional needs to be toilet trained. Continence should be promoted at all times and as stated by NHS England (2015) “the provision of continence products to this group of children should be the exception rather than the rule”. The priority is for treatment and gaining continence for children and young people (from birth to 19 years old) and this includes children with learning and physical disabilities.

Learning and physical disabilities may include children on the autistic spectrum, global developmental delay and cerebral palsy. Examples of other genetic conditions include Down syndrome and muscular dystrophy.

**Relevant national documents**

Every Child matters 2004 <https://www.gov.uk/government/publications/every-child-matters>

The National Service Framework Standard 8 Disabled Children, Young People and those with Complex Health Needs (2004).

<https://www.gov.uk/government/publications/national-service-framework-children-young-people-and-maternity-services>

Paediatric Continence Commissioning Guide

<http://www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Continence-Commissioning-Guide-2014-PCF.pdf>

Good Practice in Continence Services (DH, 2000)

The Equality ACT (2010)

Disability and Discrimination Act (2005)

When to suspect child maltreatment (NICE 2009, CG 89) <https://www.nice.org.uk/guidance/service-delivery--organisation-and.../safeguarding>

Essence of Care (2010). Benchmarks for bladder and bowel continence care. London; DOH

NICE Clinical Guideline 111 (2010) The Management of bedwetting in children and young people. <https://www.nice.org.uk/guidance/cg111>

NICE Quality Standard: QS70 Nocturnal Enuresis (Bedwetting) in Children and Young People (September 2014) <https://www.nice.org.uk/guidance/qs70>

Constipation in children and young people: diagnosis and management <https://www.nice.org.uk/guidance/cg99>

Urinary tract infection in under 16s: diagnosis and management. Clinical guideline [CG54] Published date: August 2007 Last updated: September 2017 <https://www.nice.org.uk/guidance/cg54>

NICE Quality Standard: QS62 Constipation in Children and Young People (May 2014) <https://www.nice.org.uk/guidance/qs62>

NICE Clinical Guideline 54 (2007) Urinary tract infection in children: diagnosis, treatment and long term management. <https://www.nice.org.uk/guidance/cg54>

**Assessing children and young people (CYP)**

All children and young people (CYP) must have a comprehensive assessment of their bladder and bowel with appropriate identified interventions undertaken before the product service can be accessed following completion of the assessment proforma based on a delay in achieving continence (Can children’s admin add the documents to the end of this guide as appendices?). All services working to this guideline, will work in partnership with family and clients involving them in decisions about care based on evidence based assessment which takes place in the home or other community setting wherever possible.

Health Care professionals providing assessment should attend training to include:

Medical conditions and medication and provision of a formal diagnosis will be required to access the provision of absorbent products.

Completion of the children’s continence assessment tool

Types of fluid and diet intake

Bladder diary: This is to record a pattern of passing urine. Every waking hour, for at least 3 days, the containment product should be checked to confirm whether the CYP has passed urine or remained dry. To support the charting the CYP can wear a pair of cotton pants next to the skin, under the disposable product or some kitchen towel. This would be difficult at school and so can be completed during weekends and school holidays.

Bowel diary: Record all bowel movements for 14 days. This includes stool form, straining and any encopresis.

Complete an assessment for urinary tract infections if indicated by symptoms (NICE CG 54). This is indicated by the following symptoms and if present referred to the CYP GP.

Presenting symptoms and signs in infants and children with UTI

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Age group** | | **Symptoms and signs**  **Most common ------------------> Least common** | | |
| Infants younger than 3 months | | Fever  Vomiting  Lethargy  Irritability | Poor feeding  Failure to thrive | Abdominal pain  Jaundice  Haematuria  Offensive urine |
| Infants and children, 3 months or older | Preverbal | Fever | Abdominal pain  Loin tenderness  Vomiting  Poor feeding | Lethargy  Irritability  Haematuria  Offensive urine  Failure to thrive |
| Verbal | Frequency  Dysuria | Dysfunctional voiding  Changes to continence  Abdominal pain  Loin tenderness | Fever  Malaise  Vomiting  Haematuria  Offensive urine  Cloudy urine |

Record toilet training techniques and strategies that have been tried with the child. Any unsuccessful experiences related to the toilet.

The assessment process should enable the clinician to identify and document bladder and or bowel dysfunction not related to the CYP disability. This includes poor or excessive fluid intake and dietary challenges, constipation and overflow of liquid faeces and “toddler diarrhoea”

Overactive bladder symptoms (Urgency, urgency incontinence, frequency and nocturnal enuresis)

Urinary tract infections and voiding difficulties

Occupational Therapist assessment to provide equipment to support use of toilet

Products would not normally be supplied before a child has reached their fourth birthday and then only after the child or young person has undergone a comprehensive bladder and bowel assessment, and, where appropriate, a trial of toilet training for at least three months (Guidance for the provision of continence containment products to children and young people 2016) .

Children where it is known or anticipated there may be difficulties with toilet training e.g. learning disabilities or autism should have the opportunity for early intervention (at around 2 years of age) to facilitate the development of the necessary toileting skills.

Provide the parent carers with advice and information to explain the reason for bladder and bowel dysfunction, diet and fluid advice, toilet training advice, medication to support healthy bladder and bowel (Guidance for the provision of continence containment products to children and young people 2016).

**Right to refuse assessment, treatment and or intervention**

Should a parent/carer decline an assessment or treatment for a child who has an identified continence problem the health care practitioner should explain the possible outcomes of this course of action and advise the parent/carer of their right to refuse

assessment or treatment. It should be explained that products cannot be provided without an assessment and without following the recommended toileting programme. The health care practitioner should ensure the parent/carer has their contact details should they wish to accept the assessment and treatment at a different time.

**Provision of products**

The “custom and practice” of automatically providing products to children with an acknowledged disability once they have reached their fourth birthday is not appropriate and could be considered discriminatory as typically developing children are not provided with continence products Provision of disposable absorbent continence management products will be for children who are not likely to be able to attain continence (Guidance for the provision of continence containment products to children and young people 2016).

Containment products should not be supplied for treatable medical conditions such as bedwetting and constipation with overflow, or child refusing to use toilet for bowel movements. Appropriate treatments should be sought instead, such as for constipation and toilet related anxiety. Other continence management strategies should also be considered such as urinary sheath systems, toilet aids such as foot stools, rails and handles.

Script Easy (0800 470 1930) provides a specialist nurse who can assess for sheaths and urinals that are on prescription.

Equipment loans for commodes and urinals can be accessed from Swindon Community Equipment services based at Enterprise works, Gypsy Lane, SN2 8DT. The telephone number is 01793 464775. Staffs accessing this service will need to attend training so that they can be given a PIN number. Alternatively, an assessment

for equipment can be completed by the lead supporting clinician or an Occupational Therapist or Physiotherapist.

All children and young people should be supported with a toilet training programme for at least three months prior to providing containment products, unless it is clear that this is inappropriate e.g. in children with a neuropathic bladder and or bowel.

Products would not normally be provided for night time alone except where the CYP has epilepsy or an overnight feed.

Currently Swindon has a contract with Essity supplying Tena products and these are the products that are provided. They are hypoallergenic, come in various sizes for children and young people and various forms such as Comfort, hourglass shaped pads or all in one slip pads “nappy style”.

The use of two-piece system (hourglass shaped pad and fixation pants) should be considered wherever possible as this is an effective management option and generally more comfortable and discrete. If the CYP is able to stand, this style is also easier to change and the CYP can be involved with the change process. The two piece system also provides a better fit for many CYP who have thinner legs relative to their hips and waist.

The two piece system may be mixed with an all in one as required or a higher absorbency for night time. Up to 4 products are allowed per day (Guidance for the provision of continence containment products to children and young

People 2016: <http://www.bladderandboweluk.co.uk/wp-content/uploads/2016/12/final-Guidance-Paed-product-provision-doc.pdf> ).

If the cause of incontinence of urine and or bowels is not clear a referral to a GP or specialist service, such as Paediatric Continence Nurse for enuresis may be required for assessment of a treatable bladder and bowel condition. This may include constipation and night time bed wetting.

Prior to any order being placed samples of disposable products must be tried before ordering a three month supply. The prescribing health care practitioner will assess for correct size and product based on age, weight, and waist and hip measurements.

To request samples contact CAS with measurements.

**Washable pants**

Consideration should always be made regarding the provision of washable products rather than disposable – clinical knowledge has shown that they are effective in supporting toilet training and help “normalise” the process. These should be offered in place of disposable pull-up pants for toilet training.

The products will not be mixed, i.e. provision of disposable and washable products.

Provision of washable products is up to 6 pairs and no more than 2 sets in the first 12 months. A further 6 pairs may be provided annually if required based on assessment.

Guidance on using and washing washable containment products should be given, including not using fabric softener as this reduces absorbency. Waist and hip measurements will be required. Samples are to be ordered first via CAS.

**Swim Pants**: These are not provided by the NHS. See disabled living Promocon for resources or ERIC: <https://www.eric.org.uk/pages/shop/department/swimwear>

Appropriate swimming products enables a CYP to participate in exercise which enhances their quality of life and to maintain safety any incontinence needs to be contained.

**Disposable pull-up pants criteria**

Disposable pant style products should not be provided as part of toilet training programmes for children with additional needs. Pull-up pants are less absorbent than a nappy/all in one style pad and have not been proven to support toilet training. Any assessment requesting pull-up pants should provide detailed evidence to support the request identifying a clinical rational for the pull-up. Try a 2 piece system first. The provision is the same as for adult pull-up with a provision of 2 pull-up pants per 24 hours or washable products.

Disposable pull-up pants will only be provided to children who meet the following criteria:

The CYP must be able to pull the product up and down independently and be able to use the toilet regularly. If this is the case, washable products should be considered initially.

The CYP frequently removes soiled wet products with tabs inappropriately. Consider clothing styles to avoid a CYP pulling at or removing products.

The CYP person has received an assessment which has identified that products have been tried and found to be unsuccessful.

Washable products should be the first choice depending unless bowel incontinence is a challenge. Disposable pull-up products should be used for a 6 month period at a time and the child/young person reassessed for toilet training readiness. Reorders after 6 months are based on receipt of assessment or written information from the health care professional.

**Sheaths for boys**

Consider use of a sheath urinary drainage system for boys. A sheath is a thin material, usually silicone, with an adhesive layer so that it gently adheres to the penis. It can then be attached to a drainage bag fixed to the leg. This is likely to be discreet and comfortable. This is a useful option for boys for night time, long journeys and if they are not able or not yet able to be toilet trained. The Manfred Sauer sheaths start at 18mm and go up in 2mm increments for the first 8 sizes.

For support with sheath fitting or urinals that are on prescription contact Script Easy on 0800 012 1699. A specialist nurse will visit the family to complete an assessment and provide support.

**Liaising with the Continence Advisory Service**

**The Assessment**

Health care professionals who have attended continence assessment, treatment and management training may access the product service. The assessment paper work and product request forms are to be completed (I have asked Essity to do this) and sent to the continence Advisory Service (CAS), a diagnosis identifying a reason for inability to achieve continence which maybe in the form of a GP medical summary, evidence of toilet training experience and three days of bladder and 14 days of bowel charting, weight, hip and waist measurements.

This will identify a clinical rational for accessing the product service. Samples are to be ordered via CAS, provided and tried before an order is processed. This includes the assessing professional or school support staff ensuring that they are able to use the products effectively which may require a home visit to demonstrate how to use the product to achieve the best outcome such as how to cup and fold the products, how to fasten and to avoid talc and creams next to the products as this can prevent absorption of urine.

Provision of disposable products would normally be no more than 4 pads per day including a pad and pant system (fixation pants to be purchased by parents as per adult guidelines). It is important that the provision of products for CYP is equitable

with the provision for adults. The CYP may need a different or higher absorbency product for night time, particularly if they have an overnight feed. Support to ensure the choice of product is effective can be provided by CAS.

**Exceptional Circumstances**

If more products are required per day assessment of bowels regarding constipation, fluid intake and polyuria should be completed. This is will include bladder and bowel diaries and a subjective assessment of the CYP situation and why additional products are required. An example of this might be due to Peg feeding increasing the volume of urine passed and/or causing loose stools. However, CYP should be treated the same as adults accessing the product service in Swindon and so rather than increasing the number of products an increase in absorbency may work, or use of a liner if bowels are a challenge as this can be changed frequently. Parents/guardians will need to purchase the liners and these are readily available in supermarkets and the mobility stores located around Swindon. Clinicians needing advice and support can contact CAS for guidance on product support.

Situations where an increased absorbency, number of products or needs products at an earlier age may include end of life and palliative care, CYP has been assessed by a specialist and advised that the CYP will never achieve continence or the CYP needs adult sized products at an earlier age.

**The product request form**

This should be sent fully completed with the assessment paperwork (Appendix. I have asked Essity). An alternative delivery point is to be provided to enable delivery if there is no one at home. Products cannot be ordered without this information.

The following codes are to be applied to support analysis for continence service product management:

|  |  |
| --- | --- |
| Reason for incontinence | |
| LD | Learning disability |
| PD | Physical disability |
| CA | Congenital abnormality |
| NC | Neurological condition such as Spina bifida |
| BP | Behavioural, psychological and sensory issues |
| MC | Medical condition |
| EOL | End of life |

Following acceptance of the assessment and effective samples an order will be faxed to Essity customer services by CAS. A letter will be sent by Essity informing the parent/carer of a delivery date. Essity will give the parent/carer an ID number enabling them to request further orders to be activated. Orders cannot be brought forward and the provision of products will be for 12 weeks and no longer than this. If

there is a gap of 6 months or more the order will be suspended pending further reassessment to be sent to CAS.

Products are for community use and not hospital or hospice use.

The delivery cycle is 12 weeks. If changes to an order are required, for example the child/young person has grown; notification must be made by the health care professional or parent/carer prior to any order as there cannot be any changes mid-delivery cycle (see below; reassessment).

**CAS Telephone: 01793 696671**

**FAX: 01793 696682**

**Address changes**

Advice CAS of address changes as soon as possible, preferably before any move to ensure products are sent to the correct address. The parent or health care professional providing care can inform CAS of these changes via telephone call or on an NHS email.

**Death of a child or young person**

If a child or young person dies the professional involved with care or parent carer can contact CAS as soon as possible to prevent any further deliveries being made as this can be extremely distressing for families. If the family has unopened packets of products these belong to the NHS and can be returned. In this instance return of products to Eldene Health Centre may be done by the professional, CAS team member or relative.

**Continence review reassessment**

Following the first assessment there will be a 6 month reassessment with on-going annual reassessments. Following each assessment the paperwork should be sent to

CAS to maintain the product supply. Each review offers an opportunity to assess for toilet training ability and support for the CYP and their family. The reassessment paperwork including evidence of toilet training trial should be sent to CAS to maintain the delivery or suspension of products.

Parents and carers should be advised about how much notice should be given to their HCP or CAS, prior to a change of products. Ideally parents and carers should make contact 6 to 8 weeks before the next product order allowing time for a trial of samples and the ordering of the correct products to maintain comfort and skin protection and avoid changing products mid delivery cycle (Guidance for the provision of continence containment products to children and young people 2016). This is also an opportunity to reassess toilet training skills. Any changes to orders should be based on a clinician assessment so the parent/carer can request support from their healthcare professional or contact CAS directly if it is a simple change in size of product.

Following reassessment the health care professional currently providing care will send this assessment information and a new product request form to CAS.

Product supplies may be stopped until reassessments are completed. This encourages the parents and carers to be involved with their professionals who are supporting them with their child ensuring toilet training can be pursued wherever possible or make changes to absorbent product orders. If the parent or carer has concerns that the product supply will not be changed in time they can also contact CAS for support and guidance.

It is the responsibility of parents, carers and professionals to stop orders as soon as a child is toilet trained. All products belong to the NHS. Unopened products may be returned to Eldene Health Centre, SN3 3RZ. It is usually the parent or carer who will return the products to Eldene. For advice and guidance contact CAS.

If the child is toilet trained day time, products should be stopped and child referred for treatment of nocturnal enuresis to the Paediatric Continence Nurse Specialist for GWH. Exceptions to this include night time epilepsy and Peg feeds at night where there may be a higher volume of urine made.

If a child moves from a different area or GP to a Swindon GP, CAS will supply the equivalent style of products until an assessment can be completed and samples of

Tena product provided. The first delivery, once CAS is informed, will be within 3 weeks of receipt of information about the order. The information for this initial order can come from Essity, if the previous area used the same supply contract chain, from the previous continence service provider or from the new health care professional who will be commencing the assessment process. As this first order provides a 3 month supply this provides ample time for an assessment, including assessment of toilet training ability.

**Transition of a young person across services**

A child in need of support to gain continence should be identified as early as possible. Communication amongst professionals is key aiming to support family and carers. The CYP will transition across services and may at other times need support from multiple professionals. For example school staff and school nurses.

At the age of 19 the young person should be transferred to the adult continence advisory service. The assessment paper work should be passed to the adult service and cover information provided (Appendix 1). Wherever possible there is a benefit to the young person’s assessor to meet with the community nurse or adult continence nurse advisor, the parents and the young person.

**Transition chart across services**

Child identified as not toilet trained by age of 2 or not able to achieve toilet training by age of 3

Health Visitor or Nursery Nurse to commence care pathway and assessment for toilet training ability

Child meets exceptional circumstance criteria age 4

Commence toilet training strategies. Advise parents and carers of toilet training skills, typical fluid and diet requirements. Any concerns, such as unexpected delay in toilet awareness or constipation stop assessment and refer to GP.

Complete assessment tool and send to CAS with product request form

Resolve clinical issue such as constipation or identified cause of delay and commence pathway again if appropriate

Assess 6 monthly. Just before the age of 4 reassess and if not likely to achieve toilet training within the next 12 months send completed assessment and product request form to CAS

Transition child from Health Visitor or Nursery Nurse to School Nurse at age… Liaise face to face or telephone transferring care pathway history

Transition the young person at the age of 19 to adult services. Liaise face to face or telephone transferring care pathway history

Complete assessment with parents and or carers. Promote toilet training skills and complete product assessment form. Reassess 12 monthly

Complete continence care pathway. Assess and promote toilet training ability and promote continence. If not possible complete product request form and send with assessment to CAS. Reassess 6 to 12 monthly

**Glossary of Terms and Abbreviations**

|  |  |
| --- | --- |
| CAS | Continence Advisory Service |
| CYP | Child and young person |
| Nocturia | Passing urine at night |
| Primary nocturnal enuresis | Recurrent involuntary passing of urine during sleep by a child aged 5 years or older who has never achieved consistent night-time continence (Clinical knowledge summary 2011) |
| Secondary nocturnal enuresis | Bedwetting occurs after the child has been dry at night for more than 6 months (NICE 2010) |
| Diurnal enuresis  (daytime wetting) | Involuntary loss of urine due to anatomical or functional etiology (International Children’s Continence Society (ICCS) 2010) |
| Overactive bladder  (OAB) | A group of symptoms including urgency to pass urine, urgency incontinence when unable to get to toilet in time, frequency of voids and nocturia of 2 or more times |
| Encopresis | Encopresis also known as paradoxical diarrhoea is voluntary or involuntary faecal soiling in children who have usually already been toilet trained. Children with encopresis often leak stool into their undergarments. |
| Constipation | The subjective complaint of passage of abnormally delayed or infrequent passage of dry hardened faeces, often accompanied straining and pain (NICE Clinical Guideline 99, Constipation and soiling in children and young people 2010) |
| Soiling or overflow of stools | The involuntary passage of fluid or semi-solid stool in to clothing as a result of overflow from a faecally loaded bowel (Dobson and Blannin 2010) |
| Urinary sheath | A condom style adhesive product. Drainage bag can be attached. Keeps a male child and young person dry.  https://www.manfred-sauer.co.uk/images/sauer_comfort_standard_en_01.jpg |

**Appendix 1: Handover Liaison Form**

|  |  |
| --- | --- |
| **Name** | **Contact Telephone Numbers** |
| **DOB** | **NHS number** |
| **Address** | **Last assessment details:**  **Date**  **Products supplied** |
| **GP Surgery address:** | |
| **Additional information**  **Include assessment forms to be sent to SCHS** | |