

Understanding
chromosome
disorders

Unique



Toilet training and continence

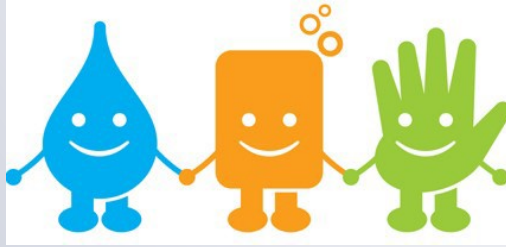


rarechromo.org

Toilet training and continence

Toilet training your child can be one of those subjects that you are never quite sure when is a good time to start. Toilet training a child with a chromosome or genome disorder can make this even more difficult, because of the differences in our children's development and when is the right time to start. For many children, toilet training is not easy and is something that families worry about. When there is a chromosome or genome disorder, anxiety can be even greater and it might take more time for the children to learn. For a small minority toilet training just isn't achievable. This guide has been created to help parents understand how to approach toilet training and to provide information and links to further sources of help.





Contents

■ Toilet training for children with chromosome and genome disorders.....	page 4
■ Bowel control.....	page 7
■ Night time toilet training.....	page 8
■ Equipment.....	page 9
■ School and early years.....	page 10
■ Medical issues.....	page 11
■ Constipation	page 11
■ Urinary tract Infection (UTI).....	page 12
■ Incontinence.....	page 13
■ Swimwear.....	page 14
■ Books.....	page 15
■ Links.....	page 17

Families say.....

“I am working on this with my son at the moment, he has a huge aversion of the toilet so we are working with another service around this so it is not easy, but I will try and find tips etc that have been shared to me in general to share! One video I was told (through an autism organisation) about and I use for A. to watch is called Tom's Toilet Triumph. It is animated but some parts are a little more graphic than people expect lol - here is the link so you can see what I mean.....

www.youtube.com/watch?v=ri5RHQ58RcM”

Toilet training for children with chromosome and genome disorders

Where to start.....

Starting on potty training will entirely depend on each individual child. If they have a developmental delay this can increase the time it takes before they are ready to understand, it does not necessarily affect the time of starting toilet training, it just might take longer to complete. For most typically functioning children potty training is usually achieved between the ages of 18 months and 3 years old. Be prepared to devote lots of time and effort into potty training and make sure the time is right for your child. If you are able to, choose a good time to start, when you have plenty of time to devote to the training, it helps if there is nothing else to get in the way of starting this, for example having a new baby or pet in the home, or moving house or some other major event - wouldn't be a good time to start potty training, however, because of the business of our lives, which is made more complex by having a child with special needs, there isn't always a 'right time', so go with your gut feeling.

How will I know when my child is ready?

Children with a chromosome or genome disorder tend to need more time to master the basic skills involved with toilet training. Make sure you start with a routine when it is convenient for you and fits in with your child.

Your child will ideally need to be able to sit themselves on the potty; some children never develop these skills. A referral to an Occupational Therapist can help with equipment to overcome these issues. If your child is able to tell you when they need to go, that would really help with training but some children might not understand this. Usually a good time to start potty training would be when the child is aware of the fact that they need to go and are able to talk about 'wee' and/or 'poo'.

Many children do not realise they need to indicate when they are aware and modern nappies reduce awareness. Understanding their own body and being able to control when they go. Many parents find it best to start training in the summer months when they can perhaps be out in the garden and their child just has underpants on. A lot of children don't like being wet, so they may get to understand that they need their potty. There may be several accidents along the way. For many children it can take a lot longer to gain control of their bowels, compared to their bladder (and for some it is the other way around). If they can stay dry for some time, that could be a sign that they are more in control as their bladder will be storing more urine and developing control, so that would be a good time to start potty training. If your child is telling you they have done a wee or a poo that is a good sign that they are starting to understand their bodies 'signals' and so that is a really good time to start toilet training. Many but not all

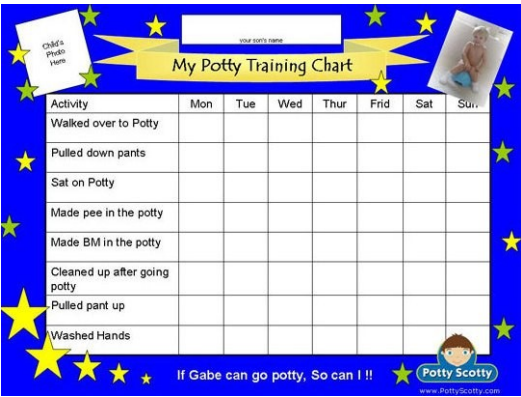
children learn by copying, so let them see that you go into the toilet too. Encourage them to pull down their underpants and pull them up again, wipe their own bottom and then wash their hands and dry them. If they are still wearing nappies or pull ups, keep some in the toilet/bathroom, so that they associate that room with wee's and poo's. If they wear nappies/ pull ups, show them inside the nappy when they have wee'd or poo'ed, so that they get to know what it looks like.

You might choose to sit them on the potty/toilet every hour, or every two hours*, or when they wake up, after each meal and before they go to bed. *Encouraging toileting too frequently can cause problems with the bladder never learning to hold a good amount of wee.

But you will work out what is best and you should create your own routine, whatever works best for you and your child.

It might help to use a toilet training chart like this one:

You can find free to download templates here: (USA based website) Potty Training concepts: <http://bit.ly/2rzSdiq> or you can purchase toilet training charts with your child's favourite characters on, for less than £3.00 from other retailers/support organisations.



Families say.....
“My son turned 10 last May. He’s without a nappy (only during the day) since he was 5. But for the night we had some problems. We tried last year but it was a failure. This year in the mild season, we tried again. We started to give him less water from 7pm and food or sugar-free drinks. For 2 weeks (every night we woke E up at 11pm and 2am to go to the toilet (he wears nappy pants) . Later we started the same but without the nappy pants. We had a bonus system: for each dry night we added stars, (and we give him a picture card of a carrot). Every card becomes a real carrot for Horse therapy. Every week he receives a medal from us. Now we are up to speed, it’s been a whole month without getting wet!”

Praise them.



If they do a wee or poo in the potty, give them lots of praise, "well done you poo'd in the potty/toilet". It may also help to keep a reward/sticker chart in the bathroom and add a star for everything they managed to achieve.

Routine

The most important thing about toilet training, is sticking to the same routine.

There is an order in which you usually teach.

- ◆ urine first
- ◆ poo second
- ◆ train for daytime first
- ◆ train for nighttime (it is not possible to train for night time in the same way that we train for daytime)

Skills to master in the toileting sequence:

- ◆ Recognizing the need to go.
- ◆ Waiting to eliminate.
- ◆ Locating the bathroom and entering.
- ◆ Pulling down pants.
- ◆ Sitting on the toilet.
- ◆ Voiding on the toilet.
- ◆ Wiping.
- ◆ Pulling pants up.
- ◆ Flushing.
- ◆ Washing hands.
- ◆ Drying hands.

*Families say.....
"Ignore the judgements & relax. I was beginning to think it was my fault ; that I must be a terrible mum, but just like everything else J. did it in her own time!"*

The Bathroom Routine

1	2	3	4
A small illustration of a person sitting on a toilet.	A small illustration of a person sitting on a toilet, wiping their bottom.	A small illustration of a person pulling down their pants.	A small illustration of a hand pressing the flush button on a toilet.

Bowel control

Bowel control is usually learnt after bladder control. Some children can find bowel movements very scary and not understand what is happening. It might help to borrow a book from the library to explain the digestion process.

There are lots of books available now for children to learn about going to the toilet. See the books link page.....

You can also use pictures as prompts, there are some appropriate ones on this website: http://do2learn.com/picturecards/printcards/selfhelp_toileting.htm
Or you could make your own and laminate them and stick them on a sticky strip of Velcro on the wall.

Families say.....

*“If they aren't having a bowel movement every day, seek advice on whether they are constipated/have slow gut transit. This often comes along with hypotonia (*and hypertonica). Buy a good waterproof mattress protector. We have a brilliant rubber one with a towelling finish on it which doesn't make him sweat (well, not anymore than usual!) and isn't noisy to lie on. Also invest in washable pads to go on top of that and under the sheet instead of disposable. They tumble dry and save a fortune. Bed pants can become habit forming. I'm in the process of weaning my 9 year old off them and we've had four nights with no accidents. He'd got into the habit of filling them in the morning. ”*



Night time toilet training

Once your child is mostly dry during the day, you will then be able to start night-time toilet training.



- ◆ Have a set bedtime routine which does not change with weekends or holidays.
- ◆ Limit the amount your child eats and drinks before bed, having no fluid an hour before bedtime, but ensuring your child has enough fluid throughout the day. Try and get your child to drink plenty of water, water is a healthy and cheap choice for quenching your thirst at any time. It has no calories and contains no sugars that can damage teeth. Plain tea, fruit tea and coffee (without added sugar) can also be healthy. If your child doesn't like the taste of plain water, try sparkling water or add a slice of lemon or lime. You could also add some no-added-sugar squash or fruit juice for flavour. The British Nutrition Foundation says that the amount of fluid a child needs depends on many factors including their age, their gender, the weather and how much physical activity they do, but generally they should aim to drink about 6-8 glasses of fluid per day (on top of the water provided by food in their diet). Younger children need relatively smaller drinks (e.g. 120–150 ml serving) and older children need larger drinks (e.g. 250–300 ml serving).
- ◆ Take your child to the toilet before they go to bed. It is no longer recommended that you get your child up in the night, as they never wake fully.
- ◆ Use products available to protect bedding.

Families say.....

“We used toilet timing rather than toilet training. It was less stressful. It is broken down into little easy steps. First step is to get the child sitting on the potty or toilet once a day, we did bath time. Then once he was happy to sit on the toilet without fussing we changed the routine to every nappy /diaper change. At this point it is important that preschool is doing the same routine. Once he was going on the toilet we changed him to undies during the day. Then we worked out a toilet routine and sent him to the toilet at those times.”

Dressing and undressing

Dress your child in clothes they can easily manage themselves, such as trousers and skirts with elasticated waistbands, E.G. Tracksuit bottoms.

What if toilet training is unsuccessful?

If you feel that you are not making progress with your child after a couple of weeks, it could be that your child isn't ready yet or you may need to try a different way; they may take longer than many to learn a new skill. It is best to leave it and then try again in a few months. It shouldn't be a problem stopping a toilet training programme and returning to it further down the line. You might want to try a different routine next time to see if it makes a difference.

Families say.....

"I'd want parents with younger children to know, it might not happen. Just like not everyone learns to walk or talk, not everyone becomes continent. For adult diaper wearers, dressing can sometimes be a little challenging. We find drawstring trousers work best, but it might take some experimenting to figure out what works for any individual. Harem pants for girls are nice as well."

Equipment

There are many aids to help with toilet training. Most children need aids to ensure they are seated in the correct position (potty or insert seat and step). Some pieces of equipment might be available via the NHS. You will need an Occupational therapist to help assess your child for the right piece of equipment. An example of the types of equipment available for potty/toilet training:-

- ◆ Musical potty
- ◆ Toilet chairs
- ◆ Step
- ◆ Hand rail close to the toilet
- ◆ Toilet training/reward chart
- ◆ Waterproof bedding
- ◆ Disposable bed pads
- ◆ Washable bed pads
- ◆ Nappies/pull -ups
- ◆ All in one briefs/pads
- ◆ Trainer pants
- ◆ Alarms – to help wake your child when wet
- ◆ Vibrating watches
- ◆ Clothing



Schools and Early years settings

Admission to school must not be refused (to refuse admission is in breach of the Equality Act 2010), simply because a child has difficulties with continence, otherwise the school may be at risk of disability discrimination (alternative legislation operates in Northern Ireland).



In 2014, ERIC, The Children's Bowel and Bladder Charity created new training to help UK schools manage children's wetting and soiling. They also launched a Right to Go campaign and guide, see: www.eric.org.uk/right-to-go



Medical Issues

Anal fissure

An anal fissure is a tear in the lining of the lower rectum (anal canal) that causes pain during bowel movements. They are usually caused by constipation which should be treated. Anal fissures don't lead to more serious problems. Most anal fissures heal with home treatment after a few days or weeks. These are called short-term (acute) anal fissures.

Families say.....
“My daughter is only able to be successfully independent and clean by using baby wipes to clean with and dispose of in a large plastic bin bag. She does go through a huge number of wipes, but is clean to the best of her ability and is independent to a degree- I still need to give the wipes and bag! She is 16 and has only successfully used this method for a couple of years. Up until that time she would also soil herself. Agree with the prevention of constipation tip. She takes Movicol every night and will do for life otherwise she ends up in hospital with impaction.”

Constipation

Is a common condition that affects people of all ages. It can mean that you're not passing stools regularly or you're unable to completely empty your bowel. Constipation can also cause your stools to be hard and lumpy, as well as unusually large or small. There may be other symptoms as well.

Families say.....
“Be aware that chronic constipation is extremely common and can be very, very hard to detect. My son (14) is toilet trained, mostly but doesn't wipe himself after a poo. I'm now trying to decided if it is worth it to try to get him to wipe him (with wipes) himself or is it better for me to do it and get it done properly (he likes being naked and also has his hands down his pants much of the time so a clean bottom is essential!).”

Urinary Tract Infection (UTI)

A urinary tract infection (UTI) is an infection in any part of your urinary system — your kidneys, ureters, bladder and urethra. Most infections involve the lower urinary tract — the bladder and the urethra. Women and girls are at greater risk of developing a UTI than men and boys are.

Symptoms of a UTI include:

- ◆ needing to pee suddenly or more often than usual
- ◆ pain or a burning sensation when peeing
- ◆ smelly or cloudy pee
- ◆ blood in your pee
- ◆ pain in your lower tummy
- ◆ feeling tired and unwell

Children with UTIs may also:

- ◆ appear generally unwell - babies may be irritable, not feed properly and have a high temperature (fever) of 37.5C or above
- ◆ wet the bed or themselves
- ◆ deliberately hold in their pee because it stings

NICE has a guide on UTI's in children on their website:

www.nice.org.uk/guidance/CG54



Families say.....

“Our son wasn't toilet trained until he was almost 8, and a trick that we learned at bed time was to have the waterproof mattress, then a sheet, then a waterproof pad, and then another sheet. When he would have accidents in the night it was so much easier to just take the top sheet and top waterproof pad off in the night and still have one clean sheet underneath. It made those night time accidents only take 1 minute to clean up, rather than changing the whole bed.”

INCONTINENCE

What is incontinence?

Incontinence is a term that describes any accidental or involuntary loss of urine from the bladder (urinary incontinence) or bowel motion, faeces from the bowel (faecal or bowel incontinence). If you hear the words **doubly incontinent**, the person is affected by both bladder and bowel incontinence. For many children and adults with a chromosome or genome disorder toilet training is just not achievable. If you are in the UK, your child may be entitled to free nappies/pads from the age of four. The quantity allocated to a child is generally somewhere between 3-5 nappies per day, however this does vary depending on where you live.

There are different types of continence products available (not all on NHS):-

- ◆ Washable cloth or terry towelling nappies.
- ◆ Standard disposable nappies in larger sizes (larger than you can buy in shops and supermarkets).
- ◆ Disposable pads with fixation pants (often more discrete than nappies or all in one style products)
- ◆ All-in-one pads (in adulthood, nappies are referred to as pads)
- ◆ Washable incontinence underwear
- ◆ Pull ups (these are not recommended for children who cannot be continent, as they are very expensive and do not offer as good a containment as other products)

If you live outside of the UK, your medical insurance might be able to cover incontinence pads or diapers.

Urinary incontinence is the unintentional passing of urine. There are several types of urinary incontinence, including:

- ⇒ **stress incontinence** - when urine leaks out at times when your bladder is under pressure; for example, when you cough or laugh. (rare in children)
- ⇒ **urge incontinence** - when urine leaks, as you feel a sudden, intense urge to pass urine, or soon afterwards (usually caused by an overactive bladder in children and is treatable).
- ⇒ **overflow incontinence** (chronic urinary retention) – when you're unable to fully empty your bladder, which causes frequent leaking.
- ⇒ **total incontinence** – when your bladder can't store any urine at all, which causes you to pass urine constantly or have frequent leaking (very rare and usually caused by a congenital abnormality, which must be investigated if suspected in a child).

It's also possible to have a mixture of both stress and urge urinary incontinence, although this is extremely rare in children.

Bowel incontinence

is an inability to control bowel movements, nearly always caused by chronic constipation in children, which is treatable. It may be as a result of a congenital abnormality which is usually diagnosed shortly after birth resulting in involuntary soiling. It's also sometimes known as faecal incontinence. The experience of bowel incontinence can vary from person to person. Some people feel a sudden need to go to the toilet but are unable to reach a toilet in time. This is known as urge bowel incontinence. Other people experience no sensation before soiling themselves, known as passive incontinence or passive soiling, or there might be slight soiling when passing wind. Overflow incontinence is usually caused by chronic constipation or faecal impaction in children and should be investigated and treated.

Families say.....

"I had years of clearing up sheets from soaking through, as nappies are big enough in the waist but don't hold enough, so I heard an amazing tip that helps us so much.

**My tip for boys only. Two nappies, one on, with a hole cut for his penis to be put through second nappy on, he pees in the second and poops in first. This has cut down my washing by 99% and he never spills over or soaks through anymore. Almost a Godsend for me. Hope this helps someone else. Re: toilet training, sit in room with them, helping with confidence, high praise when goes. Not fully trained here yet."*

**NB: It is not recommend by professionals to use two nappies at a time.*

Incontinence swimwear can also be purchased, so that you and your child feel comfortable and secure whilst swimming.



INCY WINCY www.incywincy.net/
0118 9560295 Email: info@incywincy.net
Incy Wincy specialise in all types of incontinence swimwear and flotation aids from the age of 3 months to adulthood.



FLEDGLINGS www.fledglings.org.uk/index.php/shop

01799 541 807 Email: enquiries@fledglings.org.uk

Fledglings sell incontinence swimwear. They also source and sell bed protection pads, mattress and duvet covers and other equipment.

Books/Social stories/Videos

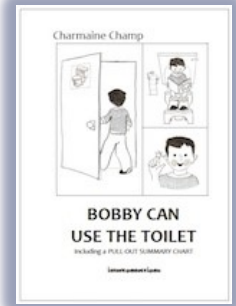
Social Story – ‘**Bobby can use the toilet**’ by Charmaine Champ, Interconnections Continence Consultant.

<http://bit.ly/2vMX8Lg> Price: £12.00 + £2.50 p&p in the UK.

Please apply for postage costs to other countries. Contact peter.limbrick@teamaroundthechild.com

This is a social story to help children learn to use the toilet. The clear text and illustrations will help parents and carers teach the toileting routine. It can be used with children who have learning disabilities, physical disabilities, autism and

complex needs, at home and in school. The pages are wipeable for use in bathroom areas. There is more information here about the Interconnections continence initiative and about Charmaine Champ, continence consultant and trainer.



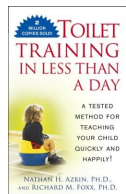
Bowel & Bladder Assessment Pack

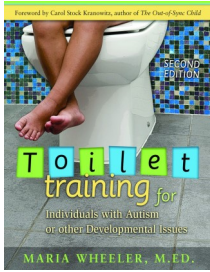
<http://bit.ly/2xyQR6i> The Bowel & Bladder Assessment Pack by Charmaine Champ (2016). Is published by Interconnections and is £18.00.

Contact peter.limbick@teamaroundthechild.com to learn more or place your order. The assessment pack is a guide to help you support disabled children and teenagers with toileting. Bowel & Bladder Assessment Pack: A guide for carers and professionals helping children and young people with a learning disability, physical disability, autism or complex needs to be successful with toileting. Some children and teenagers with a learning disability, physical disability, autism or complex needs remain incontinent of the bowel and bladder. This has a serious impact on their self-esteem and on social and play activities. For parents and carers at home or in school there are added time pressures, increased physical demands and very significant costs. With her understanding of the many factors that can hinder toileting success at any age, Charmaine Champ has developed the Bowel & Bladder Assessment Pack. This enables a comprehensive whole-child assessment, gathering all relevant information and ensuring all aspects of a child's continence needs are considered and addressed. The Bowel & Bladder Assessment Pack includes an Assessment Form and Monitoring Charts to copy for use with individual children.

Toilet Training in Less Than a Day by Nathan H. Azrin and Richard M.

Foxx was developed when these two psychologists were trying to research toilet training for special needs children. In the foreword of their book, they talk about how they could successfully toilet train severely developmentally delayed people in 3 days. When they applied these methods and techniques to normal children, the results exceeded their expectations - the average child of normal intelligence required less than half a day of training - hence the Toilet Training in Less Than a Day.





Toilet Training for Individual with Autism & Related Disorders.

A Comprehensive Guide for Parents & Teachers. It has over 200 toilet training tips and more than 40 case examples with solution. The book is written by Maria Wheeler who has her M.Ed and has spent greater than 20 years in the fields of Psychology and Special Education, with an emphasis on Neurobehavioral Disorders, Applied Behaviour Analysis and Specific Learning Disabilities. Ms Wheeler holds Texas teacher certificates/endorsements in Serious Emotional Disturbance

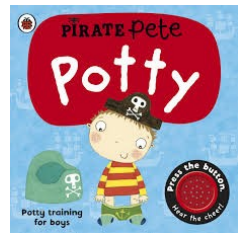
and Autism, Special Education and Psychology. She is nationally recognized speaker and trainer in the fields of autism, behaviour and learning disorders and effective discipline.

Available from Amazon: <http://amzn.to/2geeHlk>

Pirate Pete's Potty Board book

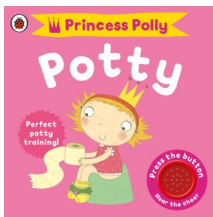
by Andrea Pinnington <http://amzn.to/2p0xebf>

Pirate Pete's Potty: Potty Training for Boys is an entertaining picture book from Ladybird that helps parents struggling with potty training for boys aged 18+ months. Clear, informative and fun pictures are aimed at tackling the common anxieties that children may have about using the potty. Each page encourages parents and children to



interact with the story by pressing the 'cheer' sound effect when the child has interacted correctly in order to eventually motivate their child into using the potty.

For further advice on potty training, please visit www.ladybird.com/potty



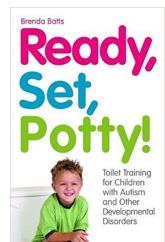
Princess Polly's Potty Board book is a version of the same story including sound effects, tailored for girls.

Ready, Set, Potty!: Toilet Training for Children with Autism and Other Developmental Disorders by Brenda Batts, a paperback available from Amazon and other book stores.

A huge variety of other potty training books for children can be found here: <http://bit.ly/2klgeBx>

VIDEOS

There are several useful toilet/potty training videos on youtube, see: <http://bit.ly/2yiCSFf>



LINKS

Bladder and Bowel UK (formerly Promocon) www.bladderandboweluk.co.uk
0161 607 8219

The service is the only UK national helpline service providing information and support for [adults and children](#) with bladder and bowel dysfunction, their carers' and the professionals who support them. With an expert team of nurse specialists and product advisors, Bladder and Bowel UK provides clinical and product advice, signposting to additional support services, training, consultancy and much more. Bladder and Bowel UK is part of the wider charitable organisation, Disabled Living (www.disabledliving.co.uk) and provides information about services, practical solutions and equipment advice for those who need it. A helpline is available for patients, health care professionals and anyone who requires further information or support.

Changing places toilet campaign www.changing-places.org/

Standard accessible toilets (or "disabled toilets") do not provide changing benches or hoists and most are too small to accommodate more than one person. Without Changing Places toilets, the person with disabilities is put at risk, and families are forced to risk their own health and safety by changing their loved one on a toilet floor.



Contact (formerly Contact a Family) <http://bit.ly/2yEV9Ow>

020 7608 8700 Email: info@contact.org.uk

Have a potty/toilet training guide for parents on their website.

ERIC - The Children's' Bladder and Bowel charity www.eric.org.uk/

0845 370 8008 email: helpline@eric.org.uk

ERIC has an online forum <https://healthunlocked.com/eric> for parents and carers to chat about childhood bowel and bladder problems. ERIC also has a guide on toilet training, see: <http://bit.ly/2rhX1J9>

Family Fund www.familyfund.org.uk

01904 621 115

Gives grants to families on low income, for washing machines, tumble driers, or towards the cost of bedding and clothing.

National Autistic Society www.autism.org.uk

0808 800 4104

Toilet training guide: www.autism.org.uk/toilet-training

Scope www.scope.org.uk

0808 800 33 33

Email: response@scope.org.uk

Scope offers support to families of children with cerebral palsy and can provide written information on toilet training. They have some great toileting tips on their website: <http://bit.ly/2geoVSN>

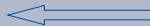
Families say.....

“When it’s time to toilet train, I’d try this as it worked for us. Our boy is severely affected and non-verbal, he picked it up in two weeks. <https://youtu.be/LH7KPTVuc6M>”

Washable bed pad (sometimes referred to as a ‘Kylie’)



Disposable bed pads



If you have any concerns about your child’s health, please consult a doctor or qualified professional.

NOTES

Inform Network Support



Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey RH8 9EE,
United Kingdom
Tel: +44(0)1883 723356

info@rarechromo.org | www.rarechromo.org

Join Unique for family links, information and support. Unique is a charity without government funding, existing entirely on donations and grants. If you can please make a donation via our website at www.rarechromo.org we would be very grateful.

Unique mentions other organisations' and websites to help families looking for information. This does not imply that we endorse their content or have any responsibility for it. This information guide is not a substitute for personal medical advice. Families should consult a medically qualified clinician in all matters relating to genetic diagnosis, management and health.

Our grateful thanks to the Wright Hassall charitable trust for funding this guide. Thanks also to all of our parents for their contributions to this guide.

WRIGHT HASSALL

This guide was compiled by Unique and reviewed by Davina Richardson, Children's Continence Advisor, Bladder and Bowel UK.



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