## **Talk About...** Bladder and bowel issues for adults and children

Spring newsletter 2020



## DO YOU NEED TO ACCESS THE TOILET URGENTLY?

Learn about BBUK's Just Can't Wait Card

## PANTS4SCHOOL

Enabling children with Down syndrome to be toilet ready for school

BRITISH PUBLIC ATTITUDES TOWARDS PEOPLE WITH STOMAS

## **CONSTIPATION IN CHILDHOOD**





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Bladder & Bowel UK are part of Disabled Living. Registered Charity No: 224742 www.bbuk.org.uk bbuk@disabledliving.co.uk 0161 607 8219

**Bladder & Bowe** 



Manufacturer of urology products with a difference, often designed by end users with unique features & benefits!

Available on prescription



## **A BAG FOR ALL SEASONS & OCCASIONS**



#### Bendi Bags

- Specifically designed for wheelchair users
- 1300ml & 700ml sizes
  Shaped to the contours
- Shaped to the contours of the bended knee



#### **Comfort Bags**

- Traditionally shaped leg bag
- 1000ml (go that bit longer) & 600ml
- 7cm shorter in length than many 750ml bags - no unsightly taps dangling!



#### **Discreet Bags**

- Ideal for sun, sports, swimming & short sexy clothing
- 500ml & 210ml
- Ideal for people with small stature & kids
- Dress as YOU want, not to cover the leg bag!

For more information or samples please contact the helpline on:

## 01604 595696

*Email:* helpline@manfred-sauer.co.uk or visit our website *Website:* www.manfred-sauer.co.uk

## Welcome to the 1st Edition of: Talk About...



Hello and a warm welcome to Talk About... Bladder & Bowel UK's (BBUK) first newsletter. We hope you are all looking after yourselves during the COVID-19 pandemic. These are certainly unprecedented times and like everyone else, we are monitoring the situation daily, following the government guidance and supporting the wider community who contact us here at BBUK for support with bladder and bowel issues.

The BBUK team are all currently working from home. We continue to provide our services seamlessly - the confidential telephone helpline and email support service, together with a range of free downloadable information and resources. We have learned how to work differently, enhancing new technology and considering as many ways as possible to communicate with you and the people you care for.

#### Why have we introduced our BBUK quarterly newsletter Talk About...?

We have responded to the many requests received by the BBUK team to produce a newsletter, asking us to share personal stories and articles, alongside information relating to products and services. I hope that you will agree, there is a variety of topics included in this first edition and I would be delighted to hear from you about what you would like to see in future editions of Talk About...

Please feel free to forward this newsletter with anyone you feel may find it useful. They can ask to receive a copy direct to their own mailbox by sending an email to: bbuk@disabledliving.co.uk.

#### Karen Irwin

Specialist Nurse/Service Manager

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## Our Helpline Is Open During the Covid-19 Outbreak



## Managed by a team of Specialist Nurses and Continence Product Information staff

The BBUK team are working remotely from home, continuing to provide information, advice, and support services. Our helpline is open please contact call 0161 607 8219 or email us: bbuk@disabledliving.co.uk

Please consider supporting our helplines through Covid-19. Click here.

## How BBUK Can Communicate with You



In today's world communication is ever changing. Individuals prefer to communicate in a variety of ways including via social media platforms. Different methods of communication suit different situations. We would like to share the ways which we can communicate with you.

#### The **BBUK** helpline

At BBUK we operate a helpline for the general public and health professionals which involves email and telephone contact. This is usually appropriate for clinical and product questions involving one person.

#### **Social media**

For other purposes BBUK fully engage with social media platforms including Twitter, Facebook, Instagram and LinkedIn when promoting study days, events and key messages from the Bladder & Bowel speciality.

#### **BBUK newsletter**

As specialist nurses at BBUK, we are involved in many national groups and projects so by following us on social media and subscribing to our newsletter, it allows you to keep in touch with important initiatives and updates.

Learning as you go, aiding personal and service development. You can sign up to our professional newsletter via the BBUK homepage on the right-hand side: www.bbuk.org.uk. Of course, this is a two-way system so if you follow or link with BBUK we can also see what is happening in the NHS services and help promote good practice across the UK. By joining forces on these platforms, we learn together.

The ultimate aim of everyone promoting continence and good practice by improved communication in any form is to improve patient care and improve the focus on bladder and bowel health.

#### **BBUK's blog**

Our blog shares information, support and guidance on bladder and bowel conditions that children, young people and adults face. We focus on a number of topics including: education, travel, parenting etc.

We are always looking for people who would like to share their story about a bladder and/or bowel problem. Take a look at our blog via www.bbuk.org.uk/blog

Communicating with you is important to us. For more information about any of our services please email: bbuk@disabledliving.co.uk or give us a call on 0161 607 8219.

We look forward to hearing from you.

# Do you need to access the toilet urgently?

Bladder & Bowel UK have launched a 'Just Can't Wait Card'

- Recognised and supported by many retail and service organisations
- BBUK confidential helpline
- Available from BBUK a charitable service



Get your FREE card! Call BBUK on 0161 607 8219 or email: bbuk@disabledliving.co.uk

## Shop Online with Bladder & Bowel UK Equipment and Products to Make Life Easier



Offering you choice from a wide range of manufacturers including mobility aids, daily living products, and continence suppliers together with telecare and telehealth equipment.

## www.bbuk.org.uk/online-shop Tel: 0161 607 8219



in partnership with



Registered Charity No: 224742

## How to Keep Your Bladder Healthy



Your bladder and bowel are key to your health and wellbeing. If they are not looked after properly then they may become a problem to you! Read on for more information on how to achieve a healthy bladder.

To maintain or achieve a healthy bladder you need to keep hydrated. A large factor in this is the amount and type of fluid that you drink.

A general guide is that an adult should drink around 1500-2000ml of fluid per 24 hours. It is important to drink this amount throughout a 24-hour period, spreading the amount of fluid throughout the day rather than have a large amount at one time. A healthy bladder should empty between 4-8 times in 24 hours. Urine should be almost straw coloured, if yellow or darker you need to drink more.

#### Fluids that are good for your bladder:

- Water
- Milk
- Diluted cordial / squash drinks
- Decaffeinated tea and coffee
- Fruity and herbal teas

#### Fluids to avoid include:

- Alcoholic drinks
- Caffeinated drinks including hot chocolate, tea, and coffee
- Fizzy drinks

#### Other advice:

- Females should sit on the toilet to empty your bladder do not hover
- Take time to allow your bladder to empty completely
- Do not empty your bladder "just in case"
- Empty your bladder just prior to going to sleep

## Seek guidance from your GP if you experience:

Pain when passing urine Pass blood in your urine Notice you are passing urine more frequently or the urge to pass urine is stronger than usual It takes you longer to have a wee

If you have any concerns about your bladder, including an altered bowel habit, please consult with your GP. If you want any more information, then please contact BBUK's helpline today on 0161 607 8219 or email bbuk@disabledliving.co.uk

## Click here to read our range of FREE downloadable bladder resources



## Constipation in Childhood Is Not Always Recognised



Constipation in children is often unrecognised. Over time, this can result, in a large backlog of poo so that the child becomes 'faecally impacted'. This is the medical term used to describe so much poo stuck in the bowel that it cannot be passed easily). When this happens children often develop soiling (poo leaking into their pants). It is the soiling which then becomes the trigger factor for families to seek help. However when the child has additional needs it is often the assumed that the soiling is a result of the child's 'condition' rather than because there is an underlying problem with constipation.

As a result of this misconception many children with additional needs, along with their families, suffer unnecessarily. The following case study is typical of some of the families who contact us.

Tommy (not his real name) is a 10-year-old boy with autism whose mum contacted us because of his soiling and the problems he had been having with his bowels since he was 2 years old. The family had been told that this was probably due to his autism and he may well 'grow out of' the problem. However, constipation does not get better on its own. In fact, it gets worse as time goes on and causes more problems. Tommy also had a problem with day and night time wetting and no one had thought that constipation could be the cause.

He was soiling on a regular basis and this was causing some stress within the family.

Tommy was also becoming more aware of the issue and was feeling very embarrassed by it all. The picture his mum painted of the problem very much reflected an underlying constipation with overflow soiling.

Healthcare professionals usually know that overflow soiling happens outside the child's control. However, Tommy's family did not know this and did not believe Tommy when he said he did not know that he had had an accident. Once this was explained his mum was upset saying:



...I know that this is something we have all since felt guilty over, not believing him when he told us he didn't know. To us it's like, how can you not know?



NICE sets out clear guidelines for healthcare professionals about the management of children with constipation, so we suggested mum take Tommy to the GP as soon as she could for him to be seen and started on some treatment.

To support Tommy's family, we wrote an email for his mum to take to the GP. We suggested that the soiling could be caused by constipation and what might be the right treatment. Following the visit to the GP Tommy's mum wrote the following:



I got Tommy into the doctors and she was lovely!! She had been through the same thing with one of her children and she loved your email and advice. She was very impressed and said that's exactly what process she went through and what she was going to recommend... So, we have been given Laxido. 1 sachet a day for at least 3 days then 2 a day depending on how he's getting on. I've been given a follow up appointment in 2 weeks to see how he's getting on.

Tommy's progress was reviewed 2 weeks later. He was opening his bowels on the toilet every day and the number of accidents was greatly reduced.

So, by seeing the child as a child first, rather than the 'condition', listening to the story and taking note of the signs and symptoms, the problem of constipation can be recognised.

In fact, if any child presents with soiling, we always consider constipation to be the cause until proved otherwise. Tommy and his family had endured the problem for nearly 8 years. But a simple solution helped him to start to get better within a few weeks. Tommy's mum has since written:



...I really am over the moon I found the organisation and appreciate all the help you have given us.



The key message is do not presume that any soiling is because the child has autism or learning difficulties and then do nothing about it. All children have the right to appropriate assessment and treatment.

Visit BBUK's resources page for more information about constipation in children.

June Rogers MBE Children's Specialist Nurse BBUK

## Share Your Story with us

Do you have a story about a bladder and/or bowel condition that you would like to share in our newsletter? Please get in touch with the team by emailing: bbuk@disabledliving.co.uk



You might also like to visit our blog: www.bbuk.org.uk/blog

# WORD BEDWETTING DAY TIME TO TAKE ACTION - 26 May 2020

Bedwetting, also known as nocturnal enuresis, is an uncontrollable leakage of urine while asleep1





Parents should be encouraged to seek professional advice<sup>4</sup>



## BEDWETTING HAS A SERIOUS IMPACT ON A CHILD





Emotional well-being, self-esteem<sup>2</sup>



Bedwetting can be treated and families should speak to a healthcare professional to seek further support



For more information about this medical condition, please visit our website WWW.WORLDBEDWETTINGDAY.COM

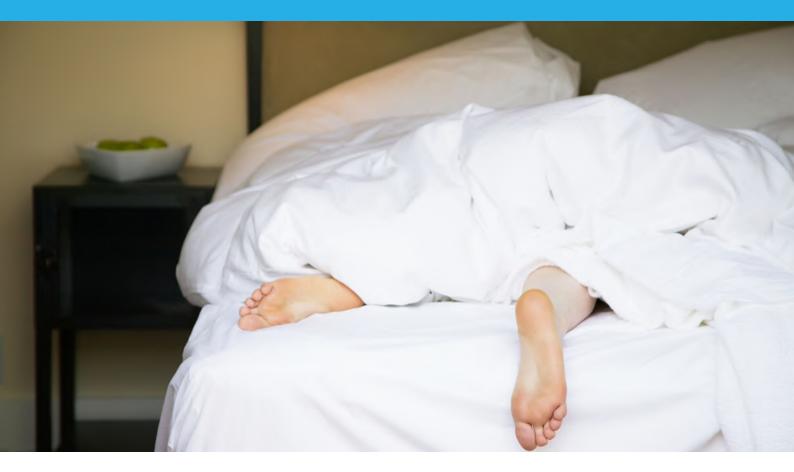
World Bedwetting Day is held every last Tuesday in May to raise awareness among the public and healthcare professionals that bedwetting is a common medical condition that can and should be treated.

The World Bedwetting Day Steering Committee brings together experts from across the globe to support this initiative and consists of the International Children's Continence Society (ICCS), the European Society of Paediatric Urology (ESPU), the Asia Pacific Association of Paediatric Urology (APAPU), the International Paediatric Nephrology Association (IPNA), the European Society of Paediatric Nephrology (ESPN), the Sociedad Iberoamericana de Urologia Paediatrica (SIUP), the North American Paediatric Urology Societies, ERIC (The Children's Bowel & Bladder Charity) and Bladder & Bowel UK. The initiative is supported by Ferring Pharmaceuticals.

**References: 1.** Austin P et al. The Standardization of Terminology of Lower Urinary Tract Function in Children and Adolescents: Update Report from the Standardization Committee of the International Children's Continence Society, The Journal of Urology. 2014;191:1863–1865. **2.** Vande Walle J et al. Practical consensus guidelines for the management of enuresis. Eur J Pediatr 2012;171(6):971-983. Erratum in: Eur J Pediatr. 2012;171(6):1005 and in: Eur J Pediatr 2013;172(2):285 **3.** Kiddoo D. Nocturnal enuresis. BMJ Clin Evid 2007:10:305. **4.** Grzeda MT, et al. Examining the effectiveness of parental strategies to overcome bedwetting: an observational cohort study. BMJ Open 2017;7:e016749. doi:10.1136/bmjopen-2017-016749. **5.** Maternik M. Understanding of and misconceptions around monosymptomatic nocturnal enuresis: findings from patient and physician surveys. J Pediatr Urol 2019;15:37.e1-37.e8.

#### Date of preparation: February 2020 UK-URO-2000026

## My Bladder & Disturbed Night's Sleep - is this a common problem?



It is not uncommon for people to experience disturbed sleep, getting up several times, to pass urine, during the main night-time sleep period. This is commonly referred to as Nocturia and it is important to be aware that this is a treatable medical condition.

It is a well-known fact, that about 60% of individuals assume that getting up several times a night to pass urine, is part of the natural ageing process and therefore should be accepted. This is not strictly true, as whilst incidence can increase with age, this is not always the case. You may be surprised to know that Nocturia is common, even in younger adults.

#### So, what do we know?

 It is not uncommon for some people to experience troublesome symptoms over a long period of time, before seeking help.

- People aren't always aware that help is at hand for this problem.
- With the right assessment and management, nighttime bladder symptoms can be significantly improved at any age.

#### **Common causes**

There are many possible causes of Nocturia . The most common cause is due to the kidneys producing too much urine at night, also known as nocturnal polyuria.

#### There are also other factors, for example:

- Overactive Bladder (OAB), where the bladder muscle contracts suddenly, uncontrollably, or too often, resulting in feeling the need to pass urine more urgently or frequently.
- Enlarged prostate (Benign Prostatic Hyperplasia - BPH) which may make urination more frequent
- Drinking too much, including caffeinated tea / coffee, carbonated drinks, and alcohol
- Some medications which may need reviewing by your health care provider.
- Other underlying medical conditions

#### Common symptoms may include

- Sleep disturbance, by the desire to pass urine. It is important though not mistake this with a poor sleep pattern
- Urinary frequency during the night, more than twice a night
- Passing large volumes of urine at night
- Inability to sleep through the need to pass urine

#### Other symptoms may include:

- Chronic insomnia
- Fatigue
- Falls potential falls and fractures
- Detrimental effects on health and wellbeing



## So, what are the potential effects of Nocturia?

- Others in the household experiencing disrupted sleep.
- Impact on an individual's quality of life
- Loss of concentration, change in lifestyle due to constant sleep disturbance and reduced amount of effective rest

Do not suffer in silence, seek help, and come forward. Either call us at BBUK on 0161 607 8219 or speak to your GP.

#### Karen Irwin

Specialist Nurse/Service Manager BBUK

## MoliCare® Premium Elastic



Better care made easy

## The new generation slip from HARTMANN

**MoliCare®** Premium Elastic is an innovative, new All-In-One Slip incontinence slip product for moderate to heavy incontinence, offering superior levels of comfort and protection.



## Easy handling & secure closing

- Self-explanatory and intuitive
- Easy use, product application in 4 steps instead of 8<sup>(2)</sup>
- Approximately 20% time saving in application enables more efficient care<sup>[1]</sup>



Our MoliCare<sup>®</sup> products are now available to order at HARTMANN Direct. HARTMANN's discreet delivery service, direct to your door. You can choose to have your all-in-ones delivered in discreet packaging, and we provide free delivery on orders over £40.

Visit: www.hartmanndirect.co.uk or speak to a member of our team on: 0800 028 9470

To receive 20% off all products please quote 'BBUK20'

The **Skintegrity** concept promotes holistic incontinence management and Incontinence Associated Dermatitis prevention. **Skintegrity** continues to improve the quality of life for people living with incontinence.

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References; [1] Laboratory report about ergonomic evaluation of MoliCare® variants A+B incontinence products. Research conducted between 5-8 October 2015 in Dijon, France. W. Schneider, H. Mutschler, R. Haller, C. le Mathe. Comparison with a slip having 4 side panels and 4 tapes. [2] Beguin et al.: Improving diaper design to address incontinence associated dermatitis. BMC Geriatrics 2010 10:86.

## Bladder Cancer Awareness Month 2020 Story



Thank you to @MediaHanley on Twitter for sharing his dad's story with us!

66

To my Dad, Big John, a true #LFC fan from Kenny, twice a #BladderCancerAwarenessMonth survivor. He's 89 soon & in remission but swears by a #Positive mantra to get by. He's my No. 1 HERO (sorry Alan Ball) @RosemereCF @UHMBT Windermere's Mr Music Man

If you would like to raise awareness of a bladder and/or bowel condition please tag us in your tweets using @bladderboweluk or email bbuk@disabledliving.co.uk

## Product Development - Can You Help Us?



People living with bladder and bowel problems have a wealth of personal experience and understanding of the impact that bladder and bowel symptoms may have on their own. And families' lives and become 'Experts by Experience'.

#### **Get in Touch With BBUK**

Contact the Bladder & Bowel UK confidential helpline on 0161 607 8219 or email: bbuk@disabledliving.co.uk

For more information visit: https://www.bbuk.org.uk/product-development/

# pants4school

Enabling children with Down syndrome to be toilet ready for school and reach their full potential

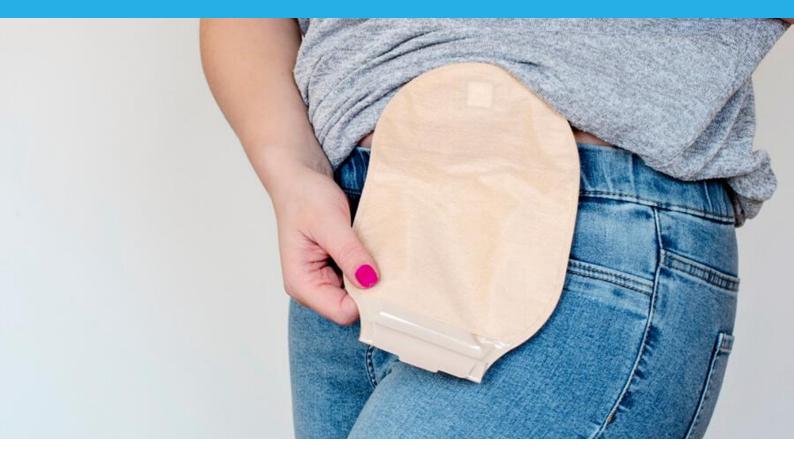
Click here to view the leaflet online or visit: https://downsyndromeuk.co.uk/pants4school.pdf? fbclid=IwAR2RBKGX6rMGIFdkO15PtDSgIQ3sYF9i92zEdvaPF7vIPL7UY7WD\_ILeeNs





A collaboration between BBUK & PADS

## Are British Public Attitudes Towards People With Stomas Improving?



For people with bladder and bowel conditions, getting a stoma can be life-changing – or even lifesaving. A stoma can offer relief from chronic health conditions or provide a vital means of helping individuals to maintain a good quality of life after a traumatic injury.

However, despite the proven health benefits that stomas can provide for those with bladder and bowel problems, this form of treatment has sometimes been poorly understood by the general public. Worse, stigmas around stomas have often made it hard for ostomates to discuss their condition and get the support they need from those around them.

Fortunately, new evidence is now emerging that suggests perceptions are starting to change. Potter Rees Dolan recently carried out a survey of 518 people to assess attitudes towards and awareness of stomas among the UK public, revealing that the average Brit is more stoma-aware than you might realise.

#### Rising Awareness of Stomas and Hidden Illnesses

According to the results of the Potter Rees Dolan survey – the full results of which can be seen here – almost two thirds of British people have a good understanding of the importance of stomas, with 65% of respondents saying they knew what a stoma is.

Additionally, 68% were either somewhat or very confident that they understand why someone would require a stoma, while 73% said they understood that bowel cancer might lead to someone needing stoma surgery. 72% and 62% made a similar link for bowel surgery and Crohn's disease, respectively.

This is despite the fact that only 28% of respondents personally knew someone with a stoma, and only 2% had a stoma themselves, suggesting that general awareness of stomas is increasing among those with no direct exposure to the issues involved.

The survey also indicated that Britons are starting to become more aware of the fact that some illnesses, including bladder and bowel conditions, do not need to be outwardly visible to have a significant effect on those affected. When asked whether they were familiar with "invisible illnesses", 86% said yes, with 42% of those saying they understood the concept fully.

#### The Spread of Positive Attitudes

As with so many aspects of public health, it would appear that this growing awareness around stomas and related issues is leading to the development of positive sentiment and welcoming attitudes, with any stigmas attached to having a stoma starting to fade away.

The respondents to PRD's survey reflected this, with 78% saying they either agreed or strongly agreed that ostomates should not have to feel self-conscious about their colostomy, ileostomy and urostomy bags being visible. Meanwhile, 59% said they would not feel uncomfortable if a friend or colleague had a visible ostomy bag.

Similarly, the results indicated that people are also becoming more understanding of the issues that ostomates with non-visible conditions often face. An overwhelming 79% of those polled say they do not believe that only people with obvious



physical disabilities should be able to use disabled toilets, with 55% saying they "strongly disagreed" with this idea.

This indicates that people with stomas are more likely than ever before to be able to depend on their friends, family members and colleagues to provide them with support and understanding as they focus on their adjustments and recoveries following stoma surgery.

#### **Keeping the Progress Going**

Although the results of the Potter Rees Dolan poll are certainly encouraging, it goes without saying that there is no reason to be complacent about this progress, with further public education and information needed to ensure that positive attitudes around stomas and hidden illnesses continue to grow. For example, attention needs to be paid to the fact that some invisible illnesses elicit more empathy than others. While the majority of those responding to the survey believe that people with conditions like Crohn's disease and multiple sclerosis should receive special allowances at work and be able to use disabled bathrooms and parking spaces, conditions such as migraines, diabetes and endometriosis generally receive a much lower level of understanding and sympathy.

This underlines the importance of continued advocacy by and on behalf of the UK's disabled community, as well as the continuation of public discussions about the issues that affect people with long-term health conditions. The more visible and wellrepresented these communities are in public life, the better they will be understood when talking about the unique issues affecting them

After all, people with bladder and bowel conditions are always likely to have challenges to face – but with the benefit of effective treatment options like stomas and the support of others behind them, overcoming those hurdles becomes so much easier.

Potter Rees Dolan provides legal services for those affected by personal injuries. To find out more about the work they do for people with stomas, please visit www.prd.uk.com.

#### **Potter Rees Dolan**

## Have You Read BBUK's Blogs?

## We have a range of useful blog posts including:

- The Myths and Facts of Bedwetting
- How to Keep Your Bowels Healthy
- Toilet Training Children with
- Additional Needs
- Self-Care With Irritable Bowel Syndrome



Read more at: www.bbuk.org.uk/blog

## Visit the Continence & Stoma Products Section on the Supplier Directory



There is a section on the Disabled Living Supplier Directory dedicated to continence and stoma products. In addition there are a wide range of categories providing information about companies and organisations that provide equipment, products and services to support disabled children, adults and older people.

You'll find the Supplier Directory on our website homepage: www.bbuk.org.uk

Click here to go straight to the Continence & Stoma section of the Supplier Directory

# don't know **USYET?**



## THIS IS WHO WE ARE AND WHAT WE DO ....

#### DISABLED LIVING

A charity which provides impartial information and advice about products, equipment (assistive technology) and services for disabled children, adults, older people, carers and the professionals who support them. We have a range of services which you can access via our helpline, through the website or at our Kidz to Adultz Exhibitions.

www.disabledliving.co.uk

#### EQUIPZ

The team comprises of occupational therapists, trusted assessors, moving and handling specialists, physiotherapists, nurses, continence specialists. We respond to enquiries via our helpline and website. Some people opt to visit the Disabled Living Centre based in Manchester for a free equipment assessment.

#### Helpline: 0161 607 8200

#### BLADDER AND BOWEL UK

The team provide information and advice for children, young people and adults with Bladder and Bowel problems. We provide a confidential helpline managed by a team of specialist nurses and knowledgeable information staff. In addition, the website offers a wide range of downloadable free resources. Helpline: 0161 607 8219 www.bbuk.org.uk

#### KIDZ TO ADULTZ EXHIBITIONS

We organise the largest FREE UK exhibitions totally dedicated to disabled children, young adults, their families, carers and the professionals who support them, with over 100 exhibitors at each event. We currently deliver 5 events nationally, in Farnborough, Bristol, Coventry, Manchester and Edinburgh.

www.kidzexhibitions.co.uk

#### TRAINING

We run a comprehensive training programme for professionals and carers. Most of our courses are accredited by Open Awards and others provide CPD opportunities. Our training courses can be 'tailor made' to suit your organisations requirements and can be delivered throughout the UK. www.disabledliving.co.uk/training







## Kidz to Adultz Magazine - Out Now!



We have introduced you to all of Disabled Living's services.

We also publish the Kidz to Adultz Magazine which is full of interesting articles to support children and young adults with disabilities and additional needs.

The latest editions of the Kidz to Adultz Magazine can be found here: <u>www.kidzexhibitions.co.uk/magazine/</u>

#### We would like to hear from you

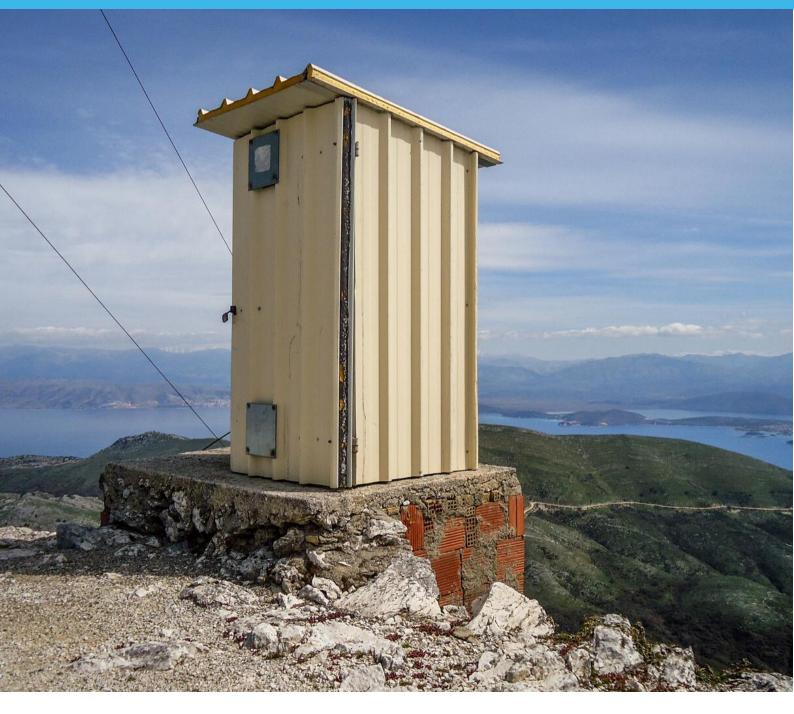
• If you have an article we can publish to support children and young adults with bladder and bowel problems

Take a look at the latest edition of the Kidz to Adultz Magazine on the Kidz to Adultz website: <a href="https://www.kidzexhibitions.co.uk">www.kidzexhibitions.co.uk</a>

For more information about our Kidz to Adultz events please see contact details below

Web: www.kidzexhibitions.co.ukTel: 0161 607 8200Email: info@disabledliving.co.uk

Loo of the Month - Portable Toilet Stationed at the Top of Pantokrator Mountain Corfu Greece



## **Connect with BBUK on Social Media**

Bladder & Bowel UK are active on Facebook, Twitter, and LinkedIn. If you have anything that you wish for us to share, please just get in touch, or tag us in your posts. Please follow us, like and connect with us!



Bladder & Bowel UK



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