

Talk About

Bladder and bowel issues for adults and children

5th edition

Find nearby public loos -
online!

New NHS pelvic health
clinics

Gill Castle: amazing
campaigner plans channel
swim

Launch of new app for local
bladder & bowel help

Traveling by air as a
wheelchair user



Bladder & Bowel UK

Supporting people with bladder and bowel problems

part of Disabled Living

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MKT-0004-08 July 2021

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References:

1. Hunskaar S, Løse G, Sykes D, Voss S. BJU Int. 2004 Feb;93(3):324-30. 2. Sander P, Thyssen H, Løse G, Andersen JT. Obstet Gynecol. 1999 Mar;93(3):407-11. 3. Thyssen HH, Løse G. Int Urogynecol J Pelvic Floor Dysfunct. 1997;8(3):130-2

Welcome to 'Talk About'



Welcome to the 5th edition of Talk About. We hope that you are able to safely enjoy some new-found freedom, as restrictions start to ease with the pandemic: see friends and family, soak up a little bit of summer sunshine and possibly have a break away or days out.

Talk About newsletter's aims are to provide information, practical advice and tips, share stories and to inform you of any general updates on bladder, bowel and continence related topics, for both adults and children.

It seems like a long time ago now since we produced our first edition. We initially started the e-newsletter in response to your many requests, with our first edition being released at the beginning of the pandemic last year. It is wonderful to see Talk About's reach continuing to grow, and the team at Bladder and Bowel UK are always really thrilled to hear back from you, enabling us all to all connect, share and support you.

The Bladder & Bowel UK team would love to continue hearing from you . We really would welcome any feedback, or ideas you may wish for us to include in future editions of our Talk About newsletter or additional resources you might like to see online. You may also want to share your own story. Please do get in touch.

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

We thank you all for supporting us at Bladder & Bowel UK. Keep safe and well .

Karen Irwin

Specialist Nurse and Bladder & Bowel UK Service Manager

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Launch of specialist clinics to offer pelvic health services to women



The NHS is opening new pelvic health clinics in fourteen areas of England under a new pilot project. Focusing on pregnant women and new mothers, up to 175,000 women are expected to benefit from the expansion of services which are due to be widened to the rest of the country by 2024.

The service will bring together specialists in one place, including midwives, specialist doctors and specialist physiotherapists. All women in the pilot locations who are receiving maternity care will have access to the service.

By providing exercises to women when they are pregnant, the approach aims to help prevent problems from happening in the first place. There will also be advice from physiotherapists on monitoring, and fluid and diet intake.

Women can be referred through their GP, but will also be able to self-refer without needing to go through their GP's surgery. Clinics will also provide training to GPs and midwives, and other local clinicians who work with women.

Urinary incontinence affects one in three women in the twelve months after having a baby, and up to three quarters of these women have ongoing problems. A further one in ten women experience faecal incontinence, and another one in 12 will have a pelvic organ prolapse.

This service expansion falls under the NHS's Long Term Plan commitment to improve the prevention, identification and treatment of pelvic floor dysfunction, to reduce the number of women experiencing problems after giving birth and later in life.



"We know many women don't report issues with incontinence because they are embarrassed about seeking help. Bringing together experts in pelvic health in one place will offer women a way of seeking help quickly and easily, as well as sending the message that postnatal incontinence is nothing to be ashamed of and can be treated."



- Professor Jacqueline Dunkley-Bent, NHS England's Chief Midwifery Officer

Emma Crookes, 34, from Barnsley, experienced life-changing incontinence during pregnancy and after giving birth to both her children and said:

“Having my children is wonderful but the incontinence I suffered was horrendous – mentally and physically. I was too embarrassed to tell my midwife, but I couldn’t leave the house because of the pain and inconvenience and my partner had to take time off work to support me. I had no idea I could get medical help for it – all the adverts for pads on TV make it seem like you just have to put up with it and my friends thought the same, they just said it was a normal part of having kids.

I spent a small fortune on pads before I sought help and got a personalised care plan from NHS specialists. These new clinics for women to get the support I got, in one place, will make a difference to so many people like me.”

The pilot services are in:

- Birmingham and Solihull
- Bristol, North Somerset, South Gloucestershire
- Cornwall and the Isles of Scilly
- Dorset
- Frimley
- Herefordshire and Worcestershire
- Hertfordshire and West Essex
- Lancashire and South Cumbria
- Norfolk and Waveney
- North West London
- Shrewsbury, Telford and Wrekin
- South East London
- Suffolk and North East Essex
- Sussex

Services will be expanded following the initial trials and will be available to women in every part of the country by March 2024.

Connect with Bladder & Bowel UK 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!



"It's an enormous challenge." : Campaigner Gill Castle continues to inspire with Channel swim



Gill Castle is a campaigner, blogger and mother with a stoma who has a thirst for adventure. She tells Bladder & Bowel UK about her journey so far, and why she'll be swimming the English Channel.

"There is something powerful about being in the freezing water," says blogger and campaigner Gill Castle. "You have no choice but to focus on your breathing, the feel of the cold water as it laps over your body, and the tingling on your toes. Your mind empties of everyday mundanity, you feel pure and invincible - especially when you see people walking along the beach sensibly wrapped up in hats and scarves!"

Gill began open water swimming as a way of dealing with the traumas of a birth that left her with a colostomy, as well as PTSD, severe anxiety and post-natal depression, and subsequently losing her job as a police officer after being medically discharged. "I was mentally and physically broken," she says now. Gill's blog, Stoma Chameleon, describes that journey in a distinct voice – honest and funny, with the message that to appreciate the light you have to understand the dark.

"After a few years of struggling to cope, I began to turn my life around. I accepted that my stoma had prevented me from a life of incontinence, and it became something I was grateful for." Gill describes how she has become consumed by the desire to face her fears and try new things, and to provide inspiration to people who find themselves with a

stoma – "because during those early weeks and months this was something I dearly needed to see."

Having completed a brutally difficult half Ironman in 2017, the National Three Peaks challenge in June 2021 and a self-set challenge to wear a bikini in the open water three times a week from October 2020 to May 2021, showing that a stoma doesn't need to prevent an active life, Gill now has a new challenge – to swim the English channel.



After a few years of struggling to cope, I began to turn my life around. I accepted that my stoma had prevented me from a life of incontinence, and it became something I was grateful for.



- Gill Castle, campaigner and blogger at Stoma Chameleon

Due to take place in August 2023, Gill will be swimming the channel solo with support from Kayleigh Adams, another mother who has a permanent colostomy due to serious injuries sustained through childbirth. They aim to raise awareness of the 30,000 traumatic births that take place each year, with numbers rising during the Covid-19 pandemic. They also want to raise awareness of hidden disabilities, such as stomas, and give fellow ostomates hope of an active life.

The channel swim is raising funds for the Birth Trauma Association, Colostomy UK and the Jacobs Well appeal, which sends medical supplies including stoma bags to low-income countries where people are forced to use makeshift solutions due to a lack of accessible medical resources. With support from sponsors Hollister and Dansac, with additional funds supported by Glynns Solicitors (Bath), Gill is hoping to become the first ostomate to swim the Channel.

Describing the challenge to Bladder & Bowel UK, Gill says: "I started my training in April 2021, after 18 months out due to shoulder injury, months of physio and treatment. I have found it hard to get going after so long as I am anxious about getting injured, but I am focusing on my stroke technique and endurance.



© Gill Castle

“

The endorphin rush when you get out and your body warms up is like no other. I feel a sense of calm all day, and my mental health has soared since I started cold water swimming. I have such great banter with my swimming friends - we are all a bit mad which helps on the bitterly cold days!

”

- Gill Castle, campaigner and blogger at Stoma Chameleon

"I am really enjoying it but I have a long way to go....and lots of challenges to overcome, like swimming on my own in the dark in the sea! More people have climbed Everest than have swum the 21 miles across the Channel so it is an enormous challenge."

As well as sheer inspiration, the Stoma Chameleon website offers lots of practical advice for people interested in cycling, swimming, travelling, camping, scuba diving, triathlons and more – with tips on bag management and what it's like to do these activities with a stoma.

In a poignant, funny video on her website, Gill uses flashcards, Bob Dylan-style, to describe her journey before dunking herself in an ice-cold bath. In it, she tells us that 'Women are amazing. We can do anything', and that 'Life is not over when you have a stoma. You can do anything.' We will be cheering Gill on as she continues to show us all how true that is again, and again, and again.

You can visit Stoma Chameleon here:
<https://www.stomachameleon.com/>

You can visit Gill's GoFundMe page here:
<https://www.gofundme.com/f/ostomy-mermums-channel-swim-2023>

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Survey captures experience of air travel as a wheelchair user



ableMove, along with Flying Disabled, undertook a survey of 336 wheelchair respondents (powered and manual) spanning the US, UK, Europe, Asia and Africa to help understand the significant concerns wheelchair customers have when travelling by air.

The findings found the biggest concerns were:

- Wheelchairs being lost or damaged
- Toileting at airports and onboard the aircraft
- Transferring on and off the aircraft
- Seating in the cabin
- Boarding and disembarking processes
- Carriage of medical equipment.

The impact of these concerns have identified that 1 in 4 wheelchair customers rate their overall experience flying by air as good, very good, or extremely good, with 43% of wheelchair customers no longer choosing to fly.

This is despite the fact that the aviation industry has seen incredible advancements in accessibility with enhanced regulatory frameworks and best practices around the globe for people with reduced mobility (PRM) in recent years.

“We believe that everyone should have access to air travel, and we welcome the significant improvements in accessibility made by UK airlines and airports in recent years.”

- Sir Stephen Hillier, Chair of the UK Civil Aviation Authority

The findings point to a clear solution, 'wheelchair in the cabin'. That gives wheelchair customers the safety, dignity and comfort they are entitled too.

Wheelchair in the cabin will get more wheelchair customers in the sky, flying more frequently in groups of more than 2, contributing to significant growth in tickets sales. It will remove the need for specialist equipment to board passengers, prevent the logistical challenges of putting wheelchairs into the hold and improve boarding and disembarking.

Various organisations such as All Wheels Up, Wheelchairtravel.org and Flying Disabled (too name a few) work to make 'wheelchair in the cabin' a reality for millions of wheelchair users around the globe. There is a significant amount of work in the immediate future the industry can address to help improve the experience of these passenger.

A superb start would be:

- A globally harmonized standard that ensures the same level of service at every airline and airport across the globe
- Provide wheelchair passengers guarantees their wheelchairs will not be lost or damaged
- Improve timing and dignity when boarding wheelchair passengers
- Increase dialog and innovation with industry about wheelchair in the cabin and accessible toileting.

Of course, this requires further investment and COVID will impact this.

For now, the fear and humility of flying amongst the WCHC community remains, preventing them from being able to explore the world like everybody else who take it for granted.



As soon as you go to the transfer chair and onto the airplane you immediately feel like you don't belong if you are disabled. Nothing is made for us and everything is so difficult too, and it is very disheartening because I would love to travel more if it wasn't so hard - **Survey respondent**



SURVEY ON AIR TRAVEL FOR WHEELCHAIR CUSTOMERS

Survey was completed by 336 wheelchair users across the US, UK, Europe, Asia and Africa

Only 1 in 4 wheelchair passengers rate their overall experience flying by air as, good, very good or extremely good



60%

have had their wheelchair damaged



2%

of wheelchair passengers feel very safe on an aisle chair



62%

of wheelchair passengers have had to dehydrate or starve themselves to fly



43%

of wheelchair passengers have stopped flying



76%

would fly more frequently if they could remain in their wheelchair for short haul flights



69%

have experienced being transferred onto the aircraft during or after general boarding has commenced



"Flying as a wheelchair user is completely humiliating and current procedures are a deterrent to fly at all."

Survey respondent

Read the whole report on ableMove's website:
<https://ablemove.co.uk/release-of-wheelchair-customers-in-aviation-report/>

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How and why?: Encouraging children to drink the right amount of water



At Bladder & Bowel UK we are frequently asked questions about the role of water for children with bladder and/or bowel conditions, as well as how to encourage reluctant children to drink the right amount of water for their age, size and activity levels. Children's specialist nurse Davina Richardson discusses the issue [here](#).

Encouraging children to drink more water

Adequate fluid intake is important for maintaining health and wellbeing. There is guidance for how much water children of different ages and genders should be drinking (see the table to the right).

Children will need more than this if they are physically active, their environment is hot, or if they are overweight.

However, many parents complain that their children are reluctant to drink and say they do not feel thirsty, or they refuse to drink water.

Not drinking enough can cause or exacerbate constipation and bladder problems including urinary tract infections, day and night time wetting, as well as being the reason for headaches, feeling tired and struggling to concentrate.

Suggested intake of water-based drinks per 24 hours by age and gender.

Age	Sex	Total drinks per day.
1-3 years	Female	900-1000ml
	Male	900-1000ml
4-8 years	Female	1000-1400ml
	Male	900-1000ml
9-13 years	Female	1200-2100ml
	Male	1400-2300ml
14-18 years	Female	1400-2500ml
	Male	2100-3200ml

(Adapted from CG 111 Nocturnal Enuresis NICE 2010 and American dietary requirements, cited in CG 99 Constipation in Children and Young People, NICE 2010)

What type of fluids should my child be drinking?

Water is the best drink, as it does not contain any sugar or other additives. However if your child will not drink water, you could try offering them water from the fridge or add ice cubes to it or use very dilute sugar-free fruit squashes as an alternative.

There are also some things that are not advised:

- Do not offer your child fizzy drinks as an alternative to water, except as a rare treat. Fizzy drinks can irritate the bladder lining. This may make your child need to rush to get to the toilet or they may need to go to the toilet more often than is usual.
- Avoid giving your child drinks with caffeine in them. Caffeine can also irritate the bladder causing the same issues as fizzy drinks – having to get to the toilet in a hurry and needing to go more frequently than is usual.
- Do not let your child have more than 500mls (one pint) of milk per day. While milk is healthy, the body uses it more as a food than as a drink. Additionally, too much milk can exacerbate or cause constipation and may contribute to excessive weight gain.



Encouraging children to drink may be difficult, especially if they do not feel thirsty. However, thirst is quite a late sign of needing fluids, so children should be drinking regularly. They should have about six to eight drinks spread evenly throughout the day. They should be having about half of their drinks during the school day. - **Davina Richardson,**
children's specialist nurse



How can I encourage my child to drink more water-based drinks?

Encouraging children to drink may be difficult, especially if they do not feel thirsty. However, thirst is quite a late sign of needing fluids, so children should be drinking regularly. They should have about six to eight drinks spread evenly throughout the day. They should be having about half of their drinks during the school day.

Things that may encourage them to drink more include:

- Build drink times into your family's routine
- Make drink times fun: sitting together with a book or game and only read the next page or have your turn at the game when your child has had a few more sips. If your child refuses to drink then put away the book or game until the next drink time.
- Let your child choose their glass, cup or straw. Novelty straws work well for some children
- You could offer them ice cubes or add slices of fruit to water
- Start by expecting your child to drink only slightly more than they currently are and then gradually increase the amount you expect them to have until they are having about 1.5 litres per day
- Some children manage better if given half a glass and told to drink it all; others do better if given a full glass and are asked to drink half of it
- Measure out your child's water into a clean jug or plastic bottle each day, so they can see what they should be drinking. Pour all their drinks from that so they can see how well they are doing and offer them a small reward if they manage to drink it all
- Ice lollies and jellies have high water content, but try to choose ones that are sugar-free
- Do not have battles over drinks

How can I encourage my child to drink more when at school?

- Ensure your child always has a sports bottle of water for school each day. Make sure they bring the bottle home at the end of the day and offer them a small reward for drinking most or all of it.
- If your child enjoys cold drinks, almost fill the water bottle and put it in the freezer overnight. The water will stay cold as it melts at school the next day.
- Ask the teacher to build drink times into the day, or to allow the children to have their water bottles on their desks
- Ask the teacher to allow the children to have their water bottles on their desks whenever possible and to use the toilet when they need to. If your child thinks they will not be allowed to go to the toilet, they might not drink at school
- Encourage secondary age children to drink when moving between classrooms, unless this is not allowed in their school



Children will need more water if they are physically active, their environment is hot, or if they are overweight.



- Davina Richardson, children's specialist nurse

Other things to consider

Do not encourage your child to drink in the hour before they go to bed as this may cause bedwetting or make it worse. If your child has a bladder or bowel problem, making sure they drink the right amount during the day can help (see the chart above). A good fluid intake can also help when toilet training.

Where can I get further advice or support?

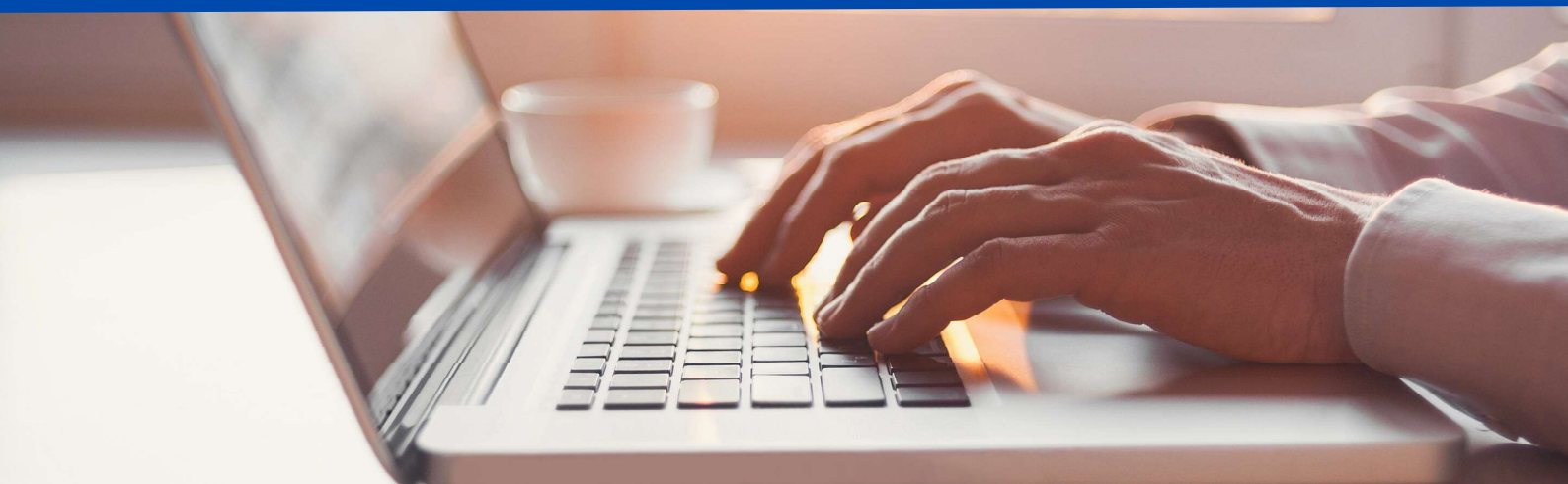
If you are worried that your child may have constipation, or if they have day or night time wetting, if they are struggling with toilet training, or you have any other concerns about their health speak to their GP, school nurse or health visitor for more advice.

There is lots of information about bladder and bowel conditions in children on the Bladder & Bowel UK website (www.bbuk.org.uk) on the Children Resources page at: www.bbuk.org.uk/children-young-people/children-resources/

Bladder & Bowel UK also offer a free confidential helpline for anyone affected by bladder and bowel issues. Contact us via our web form at: www.bbuk.org.uk/helpline-enquiries.

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disabledliving.co.uk](http://www.supplierdirectory.disabledliving.co.uk)



Disabled Living
Practical solutions supporting disabled adults, children & older people

New app offers continence information and self-care tips

It's not always easy to find the advice we need. The CONfidence app is designed to make it easy to access helpful information on bladder and bowel health, bringing together trusted and reliable information, informed by national clinical, patient and public experts.

In the UK, over 14 million people experience bladder control problems and 6.5 million have bowel control difficulties. Many people suffering with these health concerns do not seek medical advice or support for fear of embarrassment, potentially leading to further health complications. It can take patients 10 years from first presentation to their GP to reaching an accurate diagnosis and appropriate treatment.

Use the app to feel supported, get tips for everyday life and find support when you need it:

- **Signposting:** Know where to go for help and more information
- **Self-care:** Know what you can do yourself to look after your physical and mental health
- **Practical tips:** Develop skills to help you handle challenging situations and everyday problems
- **Health and support services:** Learn to make informed choices about getting help when you need it
- **Local customisation:** Get local information and links if your area has subscribed to its own page



Bladder and bowel symptoms are more common than most of us realise. We probably all know somebody who is experiencing some level of difficulty, we just don't know it because we hide these symptoms and struggle on. "Enabling people with symptoms to access this advice and information is key to empowering people to address and improve their symptoms at the earliest opportunity. Evidence-based, self-help treatments can reduce symptoms and even cure."



-Dr. Nikki Cotterill, Associate Professor in Continence Care at UWE Bristol and Director of the BABCON Health Integration Team

Bladder & Bowel UK are part of the team who advised to makers of the app, Bristol Health Partners' BABCON team with development by Expert Self Care.

It is available to download on Apple and Android phones. Search for 'CONfidence expert' or [click here](#).

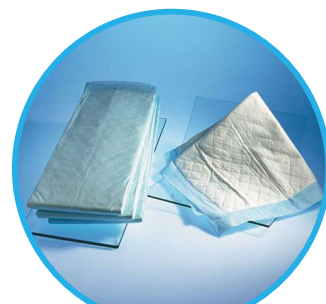
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Loocations.com: Finding loos when you're out and about



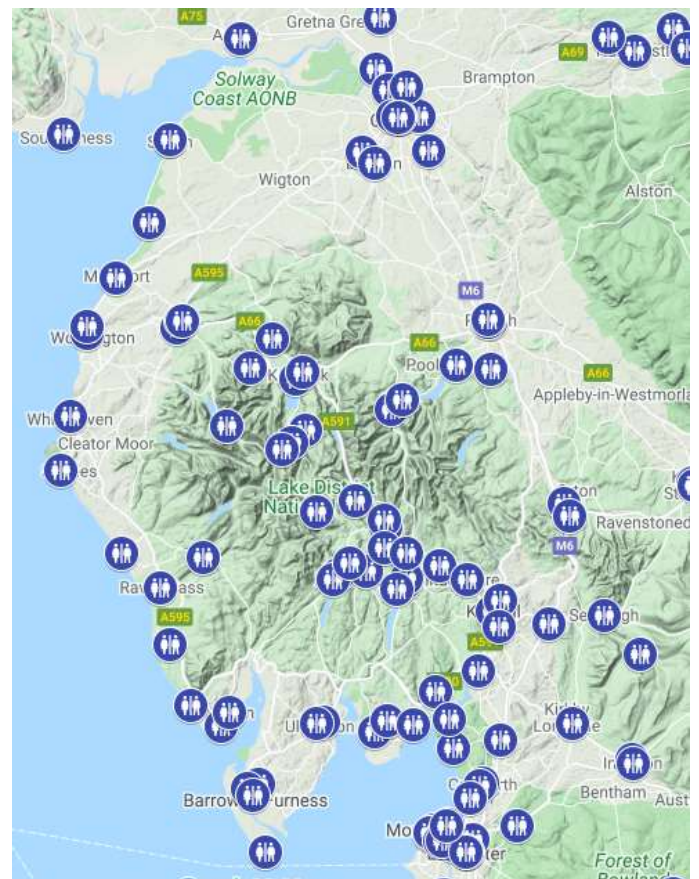
Devised during lockdown to help people find loos when many services were closed, the team behind Loocations.com aim to make it easier to plan your trips with peace of mind.

For many of us, it's impossible to relax if we don't know where we can find a loo. Enter Loocations, which plots the location of facilities - along with a short description - on a Google map for ease of use.

As well as compiling information from councils, the website uses crowdsourcing technology, meaning users send in additions and updates to the map. These are then reviewed, verified and added.

Toilets marked in blue are thought to be open, while toilets marked in red were last known to be closed. There are currently 6,000 toilets listed on the map, and the team are asking for help to continue sharing facilities, or to verify the status of those which might have changed following the easing of restrictions in May.

The creators Thomas and Charles Riley say, "our 'loo-cations' are only as accurate as the information we are sent. If you find toilets which are open - please submit them. And if you find ones that are closed, submit those too."



You can visit the Loocations site here:
www.loocations.com/

Follow Loocations on Twitter here:
www.twitter.com/LoocationsUK/

Disabled LIVING

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 occupational therapists, trusted assessors, moving and handling specialists, physiotherapists, nurses and 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 214 4590

BLADDER & 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 214 4591

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 Coventry, Farnborough, Newport, Edinburgh and Manchester.

www.kidzexhibitions.co.uk

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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 Issue 14 - 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.

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.

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[CLICK HERE TO READ THE LATEST ISSUE](#)

Issue 14 out now!

It's showtime!

Save the dates for our future events...



NORTH

NEW DATE! NEW VENUE!

Wednesday 17th November 2021
ACC Liverpool, Liverpool

MIDDLE

NEW DATE!

Thursday 17th March 2022
Ricoh Arena, Coventry

SOUTH

NEW DATE!

Tuesday 17th May 2022
Farnborough International Exhibition
& Conference Centre, Farnborough

WALES & WEST

NEW DATE! NEW VENUE!

Thursday 7th July 2022
The International Convention Centre
(ICC), Newport

SCOTLAND

NEW DATE! WE'RE BACK!
(HELD EVERY 3 YEARS)

Thursday 8th September 2022
Royal Highland Centre, Edinburgh