ERIC’s Guide for Children living with Complex Bladder and Bowel Problems

You might think you’re the only one, but LOADS of kids have special ways to manage their wee and poo. Look inside to meet some of them...

And there are lots of ways that ERIC can help you to make life a bit easier!
Hi, I'm Martha. I've had lots of tests but the doctors can't find anything wrong with my bowels; they say my bowels should be able to work properly, so the problems I've got are functional. All I know is I get really constipated, and then I leak poo, so I've had to learn to manage my bowels so I don't have accidents.

Hi, I'm Calum. I'm like Martha, but my problem is with my bladder not my bowel. I've had to learn to manage my bladder so I don't leak wee anymore.

Hi, I'm Sara and I've got Spina Bifida. That means I was born with something wrong with my spine, and that means the messages from my bladder and bowel trying to get to my brain to tell me I need a wee or poo don't get through properly. And the instructions from my brain to my bladder, telling the muscles what to do don't get through either. So I've had to learn how to manage my bladder and bowel, otherwise I would have to wear a nappy all the time.

Hi, I'm Gracjan. I've got Spina Bifida too. I've had to learn to manage my bladder and bowel too. As well as keeping clean and dry I want to look after my kidneys. Bladders and bowels that don't work properly can be pretty bad news for kidneys. Oh, and as my legs don't work properly I use a wheelchair.

Hi, I'm Arwin. I was born with Sacral Agenesis. That's another kind of congenital spinal problem... and like any spine problem the messages don't work properly between my bladder and bowel and my brain.

Hi, I'm Lyndsey. I hurt my spine when I fell off my horse five years ago. The damaged bit stops the messages getting up to my brain and down again. All four of us have got neuropathic, or nerve damaged bladders and bowels. Turn over to see how we look after them.

Hi, I'm Emma. I get really bad belly aches and I'm always running to the toilet, even in the night, because I've got Crohn's Disease. It's one of the two main forms of Inflammatory Bowel Disease, or IBD.

Hi, I'm Melusi. I've got the other common IBD - Ulcerative Colitis. I was diagnosed when I was 13 and a year later I had surgery - at the moment I've got an ileostomy to give my guts a rest.

Hi, I'm Leo. I was born with Posterior Urethral Valves, or PUJ for short. That means I had little blockages inside my urethra - that's the tube the wee comes down to get out of your bladder. I had surgery to fix it, but I couldn't really wee properly so they did another operation to make me a vesicostomy - that's a kind of hole in my belly that the wee comes out of.

Hi, I'm Rajib. I was born with PUJ too. I used to have a vesicostomy, but now I use catheters to empty my bladder. And the PUJ messed up my kidneys before I was even born, so I've had a kidney transplant too.

Hi, I'm Sumeira, and I'm Josef. We were both born with bladder exstrophy. That's a kind of cloacal anomaly...and that means something went wrong with the ‘zipping up the middle’ bit when we were growing in our Mums’ tummies. As well as problems knowing when we need to go, we've both got ‘plumbing problems’ too. So we've both had lots of operations to give us special ways of managing our wee and poo, AND to look after our kidneys too.

Hi, I'm Ning-Ning and I was born with Hirschsprung's Disease. When I was a baby I just couldn't poo, because nerves were missing from part of my bowel. That means the poo got stuck, and I had to have an operation when I was just a few weeks old. For lots of kids with Hirschsprung's that's it, but my guts still didn't work properly so I had a bag on my tummy to catch the poo called an ileostomy.

Hi I'm Mali. I was born without an opening in my bottom to let the poo out. It's called Imperforate Anus. I had an operation when I was just a tiny baby to make a new opening...but I still have lots of poo problems. So I've had to learn how to manage my poo – otherwise I would be having poo accidents.

“We’re all different, but we’re all the same...and did you know that as many as 1 in 12 children and young people aged 5 – 19 have a bladder or bowel problem? This leaflet is designed to tell you a bit about ERIC, and about the support that is available that might make living with a bladder or bowel condition a little bit easier.”
These are some of the things we do to sort our wee and poo. Maybe you do too?

Oh, so we all use catheters to drain the wee out of our bladders.

It’s pretty simple really – a catheter is just a thin, flexible tube that is lubricated to make sure it slides in easily.

About every three hours, I have to find a private toilet, wash my hands, and open a new catheter. The catheter just goes in the hole in the side of the skin. I put the catheter in the toilet and the elastic strap I wear around my tummy to hold it in. It’s in all the time. The drains are running the whole time so I have a lot of things going on all the time, so even when I have to go I have to wash my hands and open a new catheter before I go to the bathroom.

I was really scared when I first had to learn through. It seems silly now, I don’t hurt or anything. But I am bit of a pain always having to remember to take a catheter out with me.

“Mine’s lower down on my tummy, so I don’t even know if I’ve even noticed it before. It’s just another channel ready for a catheter.”

At the moment, my catheter stays in all the time. It goes in through my tummy. It’s called a supra public catheter. It doesn’t hurt, but it was a bit of a shock. I’m not going to use it until I get the catheter and the elastic strap I wear around my tummy to hold it in. I have some playing cards online. Sometimes, I just use a catheter to empty the urine out of my bladder, and I’ve got a catheter for my new catheter. I’ve got a special opening on my belly so that the poo comes out at the end of the day. You probably don’t know, but it’s really nice not to have a catheter to stick it out of the poo. Ok, I’d rather NOT have a catheter, but anything is better than being able to poo, and nothing is better than having poo accidents. In my case, I have a special bag over it to catch the poo, and I wear a special bag over it to catch the poo, but I usually take a pouch with a hanging top bag over it as a catheter. I have to pull a bag over it.

We both have incontinence. An incontinence is by a colostomy – it’s just a bit of a bowl that is brought to the surface. We have to wear special bags on our bellies to catch the poo too. I’ve only had mine for a year, and I was pretty fed up about it. I’ve got it now and it’s better.

I had a quite a lot of pain with my tummy when I was born, so I’ve always had a colostomy. I can’t remember life without it – I was in tiny baby when I was surgery was done in the any way that makes it easier because I’ve even known any different, but there are times when I have it all the time. I never wear a bag over it to catch the poo, but I am going to learn how to do it properly. Like the guy who used to wash their hands into their bum or through an ACE, you can put warm water in through the colostomy to make all the poop come out of your bum and just empty it down the toilet, and cover your colostomy with a really tiny bag.”

We both have sacks of medicine every day to stop or getting constipated, but we see doctors every week to help get the poop out. Superstitions – you just have to take a lot of your hands, wash it, then sit on the toilet. It works pretty well for me. I’m always clean.

I’ve used to be a clean, but I’ve had some problems lately, so might need to a bowel washout. There are some people who have had problems with their bowels before too.

“Like Sumeira, I can’t remember life without a poo bag on my belly. But maybe I won’t have it for much longer... I might be able to have it closed if I need tests and the doctors say I won’t be able to poop properly by myself, but I could have an ACE. Then I would do a flush to push the poop out. I don’t have a normal bowel I know, but it would be nice to be able to go to the toilet and poo like other people. I guess it will feel pretty weird at first though.”

I do bowel washouts too, but he’s had surgery to create an ACE diversion. So instead of the water in through my bum, mine goes through a drain and out through the skin. I just push the poop out of my bum and into the toilet. Like renal washout, it’s not a nice feeling while, but it’s much better than having poo accidents.

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“Having IBD means taking a LOT of medication. And having a special diet too. Most of my medications are tablets, but I have to give myself injections every two weeks too. So every course of steroids I have to go into hospital for the day for more medicine through a drip.”

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Glossary
*This information is a list of medications, both for the participating institutions and a range of medications to see the list, website address is “http://www.bhcs.org/" to check all the sites, and other web sites.*
There are lots of organisations that provide information and support about particular conditions. Here are some of them...

www.shinecharity.org.uk
Spina Bifida Hydrocephalus Information Networking and Equality

www.sbhscotland.org.uk
Spina Bifida Hydrocephalus Scotland

www.crohnsandcolitis.org.uk
UK charity working to improve the lives of people with Crohn’s Disease, Ulcerative Colitis, and other kinds of Inflammatory Bowel Disease

www.mitrofanoffsupport.org.uk
UK charity offering support and reassurance to those with or about to have a Mitrofanoff, and their families

www.breakawayfoundation.org.uk
UK charity offering support to children with bladder and/or bowel diversions/dysfunction and their families

www.contact.org.uk
Advice and support for families with disabled children

www.diversions.org.uk
Support network based in NW England for families with a child or young person with a bladder or bowel diversion/dysfunction

www.otw.org.uk
Over the Wall activity camps

www.cicra.org
Better lives for children with Crohn’s and colitis

www.colostomyuk.org
A UK charity that supports and empowers people with a stoma
HOW ERIC CAN HELP YOU:

www.eric.org.uk/Pages/Category/Kids
Lots to help children learn about wee and poo, and lots of fun stuff too!

www.eric.org.uk/Teens
Find out what other teenagers say about growing up with bladder and/or bowel problems, and some of the tips they have shared.

www.eric.org.uk/Help-at-school
Managing bowel and bladder problems at school is not easy. Find out what your school should be doing to help you.

www.eric.org.uk/Shop
Living with bladder and bowel problems is much easier if you’ve got good products to help you. From swimming costumes that contain poo accidents to special absorbent sheets to contain night time leakage.

www.healthunlocked.com/eric
A network where you can connect with others who understand, particularly in the ERIC community.
For information and support on bedwetting, daytime wetting, constipation and soiling and potty training call ERIC’s Helpline on 0808 169 9949

Email
helpline@eric.org.uk

Website
www.eric.org.uk

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Also in this series of leaflets:

If your child is of school age, they may well need support during the school day. To find out more see Help at School on the ERIC Website

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