

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 Callum. 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 PUV 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 PUV too. I used to have a vesicostomy, but now I use catheters to empty my bladder. And the PUV 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 extrophy. 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?



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

SARA



ARWIN

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

"I was really scared when I first had to learn though. It seems silly now; it doesn't hurt or anything. But it is a bit of a pain always having to remember to take a catheter out with me."



CALLUM



SUMEIRA

"We all catheterise too, but instead of through the natural channel we've all got a special channel called a Mitrofanoff. Mine's in my belly button."



RAJIB

"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 the wee comes out of – you know you're in the right place when the wee comes out...that's all there is to it really!"



JOSEF

"Mine's lower down on my tummy, so it doesn't show when I wear swim shorts. The wee doesn't leak out of the Mitrofanoff – it's just a channel ready for a catheter"



GRACJAN

"The catheter doesn't stay in all the time – about every three hours you have to slide a catheter in, let the wee out, and take the catheter out again. You can hardly feel it going in!"

"At the moment, my catheter stays in all the time. It goes in through my tummy – it's called a supra-pubic catheter. It doesn't hurt, but it was a bit uncomfortable at first until I got used to the catheter and the elastic strap I wear around my tummy to hold it in place. In the daytime I have a kind of tap on the end, so every three hours I have to open the tap to empty my bladder. When I go to bed I attach a bag so the wee can drain all night."

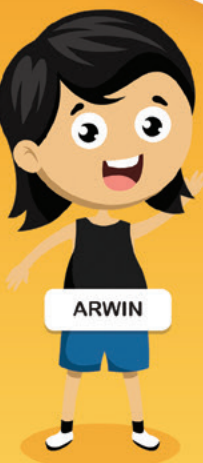


LYNDSEY

"When I was born my bowel and bladder and stuff was all messed up. I've had loads of operations, including a massive one to make my bladder bigger, called a bladder augmentation. So now, I use my Mitrofanoff to empty the wee out of my bladder, and I've got a colostomy for my poo. That means I've got a special opening on my belly that the poo comes out of. It sounds a bit yuk, but it's ok really – I've got really neat bags to stick over it to catch the poo. Ok, I'd far rather NOT have a stoma, but anything is better than not being able to poo, and *anything* is better than having poo accidents!"



JOSEF



ARWIN

"We all use bowel washouts to clear out our poo. Some people call it rectal washouts, and its proper name is Trans-Anal Irrigation...but we've all got our own names for it. I call it 'pump and dump'..."

"Arwin!!! The principle is the same for all of us – sit on the toilet, the device goes into your bum, you put warm water in, then take out the device and wait for the water and poo to come out. My kit has a sort of soft plastic cone on the end of the tube"



MARTHA



LEO

"I've got a stoma too – a vesicostomy, which is when the bladder is brought to the surface. Maybe one day I'll use a catheter like the other guys – but not till I've had more surgery. For now, my wee just drains out of my vesicostomy. I wear a special bag over it to catch the wee, but sometimes it leaks so I wear a pull-up over the top just in case. I hate having to wear a pull-up....but I know having a vesicostomy keeps my kidneys safe."



GRACJAN

"Mine has an electric pump to get the water in – there are lots of different kinds. It can take a while to let all the water and poo out – but it's worth it to stay clean all day! I do my homework while I sit on the loo – or catch up with friends on my phone. And sometimes doing it every other day is enough – everyone is different."



SUMEIRA

"I had quite a lot wrong with my insides when I was born, so I've always had a colostomy. I can't remember life without it – I was a tiny baby when the surgery was done. In some ways that makes it easier because I've never known any different, but there are still times when I hate it. At the moment I just wear a bag over it to catch the poo, but I'm going to learn how to do irrigation soon. Like the guys who do bowel washouts into their bum or through an ACE, you can put warm water in though the colostomy to make all the poo come out at once. Then you just empty it down the toilet, and cover your colostomy with a really tiny bag. Cool!"

"We both have ileostomies. An ileostomy is like a colostomy – it's just a different bit of the bowel that's brought to the surface. So 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 freaked out to start with. I've got used to it now and it is better than constant belly ache and running to the loo all the time, but all the same I hope it can be closed again one day."



MELUSI



NING-NING

"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. I've had tests and the doctors say I won't be able to poo properly by myself, but I could have an ACE. Then I could do a flush to push the poo out...I won't have a normal bowel I know, but it would be nice to sit on the toilet and poo like other people. I guess it will feel pretty weird at first though!"

"We both have sachets of medicine every day to stop us getting constipated, plus we use suppositories every night to help get the poo out. Suppositories are tiny – you just have to slip it up your bum, wait a few minutes, then sit on the toilet. It works pretty well for me – I'm always clean."



MALI

"I used to be clean, but I've had some problems lately, so might swap to a bowel washout. There are lots of choices...the most important thing for me is keeping clean. Poo accidents are SO embarrassing!"



LYNDSEY

"I do bowel washouts too, but I've had surgery to create an ACE stoma. So instead of putting the water in through my bum, mine goes through a discreet little channel leading from the tummy wall into the large bowel. No poo comes out of the channel – you have to sit on the toilet, put a catheter in and put water through it. That pushes the poo out of your bum and into the toilet. Like rectal washouts, it does take a while, but it's so much better than having poo accidents!"



SARA



EMMA

"Having IBD means taking a LOT of medication. And having a special diet too. Most of my medication is tablets, but I have to give myself injections every two weeks too. And every couple of months I have to go into hospital for the day for more medicine through a drip."

GLOSSARY

This leaflet contains a lot of medical terms, both to describe particular conditions and a range of interventions. Go to the ERIC website and search 'Glossary' to find out what they, and other words mean.

FIND OUT MORE:

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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