

How to use your

You have just been prescribed a Peristeen Anal Irrigation system which we hope will completely improve your bowel management.

No more accidents! No more uncertainty!

But, Peristeen Anal Irrigation isn't a magic solution to keeping you clean, comfortable and explosion free - you have to listen to what you're taught, use it exactly as your continence adviser tells you (no short cuts!) and be patient.

Life isn't going to change overnight; you may need several weeks to get used to

using Peristeen Anal Irrigation, and for your bowel to adjust to this different way of coping with a very natural (but not always easy) function.

Practice really does make perfect! Time will fly, you'll get good at it – and your life should change for the better!

Look forward to sleepovers, going swimming with no worries, planning ahead for days out and shopping trips.

And think of the shopping (boys you'll enjoy it too!) Light coloured skirts and trousers, nice underwear, well-fitting jeans and white sports shorts! No more hiding behind baggy clothes so no one will see you're wearing big pads; no more grungy colours in case of accidents.

Peristeen Anal Irrigation

Your continence adviser will already have gone through the procedure with you using Peristeen Anal Irrigation, but going it alone for the first time is bound to be a worry – after all, it looks complicated! And it looks like there's so much to remember!

These guidelines are meant to help you through the early times of using Peristeen Anal Irrigation when you might need a bit of a reminder.

First things first: take all your kit (and a book to read while you're sitting on the toilet - or your Game Boy if you're not keen on reading) into the loo.

Fill the water reservoir from the tap – not too hot, not too cold. Fill it to the top even if you won't be using the lot.

Now connect the equipment up – blue connection to blue, grey to grey, then open up the packaging of the anal catheter just like you have been shown.

All set?

Turn the control knob to the water symbol (fig 1) and pump 2 or 3 times just to prime the tubing with water and make the coating on the catheter nice and slippery.

Then turn the control knob to the balloon symbol (fig 2) Wait 30 seconds! Don't pump it up yet!

If you're not on the toilet by now, it's time to get on there.

Put the catheter gently into your bottom. Don't push or shove - it should slide in easily. If it doesn't, take it out and shout for help. This is why you need to have mum or dad in the

house until you (and they!) are happy that you're OK using Peristeen Anal Irrigation.

Hold the catheter in place and pump the balloon up. Your continence adviser will have advised you on the number of times to pump – it will probably be 3 or 4. Concentrate – don't just keep pumping!

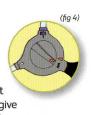
The catheter should be firmly in place so you can let go of it. See the water symbol? (fig 3) Turn the control knob to it and pump to let the water flow. Until you get used to the rate you need to pump, count out loud "one one hundred, two one hundred' pump "one one hundred, two one hundred" pump. This will get you pumping every 2 seconds or so until you've put in all you were told to use.

It may help to mark the right amount on the reservoir. Use Magic Marker or a sticker.

It can take a few minutes to pump in all the water you need - maybe longer if you have a spinal injury and have to go slower.

Once you're sure you've pumped in all the water you need and haven't stopped 'cos you're bored, remove the catheter by turning the control knob to the air symbol (fig 4) and the balloon will deflate and drop out of your bottom. You might need to give it a tiny pull not a great tug though!

Now turn the dial to the "resting" position (fig 5)- the orange arrow - you're finished for now and ready to go again!





Now you know how to use it, what else do you want to know?



When do I need to do it?

Most people use their Peristeen Anal Irrigation every one or two days and usually in the morning. Once you've been using it for a while, you'll work out your own routine, but don't get cocky and think you can leave it for more than a few days – it won't work properly if you're bunged up. And remember that you'll get the best results half an hour after a meal.



Everyone uses different amounts – you and your continence adviser need to work together to find out what's best for you. Mostly you'll find that 500 – 800 mls is about right. But don't keep changing the amount – give it time to work.

What about going on holiday?

Your Peristeen Anal Irrigation kit has a specially designed bag – no one needs to know what's in it. All you need is a loo, some privacy and a water supply. If you go abroad, carry the kit as hand luggage (you don't want to risk it getting lost!) and, if you're going somewhere where the water is dodgy, use bottled water (still, not fizzy) or cooled boiled tap water.



So, can anything go wrong?

Despite what it looks like, Peristeen Anal Irrigation is a really safe piece of equipment. Just be sensible, be careful and do exactly what you were taught to do.

Problems?

Highly unlikely but...

What if it hurts?

If pumping in water causes pain stop for a minute – this might just be bellyache caused by you pumping the water too quickly or the water being too cold.

If you see blood on the catheter of course you will worry. Speak to your continence adviser for reassurance.



What if I feel unwell?

You might feel a bit sweaty or dizzy when you're using Peristeen Anal Irrigation system or just afterwards. This will probably pass as you get used to it, but until it does make sure that Mum or Dad are in the house when you're irrigating.

What if the catheter falls out?

- make sure it hasn't burst
- did you pump the balloon up
- girls is it in the right place, ie not in your vagina

If in doubt, try using a new catheter.



What if it doesn't work?

If nothing comes out, you might be dehydrated or you could be really constipated.

If only water comes out, there may not be anything else to come out or, again, you might be very constipated. Make sure you are drinking plenty — water, fruit juice, sugar free squash etc

And speak to your continence adviser.

What if I leak?

It may be necessary to wear a small pad when you first start irrigating and until you know from experience that this will not happen.

- try sitting on the toilet longer to make sure that you are empty
- try using more water
- try using less water
- if you are losing a bowel motion between irrigations, you may need to irrigate more often
- an anal plug may help if the problem persists

Now you know how to do it!



bowel management is important?

Having a bowel which is overloaded with poo all the time will probably cause you a lot of problems:

- The full bowel might stop your bladder emptying properly. This will probably give you urine infections, making you feel ill and making your wee smell.
- Bacteria will start to break the poo up into a smelly, brown liquid, which can explode out as uncontrollable diarrhoea. This is 'constipation with overflow'
- If the lower end of your colon is never properly empty, poo may leak out slowly right through the day, leaving 'skid marks' or more noticeable mess
- People with high spinal cord injury can suffer autonomic dysreflexia* from being constipated
- · Constipation might make you feel grotty and a bit sick. It might put you off your food, and not eating the right things will make you more constipated which.....I think you get the message!

So it makes good sense to find a way of managing your bowels to avoid constipation.

Peristeen Anal Irrigation will aim to empty your colon from the anus right up to the bend near your ribcage, all in one go and at a time that suits you.

This way, poo is not in the bowel long enough to get hard, and the rectum will (hopefully) stay empty until at least the next day, stopping incontinence and all the anxiety that brings.

* Autonomic dysreflexia is a complication of high spinal cord injury. It involves episodes of sweating, high blood pressure and headaches, and can be brought on by an overloaded bowel.



Just because your bowel is different it doesn't mean you have to accept incontinence as part of life. There are plenty of things to try to get your bowel working in a good pattern. In the past you might have tried:

Looking at your diet and drinks - cutting out caffeine and fizzy drinks, going easy on the junk food, eating more fruit and veg and making sure you drink plenty of water or fruit juice so you don't get dehydrated.

Laxatives - these might be to get the poo soft, like Lactulose®, or Movicol®. They might be laxatives to give the poo an extra 'push' round the bowel (stimulant laxatives, like senna or Bisacodyl®) These can often help you to clear more of the bowel in one go, so you leak less.

Enemas - some contain fluid which is squirted into the rectum to flush poo out, Micro enemas squirt small amounts of fluid containing laxative into the rectum.

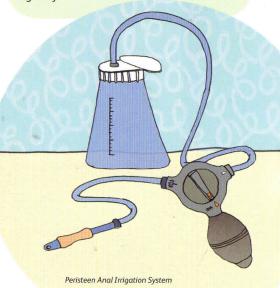
Digital stimulation - putting your finger into your anus to start off an 'emptying' reflex.

Manual evacuation - using your finger to hook poo out of your rectum.

Exercise - keeping moving (and yes, this means wheelchair users too!) will help keep the poo moving through your bowel as well as keeping you fit and healthy. If you aren't sure what exercise will help, ask your continence adviser or physio.

Now there's something new for you to try:

Peristeen Anal Irrigation System can be used to clean out the bowel instead of enemas, or manuals, and most people find they need fewer laxatives once they start using the system regularly.



Why is my bowel different?

Poo is made in the large intestine (colon); it starts off as a liquid made of water, waste food and bacteria. As it passes through the colon, water is soaked up by the bowel wall, so it becomes soft but solid. When it reaches the rectum, near the anus, the nerves send messages to the anus that we are ready to poo. The sphincters around the anus relax, and poo is pushed out, helped by the pelvic floor muscles. During childhood, children learn what this feels like, then begin to control when and where they poo.

Some conditions, like spina bifida and spinal cord injury affect the nerves that control muscles and let the brain know what our body feels. Muscles in our pelvic floor are very important in helping us to poo properly, but most people with bowel nerve problems (neuropathic bowel) have baggy pelvic floors. This means poo is not pushed out properly, and stays in the colon where more water is taken out. The poo gets hard and knobbly, which makes it harder to pass, so it stays in the colon and even more water is taken out......and so on! Poo should be firm, not hard and knobbly, or slushy.

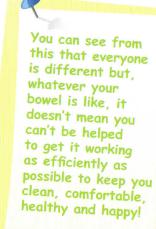
The nerves to the rectum often don't work in neuropathic bowels; this means that when the poo gets to the rectum, the pooing reflex doesn't start. This lets the poo drift out of the anus through the course of the day, with a lot of 'skid marks', not all in one big log like it should. Because the brain doesn't get messages from the rectum, it can't 'feel' when it is full and can't get control over pooing.

The nerves to the sphincters may not work, and

leave the anus loose and open, so poo can leak out easily.

Some people have conditions where the bowel just doesn't push the poo around, leaving it to go hard and knobbly and overloading the colon.

Some people get very, very constipated but the doctors can't find out why.



Diet

What you eat and drink affects your stool consistency and the look of your poo! Good stool consistency always means good control of your

Having control means that you can decide when you are going to empty your bowels. So, along with your regular Peristeen Anal Irrigation washouts, you need to also put the right things in your mouth. As the old saying goes, "what goes in, always comes out...it just looks different". So, a balanced diet is just as important as your washout programme.

Children and adults need a variety of foods as part of a balanced diet. This means you need 20-40gms of fibre daily! If you aren't used to eating so much fibre.

start with a small amount each day, and increase it slowly. This is important to do because fibre may cause bloating or gas and diarrhea.

Dietary fibre can be found in many fruits, vegetables, grain breads and pulses. There are two types - insoluble (which stays undigested and helps keep things moving through the bowel) and soluble (which absorbs and holds on to water, keeping the stool soft).

Sometimes, you have to adjust your fibre and fluids for your specific needs though. Here is a good rule to follow, if you are bunged up a lot, increase your fluid and work out what foods

cause the constipation. If loose or watery stools are the problem, bulk them up with insoluble fibre foods like bananas or rice.

You should always drink a glass of liquid, preferably water or diluted juice, with every meal. This is important for the soluble fibre to absorb. More drinks should be added between meals because fibre without fluid will cause constipation. If you read the labels on food packages for fibre information, you will start to understand more about it.

Some people find certain foods cause them to have diarrhoea or to be constipated. Usually, things like milk, eggs, cheese and refined foods, such as white bread can cause bowel problems. Remember, whole grainy bread is better. Grapes, sweetcorn or food and drink containing caffeine or artificial sweeteners (tea, coffee, cola, chocolate) or very greasy things like chips or crisps, can cause diarrhea too.

You should keep track in a food diary, of all the foods that cause problems, and that will help you cut back on those things for foods with healthier options.

Some people find that their bowels work better when they eat small meals more often than eating 3 large meals each day. Large meals cause

> your bowel to contract (squeeze), and that can cause diarrhea or general discomfort. Constipation may make you feel short tempered, or sluggish; and an impacted colon

will push on the bladder causing urinary incontinence to worsen.

So what about **Peristeen Anal Irrigation?**

You might find that although Peristeen Anal Irrigation is really helpful, you just can't do it by yourself. Sometimes that means you only need more practice. If you still can't do it, and you have done everything just like the continence nurse showed you, then you might need to have a helper. Normally, mum or dad will offer to help until you can take control and use your Peristeen Anal Irrigation system independently (because that is what it's all about...independence).

But other times, let's be honest and say that some teens just can't be bothered to follow the instructions or do it everyday. Peristeen Anal Irrigation doesn't work if you aren't committed to doing it regularly. Everybody needs to go to the loo everyday (or every other day) to empty their bowels. You are no exception. Peristeen Anal Irrigation won't work if you aren't responsible and committed.

If nothing happens when you have used Peristeen Anal Irrigation correctly, this is what you need to think about: Are drinking enough fluid? Remember to drink 6 to 8 glasses of water or other clear fluids everyday. Is the catheter in your rectum as far as it should be? Sometimes it is worth removing and trying again. Did you pass a lot of stool the last time you used Peristeen Anal Irrigation to empty your bowels? If so, then maybe there isn't any to get rid of this time. Although it's possible, normally there is some stool to eliminate. So Peristeen Anal Irrigation should be used regularly- even if there are no results once in a while.

If you haven't been successful in removing any stool for several days, you may be constipated. Your stool may be very hard and could be stuck in the bowel (this is called an impaction), and may need extra fluid, stool softening medication, or help from your continence nurse to pass the poo when it is like that.

Exercise

Believe it or not, you just learnt how to exercise and strengthen your bowels. Hopefully, you realize now how important that is for good health. Just as important though, is exercising your muscles. This helps not just to make you feel better, but also to keep your bowel motility.

If you don't get enough exercise, or are stuck sitting in a chair much of the time, and nothing moves on the outside, you can be sure it's also not moving on the inside either.

Lack of exercise can make your constipation worse. So, whenever possible, try to exercise (in a wheelchair or otherwise). Just a LITTLE moving, walking or playing sports everyday will make a BIG difference! If you can, it's worth the bother to get out for a walk, a dance or just lifting yourself up in your wheelchair. Even just shifting position if that's all you can do, will make things work better.

Small Problems

When you first start using Peristeen Anal Irrigation you may want to wear a small pad until you are confident you won't have any leaking. You should always wear cotton underwear to absorb any wetness and reduce odours, and it's good to wear clothes that aren't too tight. These things allow your skin to get fresh air, and help to reduce your risk of bladder infections. You may feel more confident wearing padded washable underwear if your bowels (or bladder) leak quite often. Some teens wear them all the time just to feel more confident, or have extra protection.

There are many companies that sell "normal" looking underwear, boxers, briefs and yes...even thongs! If - and this is unlikely - you continue to have messy leaking even after you feel you are in a good routine with your Peristeen Anal Irrigation system, speak to your continence adviser. Get her to run through your routine with you and, if you're still worried ask her about using anal plugs for activities like swimming until you are happy that everything is under control. It is important to feel good about yourself while you are managing your bowels.

When you feel confident, you can be relaxed, enjoy hanging out with your friends, going to the movies or parties, and being a normal teen.

Taking Control While Away From Home

When you first start getting used to the Peristeen Anal Irrigation, you may be a little nervous about going too far from home. Worrying about incontinence can be distressing. So here are some tips to get you prepared for the odd day when there is a problem:

- Use the toilet before going out of the house.
- Wear a pad or disposable underwear.
- Carry clean-up supplies.
- Wear loose clothing that you can easily change out of, and carry clean clothing that you can quickly put on.
- Know where the toilets are before you need them.
- Contact the ASBAH Helpline about getting a "need to go" continence card for when you need to get into the public loo right away.

Remember to plan ahead, and the small problems won't seem so bad.

And that's what it's all about!

Bigger Problems...

If you feel unwell or dizzy when you first try to do your washouts, it might be a little scary, but isn't unusual, and sometimes happens when you are getting used to the washouts. Some people feel sweaty or get a funny feeling in their chest or throat (fluttering). If you are worried about this when you first begin using Peristeen Anal Irrigation, have a responsible grown up nearby in case you need help. If you feel poorly with abdominal cramping or pain, while you are using Peristeen Anal Irrigation or just after, then try pumping the water in more slowly. Sometimes it's good to stop for a minute and then re-start when the cramps settle, or try changing the temperature of the water. Usually, the cramping means that the water has started the gut working, and that can be a good sign that the Peristeen Anal Irrigation is working as it should.

Another problem that you might find when using Peristeen Anal Irrigation if you have haemorrhoids (piles) is that it might hurt when you insert the catheter, or you might have some minor bleeding. Minor bleeding means occasional spots of bright red blood. If you have any problems with increasing pain or bleeding that becomes heavy or dark red, you need to tell your mum, dad, or your continence nurse so they can get you to the doctor. He or she will help you sort out the problem right away. Once it is sorted, you can probably go back to using your Peristeen Anal Irrigation.

Other important issues that must be discussed with your doctor before starting Peristeen Anal Irrigation include: if you become pregnant or are planning to become pregnant, if you have any infections in or around the anus, if you have had radiation or any other procedures that may have caused bowel problems, or you have had any surgery on your anus or colon during the past 6 months.

Your doctor probably already knows about most of these things, but it's always important to talk about it with him/her before starting the washouts. Sometimes, the medication you take such as Oxybutinin and some anti-epileptic drugs, can cause constipation or can make existing constipation worse. If this is a problem for you, talk to your doctor about it. Some medications can be changed.

Although Peristeen Anal Irrigation is the perfect solution for lots of people, it isn't right for everyone. If it doesn't work for you after doing everything as you were shown, and you have received all of the support available, then don't feel bad. For a few, it isn't the right solution.

For more information about underwear and fashion, check out the following websites:

www.allaboutincontinence.co.uk

P & S Healthcare Ltd. 0115 968 1188 or email: www.pshealthcare.co.u.k

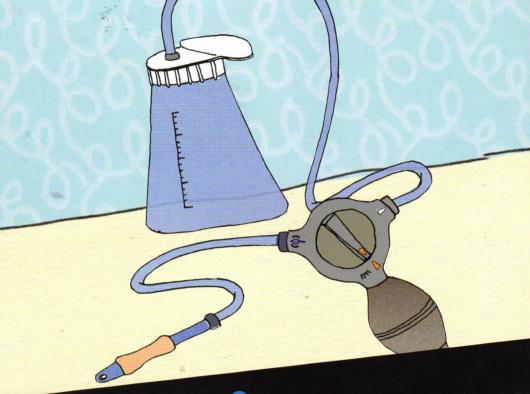
www.hds-uk.com

www.pshealthcare.co.uk

www.dlf.org.uk

www.racketys.com

www.Able2Wear.co.uk



Coloplast and ASBAH are working in partnership to campaign for an increased awareness of bladder and bowel health and to support families and individuals living with spina bifida and hydrocephalus to have a full and satisfying life.





For more information make our helpline your first point of call:



0845 450 7755 (local call rate)

or visit www.asbah.org

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