

Patient Information Leaflet



Coping with a leaking ileo-anal pouch

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Most pouches do not leak stool, but unfortunately a few people do experience problems. This may be a passive seepage during the day, or when you are asleep at night, or, more rarely, difficulty getting to the toilet in time when the pouch is full. This can be a very miserable problem as it is both uncomfortable and embarrassing and causes some people to avoid doing things just in case of an accident.

There are no ideal answers to a leaking pouch. It is always worth discussing the problem with your doctors and nurses - don't just accept it. Sometimes the situation can be improved by taking medication to make the stool less liquid, or by improving pouch emptying.

The ideas on this sheet are designed to help if the leakage persists.

Sphincter strengthening exercises

Sometimes doing some exercises to strengthen the anal sphincter muscles and their speed of reaction can improve your control. These exercises are very similar to pelvic floor exercises, but concentrating on the muscles around the anus. You will need to do a lot of exercises to make a difference. Please ask if you would like an information sheet about these exercises or if you would like to see someone for advice on this.

Pads and pants

There are very few products designed specifically for managing bowel leakage. Most of the disposable pads used for urinary incontinence can be used for containment, but some people find them unnecessarily thick, bulky, and not exactly the right shape to contain anal leakage.

The simplest sort of pad for minor leakage is a panty liner, available in supermarkets and chemists. The more modern ultra-thin versions often have a sticky strip for fixing in place inside your pants, and some have "wings" which overlap the edges of your pants. Some of the "stay dry" surfaces can feel quite rough, especially if your skin is sore, and some people find that ones without the stay dry layer are softer.

Unfortunately, if used stuck inside your pant gusset, the area between the buttocks often becomes sore as stool is on the skin. Some people have found that folding a panty liner between the buttocks and holding it in place with a close-fitting "G-string" (available in Marks & Spencers and other underwear departments), helps to contain soiling and prevents the skin from getting sore.

For people with an occasional leak, it may be reassuring to wear pants with a built-in waterproof gusset when you know that you will be away from toilets for a long time. These are not ideal as they are designed for urinary leaks, and can be stained by

stool, but they should stop any leaks from coming through to your clothes and embarrassing you. Versions are available in black or grey lace for women and Y-fronts for men.

More major incontinence will require larger pads. These come in all shapes and sizes. Many are available free of charge on the NHS via the district nurse or local continence nurse if you have a severe or regular problem. If you are not already in touch with your local services, ask at your doctor's surgery, or phone the Continence Foundation Helpline (0845 345 0165, Mon-Fri 9.30am – 1pm <http://www.continence-foundation.org.uk/>) talk to a nurse in confidence and to find your local contact.

If you need to dispose of soiled pads when out you may find the scented sanitary towel disposal bags or nappy sacks available from most chemists and supermarkets helpful.

If you have a major problem with leakage at night you will probably need to protect your bed. Simple plastic mattress covers and disposable bed pads are usually available through the local nursing service. You may need to buy more sophisticated breathable mattress covers yourself. They come in single and double bed sizes. There are also duvet covers in a waterproof fabric which is virtually indistinguishable from ordinary bed linen.

Controlling or disguising smells

Remember that we are all much more sensitive to our own smells than other people are. If you know you have leaked, you may be convinced that everyone around you know what has happened. But remember that they do not know, and are unlikely to be as sensitive to it as you are. If you are leaking stool and are worried about others noticing an odour, some of these ideas may be of help:

- Try to ensure good ventilation of the room you are in
- Use an aromatherapy oil burner, scented candle, joss stick or incense stick, or a dish of pot porri (remember to renew regularly as the scent wears off)
- Use aerosol air freshener with care - some smell very obvious, or even worse than the smell you are trying to disguise! Try a brand with an odour neutraliser in it as well. These come with or without a scent. 'Ostomist' odour neutralising spray produced by Ostomart can be used and is available in a range of environmentally friendly sprays. Call free on 0845 757 3023 for a sample
- There are many solid block air fresheners that work all the time - available from chemists or supermarkets
- Essential oils such as lavender or lemon oil can be useful
- Try striking a match and then blowing it out immediately and allowing the small plume of smoke to drift into the room. You may like to keep a box of matches and an egg cup for the used match in your toilet.

Deodorants

Your chemist may stock some deodorants specifically designed to control smells from urine or faeces. Neutradol spray or gel (MS George Ltd), Atmocol (Seton Healthcare), Chironair (Sims Portex), Daydrop (Loxley Medical) are among the most commonly available.

Skin Care

If you are leaking pouch contents onto your skin, there is a possibility that you will become sore. This is more so than with ordinary stool as pouch contents contain digestive enzymes and can be quite corrosive. The best way to prevent soreness is by cleaning as soon as you can, and meticulous attention to removing all trace of stool. There are also many different creams that can help with sore skin, or used as a barrier. The success of different creams seems to be very individual - it is worth experimenting to find the best one for your skin. A barrier cream and spray are also available. It may be worth contacting your GP or stoma nurse for advice on available products.

Planning ahead

Having a bowel accident when away from home can be very embarrassing. A little forward planning can make this easier to cope with. Some of these ideas may be helpful:

- Public toilets seldom have a wash basin in the toilet cubicle, and it is often impossible to get clean with dry tissue. Take a packet of wet wipes in your bag or pocket
- Or take a small squeeze bottle that you can fill with warm water to take into the toilet with you (available in Boots the Chemists)
- If you need both hands to get clean or change a pad, a couple of clothes pegs can keep your clothes from dangling in the wrong place.
- A small pocket mirror can be useful to check that you are clean
- Dark colours and patterned fabrics tend to show any stains less than light fabrics
- Take a spare pair of underwear and an extra pad.

You may find it convenient to carry a clean-up kit in a small wash bag (the sort many airlines give free is ideal), or on a waist belt.

New developments

This has long been a neglected area for research. Now more interest is developing, and there are some possibilities on the horizon. One is a cream which raises the resting tone in the anal sphincter muscles, so helps to close off the anus more effectively. This is still very experimental at the moment.

Another is an anal plug. This will not be helpful to people who have to empty a pouch very frequently and many people find the current version uncomfortable. But it may be worth a try in special circumstances where a leak would be dreadful, and newer versions are being developed.

Above all, we need people to tell us any ways that have been found to cope with a leaky pouch. It is only by sharing tips and information that we will develop better advice to help each other.

Contact details:

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Stoma Department – 020 8235 4110

Call centre – 020 8235 4061

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