

*This page summarises women's accounts of treatments and management techniques they have tried with extracts taken directly from interviews with injured women. To protect women's identities, we have not used their real names.*

*There also links to some resources that may be useful. Please be aware that some people may find this content distressing. If you have been affected or need extra support, please follow this [link](#).*



## Treatment and Management

Most the women we interviewed talked about various approaches they had tried to manage their anal incontinence and its impact. This included self-management techniques, use of technology, changing diets, taking medication, having therapy, and surgical procedures. Although this page host women's accounts of some of the approaches they tried, we are not promoting or endorsing these (as what works for one woman, might not work for another) but rather presenting what women thought about them.

### Day-to-day self-management

Women used various approaches to manage the daily impact of anal incontinence, often learnt through experience. Personal hygiene was considered very important, but often difficult to manage. Not only did women want to feel clean, but it was often vital to minimise the risk of infection in a new injury. However, the time it takes to clean themselves and having accidents in public meant personal hygiene was sometimes difficult to manage.

Hayley talked about how many women are concerned about recurring infections and she feels there should be more advice.

*"Women with any anal incontinence symptoms will feel terrified about recurring infections and the sense that everything is all open down there. So I think there should be better information about how you should shower, how often, e.g. twice a day? What products to use e.g., there are sprays which caused me real pain, so I stopped. And how to dry, I used a hair dryer which consultant said to use. The standard advice is keep it clean and dry. Which given the area we are talking about, and the exhaustion of the patients is really not easy! Also for people like me with these kinds of symptoms this is a regime that has to keep going for maybe 6-12 months" P2*

Making sure she kept clean took a lot of time for Rahma, especially when she was with her children.

*“I think I just spent many many years up until now dealing with the problem. And prayers is a very big thing for us, we need to be clean for our Islamic prayers, so every time I'd have an accident whether whatever time of the day is, I need to go for a shower, clean myself, get rid of my clothes. So that's another half an hour, one hour with little kids, and then kids getting older, school runs, other runs. It was very hard for me and it still is hard for me.” P39*

Jackie tried very hard to keep clean and felt really embarrassed with a healthcare professional advised her to take care with hygiene.

*“They examined me just said I was fine and just to take care with my hygiene, which was deeply embarrassing because that's all I was doing, because I kept seeing faeces down there and I was having a bit of a tough time. So, I was showering and couldn't get clean. Just constant baths, showers.”*

It was common for injured women to put a lot of thought into ways to reduce the likelihood of an accident or how to keep clean whilst out. Some women always made sure they emptied their bowels before going out or arriving at a venue. Some talked about how they limited how much they ate in the time leading up to an outing, to stop bowel movements whilst out. Many talked about having to find out about toilet facilities (location and availability) before, or as soon as, they arrive at a venue. Disabled toilets were particularly useful for many women as they often have a sink and space to get changed. Certain items of clothing were often avoided and always having spare clothing and baby wipes or wearing pads was essential for many women. Some of the women we spoke to just found it too challenging to manage whilst out and often decided to stay at home instead (see 'Impact on Life' section).

Working as airline cabin crew means that Anita has to make sure she stops at service stations on the way to work to ensure her bowels are empty before getting on a flight.

*“Yeah, I'm cabin crew. So, I commute to London, that is a worry every time I go to work if I'm going to get to London, but fortunately there's four services on the way and even if I don't want to stop, I make myself stop. If I go past a services and I haven't stopped and a couple of miles down the road there's a traffic jam, I'm in big trouble in my uniform, I could be in big trouble here, so I make myself stop. I normally*

*make sure I've stopped all the way and made myself think, "Right, I definitely do need to go to the toilet now because I've stopped," even if I have to sit there and, you know, 20 minutes, have a coffee and try and go to the toilet, it's simply to give myself peace of mind that I'm empty. But I have been caught out a few times, not like, I've had an accident on the plane, but there's been an urgency, I remember once I was doing the inflight demonstration and you can't leave that position, when you're pointing at the exits, and I could feel the sweats coming, thinking, "I've got to finish this," and it felt like the longest, sort of, three or four minutes ever. And I was like, I just had to run. I mean, that was a close one." P28*

As a teacher Maya finds it hard to leave the classroom to use the toilet, so she does not eat much the day before teaching.

*"I'm a teacher, I'm in front of children. For example, tomorrow I'm working in a school, in a mainstream school, so I will be faced with 30 children times five in the, you know, in a class, so I have 120 to 160 kids, but I won't eat much today 'cause I know I'm working tomorrow. I don't want an accident, and I can't leave them and go to the toilet, because if I come back to 30 kids they won't be sitting at the table just working, and they'll just mess around so it does impact me, and I've got used to it, I've learned just to manage it, because it's been now five years.*

*"Yeah, I get tired, I take, I'm on B12 injections which the doctor says have to have, I need to improve my diet. I've lost weight since having my baby, because of that, because that's what I do, I just don't eat as much and then I won't have any accidents." P40*

Bernie talked about how she managed her condition by what she ate and thought this was quite common for women with injuries.

*"I've tried to manage it so if I needed to go out I just wouldn't eat any solid food. I would just have liquids so I just used to manage it in that way. So the main thing for me in managing my symptoms is to have Imodium when I know I've got to go out and no food. So say I had to go to London for the day for an appointment, or whatever, I would literally have no food, I just drink water and then I would eat when I came*

*home and that's all that I can do so, and a lot of the women that are injured like me, that is the only way they can cope is to have no food inside you. Yeah, so that's how I manage at the moment. And I can't drink hot drinks when I'm out because it stimulates my bowel, so I always order a hot drink and leave it to get cold. All little things like that. I can't go out for lunch, dinner, breakfast. P4*

Emma talked about how it was important for her to know about the toilet availability before going to visit friends and family. She now feels happy to let people know she has an injury but does not give details.

*"I think it makes me think twice about what we're actually doing and where we're going. And yeah, some things that, probably some things I'd be more conscious of, I like to know that toilets are there.*

*"I went to see my best friend and found it really difficult because she only had one toilet so I was panicking a little bit about staying with her and even though she's my best friend, I didn't really want to tell her. And even a little thing like this was before one of the GPs I spoke to then said... I was going to stay with my Gran, and she's just moved house and I didn't know she had two toilets or not and I was panicking about that and the GP said it's OK just to tell people you've had a childbirth injury, you don't need to explain things. And said actually if you say to your Gran "I've got a childbirth injury, do you have two toilets?". You don't need to spell something out. But we were, we've gone to a family party and there's a bit of a queue for the toilets and my Gran winked at me and that was quite nice actually. In the queue for the toilet that she winked, and I know she'd let me go in front and stuff without any you know, yeah, and that felt better and even something like that, just saying to somebody got childbirth injury, you know I want to know where the toilet is? That's a much easier thing to say than anything else." P34*

Finding a toilet with a sink is particularly useful for many women like Fiona.

*"I mean the other thing I would say about management is when you're out and about, for me when I find a toilet that's got a sink inside the toilet, because you can't wash yourself at a sink in a communal area, but you usually need to wash yourself with this condition. So, if I can find a toilet that's got a sink in it, now these will often*

*be a disabled toilet but they're not everywhere you know, and even at work when I'm on the wards, the staff toilets, sometimes there's a sink in it, sometimes the sink is outside, it depends how it's set up. But I love it when I find a toilet with a sink it because it's so helpful for this condition when the sink is on the inside, and you can do a proper job, but I mean I always carry like baby wipes with me and stuff like that so you know, I can manage if it's not there, but sink is, is a great tool to have". P16*

Some talked about the [Flush App](#) which helped them to find the nearest public toilet when away from home.

Claire talked about how soiling herself was so common that she managed with clothing choices and having a routine to clean herself when she got home.

*"I then started to take out spare changes of clothes. And I found that the winter was better for me, because I could wear more clothes. And I wanted to walk with my pushchair and show my baby off, like every other mum. And so I used to either tie a jumper round my waist or wear a long coat, so that by the time I'd got home and I had had an accident ... because at that point it was an inevitable, totally foreseen incident. I would wear a long coat. I'd park the pram in the hallway when I got home. I'd have the toys out on the side ready for when I got home, so that she was catered for. I would go straight upstairs and get straight in the shower. So clothing was a big factor. But then you ruin so many things. You can only wear certain things. You know, so I started to then wear old clothes out, which didn't make me feel very good about myself because I knew I was going to soil them". P9*

Maya also talked about how experiencing anal incontinence affected her choice of clothing.

*"Yeah, oh another thing when I'm working I wear black trousers in case I have an accident, and I always carry a deodorant. So I mean, I've never had a big accident but they're the two things that I do, like, I wouldn't wear white trousers. I have bought some light pastel trousers, like, lilac, and I want to wear it but then if I wear it I will, I will wear two pants, tights underneath, or I will wear my shorts underneath. P40*

Amy makes sure she always wears pads and keeps spare clothes and wipes with her.

*“I just found myself wearing a sanitary towel the whole time because I was just always leaking and the urgency as well. I've always managed it by just like wearing sanitary towels the whole time. I always make sure I carry like spare knickers with me. Spare sanitary towels with me. I just get used to just wearing sanitary towels the whole time and you know, I was having wipes because like toilet paper doesn't always do it. You know, washing if I need too. Yeah, like this, that's just kind of a way of life I suppose. P8*

Many women found that sanitary products were not adequate and often had to wear two pads to cover a larger area. Fiona found that pads were better designed for older people with urinary incontinence than young busy people with anal incontinence

*“It's just not the right sort of size and shape really for anal incontinence, it concentrates on urinary incontinence and periods and that. So yeah, but you're sort of almost having to you know, not exactly make your own but you know, I always wear two pads, one at the front and the other one I deliberately stick further back but you know, really it would be good if there was a pad that just did the whole thing for you.*

*“Yeah, and they sell these sorts of actual disposable pants, but you know, there's problems with those, you're going to change those in a public place you're going to have to take your trousers off to get the new ones on you know, which is not always something you want to do in some rather dodgy public toilet where the floor's wet and god knows what ... I mean they're not easy to manage, and I, I did a long distance walk recently so you know, I thought, “Okay, I'm going to use those pants you know, it'll be better”, but actually it wasn't because I got terrible sores from the way they rubbed because they're just not the right shape and there's too much of them you know, they're so bulky that after two days I gave up on those. I just don't feel any money has gone in to looking at this problem and designing the right product. I mean you know, you can get products for the elderly who are just sitting in a chair or lying in bed and you know, can wear these enormous pads, but that's not good enough for a woman going to work you know, or somebody who's doing a long distance walk of ten miles a day you know, it really ... they just don't work at all. P16*

Many women also carried out various physical approaches to manage their condition. Some carried out breathing techniques and used heat to manage pain. Others talked about how they retrained their toilet habits and found that positioning helped them ensure they had emptied their bowels effectively (e.g. rocking back and forth whilst on the toilet). Some apply pressure on their vagina or bottom or perineum (the area between the vagina and the anus or bottom) to push the poo out. Many women talked about how they carried out 'self-digitation' whereby they put a finger into the vagina or bottom to help empty bowels.

Previously Caroline would rush to the toilet, but now she has learnt to use pelvic floor and breathing techniques to improve control of her bowels.

*"It's kind of retraining my pelvic floor. Before I thought I need to go to the toilet and I would just run and go. Whereas now I kind of need to retrain it to be like you need to wait and wait and wait. So before I did lots of other things where I kind of, it was weird, kind of holding on to the sink and squatting and holding for 10 and then like sitting on the lid of the toilet and holding. And that was really hard at times because obviously my brain was like 'no, no you need to go to the toilet, need to go to the toilet now'. And I just had to be like 'no, no we're going to just hold, breathe, and we're going to...' you know. And I did lots of deep breathing, that's what my physio always told me as well, lots of kind of breathing into my diaphragm and kind of pushing out and holding so that kind of pelvic floor. Before I didn't realise, I just thought it was just holding, but it is kind of breathing out, but then squeezing up at the same time and the deep breathing has really helped me with kind of connecting my pelvic floor." P5*

In the months after giving birth, Robyn found bowel movements very uncomfortable and the only way she could manage was to remove stools manually whilst in the bath.

*"I couldn't go for a poo at all. The only way I could poo was in the bath. Basically, I sat in a warm bath and cried for about an hour and a half and manually extracted poo. That's the only way I could go. And I did that on and off for months. Months and months and months." P10*

If you find that pushing a finger into the vagina or applying pressure helps, then we would suggest that you go to see your GP or a women's health physiotherapist as you may have a rectocele (bulge in the vagina). If you regularly put a finger into the bottom to go to the toilet then you should see your GP as you may need a referral to see the bowel surgeons (colorectal) or a pelvic health specialist. Frequent self-digitation of the bottom can lead to pain, bleeding and may lead to ulcers on the lining of the rectum, so we advise those doing this to seek medical advice.

## Other approaches to self-management and treatment

There are many other treatments and self-management approaches women tried to manage their incontinence and pain. These included pelvic floor exercises, use of tools and technology, diet changes, therapy and some women had surgical procedures. For further information and advice, please see links to resources below:



### *Additional Resources:*

The MASIC Foundation is a great resource for women. They have lots of information about [where to seek help](#), as well as [Nurse Led Coping Advice](#) which summaries treatments and ways to self-manage.

[POGP \(Pelvic, Obstetric and Gynaecological Physiotherapy\) Webpages](#) provide advice on self-management, including diet, positioning, exercise, pelvic floor exercises.

The Pelvic Floor Society have a range of information leaflets, including information about surgeries: [Patient Information | The Pelvic Floor Society](#)

The [Birth Trauma Association](#) provide information and support to those impacted by birth trauma.