

Carol's story

Carol first realised something was wrong after the birth of her first daughter. She was 23 years old. Her symptoms began with severe lower back and bladder pain, as well as a constant feeling of nausea. Over the next 10 years, Carol went back and forth to her GP who thought she was suffering from bacterial cystitis and prescribed several courses of antibiotics, despite urine samples showing no signs of infection. The antibiotics had no effect but despite Carol's continued pain and discomfort, her GP was adamant nothing more could be done to help her. Carol felt frustrated and very alone.

After the birth of her second daughter, Carol had a hysterectomy. Soon after the operation she was once again prescribed antibiotics for what her new doctor thought was a kidney infection. But it soon became clear that once again, the antibiotics were not helping. Carol was still in pain and had a high temperature. Carol's GP finally referred her to a urologist who suggested she have a cystoscopy. The results unfortunately failed to provide a concrete diagnosis, but the urologist explained to Carol that her symptoms might be linked to a condition called interstitial cystitis (IC), which can often be hard to detect at first. This was the first time Carol had ever heard about IC.

Carol immediately felt a wave of relief: *"Finally I felt like I wasn't going mad. Why had no one suggested IC to me before?"*

When Carol went back to her GP however, he dismissed the idea of IC and despite protests from Carol, suggested she try a continuous dose of antibiotics to alleviate her symptoms. *"I knew the antibiotics would have no effect, but to my amazement, my GP refused to accept that I might be suffering from IC simply because he had never heard of it."*

Carol went home feeling angry and alone once again. Her symptoms were now taking an enormous toll on her quality of life and she was no longer the bubbly, sociable person she once knew. Her pain rendered her housebound for large parts of the day and had forced her to give up work entirely.

Finally, Carol went to see a new GP, who much to her relief, knew about IC. *"The relief was incredible. Finally, here was someone who was actually listening to me and taking what I said seriously."*

Carol was referred to her local pain clinic who suggested she try using a TENS machine as well as acupuncture, both of which have helped to relieve her pain.

Carol has also learnt to moderate her diet and avoids food which might trigger an attack. Carol also takes painkillers during the day, and stronger prescription tablets at night so she can at least get some sleep.

*'I have learnt to live with IC and found ways to deal with my pain and if a big occasion is coming up, I need to plan ahead. For example, at my daughter's recent wedding I bought a beautiful new dress which meant I couldn't wear my TENS machine, so I went to see my GP a few weeks before to make sure I had adequate painkillers for the day. It was such a wonderful wedding – I wouldn't have missed it for the world.'*

*"My friends have been wonderfully supportive, but it's hard for them to truly understand what it's like to live with IC and I feel guilty when I have to cancel a lunch date or evenings out".*

A few years ago, one of Carol's friends suggested she got in touch with the Cystitis and Overactive Bladder Foundation (COB), a charity which provides information and support to sufferers of bladder problems, including Interstitial Cystitis, Bacterial Cystitis and Overactive Bladder. Carol found the COB Foundation website to be an enormous source of support. *"Realising that there are other women out there facing the same pain, worries and frustrations was such a relief."*

*"If I could offer one piece of advice for anyone who has or thinks they have IC, it would be to not give up hope. There are times over the last 28 years when I have felt such despair, especially when nobody knew what was wrong with me, but I refused to let it get me down. Don't be frightened to ask questions and if your symptoms persist, go back to your GP again and ask about IC. It might take a little while to figure out what works for you but you will get there eventually, I promise".*