



My two stomas 'Ping' and 'Pong'

Vicky Sykes



Nobody would claim that stoma surgery is a walk in the park. The body can take months to heal. Ongoing stoma management is the next concern as well as dealing with the likes of leakage and sore skin. Issues which, as we know, have a habit of returning with changes in body weight and stoma size. Thankfully, there is plenty of help out there. As editor of *Tidings* I am fortunate enough to have access to every edition since the magazine's launch in 1998. I can tell you, it is a treasure trove. In fact, it is testimony to the wider efforts made over the past two decades to make things just a little easier for each new ostomate.

And, this quest goes on. Surgical techniques keep developing. Ostomates continue to draw on the collective experience of our volunteers. As a charity we are also involved in research on everything from parastomal hernias (CIPHER study) to pancaking. The stoma companies continue to play their part too; think of bag technology and how the latest designs have moved on from those described by Lynda on page 28.

However, there is another side to having a stoma which, until very recently, was rarely spoken about...and that's the affect it can have on mental health. The silence has much to do with the general stigma surrounding mental illness, the edifice of which has only recently started to crumble. But progress is being made. The positive links between being active and mental wellbeing are now widely acknowledged. Indeed, research findings in this area have been important shaping **Colostomy UK's**

Active Ostomates project and the recent addition of creative minds art sessions to our offering. But, despite these advances, we would be the first to concede that more needs to be done, both to understand the impact that stoma surgery can have on mental health and to help those that suffer. Moving forward, everyone needs to work towards creating an environment where mental health can be spoken about openly. This will need courageous people. People willing to share their experiences, people like Vicky Sykes, who I had the pleasure of interviewing a few months back.



Vicky is 44 years old and has two stomas. She has named them 'Ping' and 'Pong', hence the title of this article and the rather esoteric front cover to this *Tidings*. Her story illustrates perfectly why we need to get better at talking about mental health and stomas. Vicky's story began when she was 25 years old and suffered a spinal injury. This occurred from a simple, but tragic accident. Her son, who was a baby at the time, had just woken up and Vicky was carrying him downstairs, when she lost her footing. The injuries she sustained didn't require emergency stoma surgery. Indeed, Vicky had her loop colostomy 14 years later. It was performed as the final option, after other procedures and medication had failed. This gave Vicky plenty of time to research what the surgery entailed. But, as she said, you can only prepare so far and she still remembers waking up afterwards, seeing her stoma and thinking: "I can't do this!"

Of course this is not an uncommon reaction. Nor were Vicky's subsequent

feelings of relief when she mastered bag changing. Shortly afterwards, buoyed by how she was coping, Vicky made her first trip out. But an incident at weight watchers changed everything and made Vicky realise that she was far from recovered: "I was sitting there and my bag made a noise. I was mortified, but tried to act normal and ignore it...that was until the people by me laughed and made unpleasant comments. I left in tears, not wanting to return or, in fact, leave the house for fear of this happening again". Vicky found herself in a situation where her body was healing well but mentally, (to use her own words), she was a "mess". She worried constantly about leakage, noise and smells. She also started to develop irrational fears about using public toilets. Bag changing wasn't the issue. Instead Vicky worried what people using the facilities after her might think. I'm sure many readers will be able to relate to how Vicky felt at this time. But in Vicky's case, it led to her becoming a virtual recluse.

Vicky can't put her finger on a particular moment or incident but, over time, something changed. Perhaps the critical thing was that she began to accept there was a problem. This led eventually to Vicky giving herself "a good talking to". I told myself: "So what! I have a bag. We all go to the toilet; I just do it in a different way". As this fresh mind set became embedded Vicky started to cope again, helped by the ever present support of her family. As a mark of how far she had come, she plucked up the courage to go on holiday and even took the brave step of wearing a bikini. Vicky says that although she still harboured paranoid thoughts, she had recognised that if she didn't start to think and act differently, then her stoma was

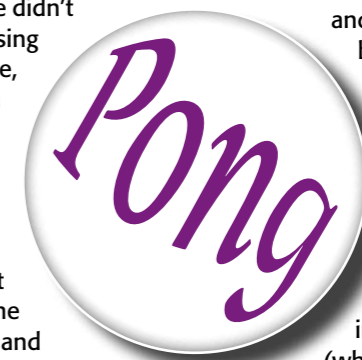
going to take away her life. It might have helped her 'physical' body, but it was in danger of destroying her mental wellbeing and sense of 'self'.

Sadly, as Vicky started to cope, so it became clear that her loop colostomy had not resolved all the problems from her spinal injury. In 2018 she was told that she would need a bladder diversion and a second stoma (urostomy). This was a great shock and a devastating blow. But Vicky says she still managed to stay positive (at least at first). Despite dreading the thought of more major surgery, she was doing well with her first stoma and thought: "If I can cope with one, I can cope with two". However, Vicky found things much more difficult second time round. She suffered with infections and soreness. She also quickly discovered that management and care of a urostomy is more intense than a colostomy. It took a while to find the right bag and all the while she was leaking daily and the skin around her new stoma was sore with blisters. Hearing this, I wasn't really surprised when Vicky said that all her old fears returned and "with full force sent her flying backwards". So much so, that she began to push away her family, who were desperately trying to support her as best they could: "they would say to me 'you are what you are' and 'what you have makes you' – but to me these were just words".

The physical recovery was slower this time round. Its impact on Vicky's mental health can be measured by the fact that she was pleased. When she said this I was taken aback, immediately wondering why this was the case? Vicky explained: "I was glad my recovery was slow as I saw this as a way of living in my little bubble and hiding away from the outside world. Just walking to the local shop was a challenge. I would

look down at my stomach area and think everyone would hear the urine". As Vicky's body started to heal, her mental struggles intensified: "I would wear layers of clothes and hold my stomach to hide the two bags, even though I knew they were covered. I constantly gave excuses to my family and friends if I got invited out. I remember doing the first post-op school run. I got to the school and just wanted to turn round and run back home. I sat in my car frozen, I couldn't move. My son had to be taken into school by another mum".

This was a very dark time for Vicky. Her relationship with her husband also started to suffer, as she found herself wanting to hide away from the man who loved her. Perhaps it was this that triggered something in Vicky again. She began to realise what was at stake and that if she didn't act, then she risked losing everything. Just like before, Vicky made the decision to fight her negative thoughts and grasp back her life. I asked her how she managed to do this and her answer was: "Little steps. One day at a time". One strategy she developed was to try and change one negative thought into two positive thoughts in the hope that this would help her to begin embracing life with two stomas. It was this that led to the naming of her stomas 'Ping' and 'Pong'. She also did her best to imagine what her life would have been like if she had tried to carry on without having stoma surgery. Gradually her efforts paid off, although Vicky was at pains to point out that the road wasn't straight and level, but bendy and with plenty of dips. Thankfully, Vicky is



now in a better place and firmly believes that mental scars can heal just like physical ones. If you are suffering then her advice is simple: no matter how hard it is, try to pluck up the courage to talk to people around you about how you are feeling, rather than hiding away.

Vicky was keen that people learn from her experiences. From my point of view she has succeeded. Vicky's story helped me to appreciate the far reaching implications that poor mental health can have, not just for the sufferer but for those around them. This reinforced my view that more needs to be done, with mental wellbeing figuring in the aftermath of stoma surgery. This means talking about the fact that mental health can take a knock and equipping patients and their families accordingly – both to spot the signs and to know what interventions are available. The coping strategies that Vicky developed also spoke to me about the responsibility we have for our physical and mental health. Finally, Vicky's incident at weight watchers (which seemed to 'tip the balance' of an otherwise promising recovery), made me realise how important it is that **Colostomy UK** continues to raise awareness through its 'Stoma Friendly Society' campaign. It's more than just seeking practical changes to things like public toilets (important as these are), it's also about educating people to think before giggling.

Written by
Richard Biddle