Jeff Manthos (USA)

My story is not unlike that of many others who have suffered from ulcerative colitis (UC). I first started having symptoms at the age of 23 in the fall of 1976, not long after I had been discharged from the US Navy. Given my world travels it was suspected that I had contracted a bowel parasite or virus overseas but as the disease continued on its unrelenting course of destroying my colon and my life along with it, UC became the diagnosis.

By 1978 it had progressed to the point of my needing to be hospitalized and massive blood transfusions and steroid dosages pulled me back from the brink of death. At that time the pouch procedure wasn't an option and the next few years were an endless cycle of flare-ups, steroids, and remissions. By 1984 I was in a flare-up that was very difficult to control and the pouch procedure was discussed. In the US at the time it was called an ileo-anal pullthrough, but J Pouch seems to be a good description. It was my impression that at that time it was a new procedure and I felt very much like a pioneer, or guinea pig, as there was a lot of uncertainty.

As it turned out, the surgical procedure was more complicated due to both the extent of my involvement and my physical make-up, the surgeons almost gave up trying to build the pouch for physiological reasons. But they persevered and were successful in building the pouch. As with some people, I had a propensity to grow internal scar tissue, or adhesions, and had close to a dozen small bowel blockages, one resulting in more surgery to remove the offending tissue in 1985.

The first few years were the most challenging, and I had many accidents, mostly at night, and control was almost non-exsistent. But as time went on things settled down more and I learned what not to eat or drink and to think ahead as to what I had planned as far as where I might be when I would need that toilet.

It's an imperfect system but I have accepted my "new normal" as a lifestyle, and to be free of the destructive power of ulcerative colitis is liberating. There is little the pouch prevents me from doing. I have stopped overnight camping since crawling out of a tent to find that hastily dug latrine has taken the shine off of overnight wilderness experiences. But there is much I can do, from bicycling to weight lifting to travel. I can't emphasize enough that planning ahead is helpful, if I know I have a drive of several hours ahead I won't eat or drink anything that might make that drive uncomfortable. if I'm in the comfort of my own home or another familiar setting, I eat or drink whatever I like.

I spent a lot of time back in the 1980s worrying about what it was going to be like later in life, dealing with the pouch. It was needless worry! My most recent pouch exam was fine, the physician complimenting my surgeons on a job well done. The pouch, 27 years later, is holding up great.

I have no regrets taking this route and recommend anyone facing colon removal surgery to give it some consideration. I have forgotten what it was like to have a normally functioning colon, but I have not forgotten the hell that is ulcerative colitis. My "new normal" now is integrated into my daily, and nightly routine, and while my awareness of the nearest facilities is lazer-like and always in the back of my mind, life is full and worth living and I have the freedom to do things that were impossible with the disease.

On the practical side, I have come to like using Metamucil caplets, they are portable, easy to swallow and effective. There are times when, regardless of doing everything right, I'll have diarrhea. So it goes. Staying hydrated is vital and if that's the small price I pay for the life I've been given back, it's OK.