

## The Chaplain as Patient

### *Chris Levison*

Perhaps it is good to have been a patient? When I went to my parish in Paisley in the summer of 1983 the induction had to be delayed for three months. A day or so after accepting the call I was struck with a bout of colitis, and had to spend several weeks in hospital in Aberdeen. I went to Paisley helped by steroids, still hoping that the dosage could dwindle to nothing. I received regular check ups, and for 5 years managed without any major difficulties. Then came the stage when the steroids were no longer coping and the amount of medication needed was going up. My consultant suggested I should now go to the specialist surgeon, "I think we should have an operation" was his conclusion and advice. "Take out the colon, make a new pouch with small intestine, it means having an ileostomy for a while, but should be the cure. Something needs to be done." My immediate feelings were of relief, something was going to be done, a wee holiday from work plus recuperation - quite buoyed up by the thought. My wife and family were similarly relieved, and I enjoyed the concern of Kirk Session when I told them.

The operation was to take place in 3 months time. Then it was delayed for a month because the surgeon was involved in a court case. I read about it avidly, and was pleased that he was without blemish thereafter. When the time came I wasn't particularly worried, Scots stoicism: it will be no bother!" "I'll cope!" Admission followed by loads of questions, charming nurses, "This isn't bad!" And it's all free! Stoma nurse very caring - prepared the way. The first thing I wasn't prepared for was the registrar coming to see me, the night before the operation. "You realise," he said, "that the operation might leave you impotent!" It had never crossed my mind; why should it have? The implications of this new revelation were, to say the least disturbing! I ought to have been told. It was a bit late to think about and I didn't really think there were any options but to go ahead.

As it turned out, the operation went well. I remember being turned over by a group of auxiliary nurses, several times that night. I was very impressed by their tenderness. Next day very groggy - many tubes - but felt reasonable. Next day, first tube out, very sick, tube back in. (At one point didn't want to be visited - it would be too upsetting - but recovered a bit) That night two days after the op, very much under pain relief morphine based.

Two days later I was told to have a shower, still doubled up, still with tubes, managed to soak the floor and flood part of the ward. Seemed very soon but I wanted to be game and a good patient. More

tubes were taken out; then my temperature began to soar. Various antibiotics were tried. Painkillers were changed to codeine, too soon, still remember painful days, and after a few surreptitious aspirins, asked for more pain relief, and was given stronger pills. Still feeling quite confident that things were going OK. Managed to work my ileostomy appliance independently and was not particularly bothered by it. It was, after all to be temporary! Sent home after a fortnight, initial elation, then more pain, couldn't eat or drink, ambulance back, dehydrated. Temperature soaring again, strong antibiotics, then pains in legs and in chest, tests showed blood clots, deep venal thrombosis in the leg - worst was in chest - pulmonary embolism. When x ray showed this, just for a second, the three nurses round my bed, took a slight step backwards. "This, I thought, must be serious!" And it came to me that I was not really prepared nor ready to die just yet. Things to do, wanted to see my family grow up, there were things I still wanted to do etc. Surgeon visited and assured me that they had got to it in time. Put on anti-coagulants, given white stockings, time also stretched. Sent home again, two days later pain, rushed back in - remember every joint jolted over by the ambulance on the Kingston Bridge. Long wait before being given any pain relief. On duty doctors were all seemingly treating drunks in accident and emergency. Friends who had followed ambulance somewhat angry. Infection discovered in wound, large bit eventually opened up; once it was lanced there was much relief. Surgeon attempted to lance it with scissors before it was ready, remarked "You look worried." Replied that worry seemed to me a perfectly logical thing to be feeling. Last time I was sent home I was a bit fearful. I had become quite institutionalised. Felt that things were still going to go wrong and I was safer in the hospital. Three weeks after I was eventually home, a swelling in the ankle, back in for a weekend, it was almost like going home. A strange change had happened to my attitude.

One or two people I knew who were asked to consider a similar operation told the surgeon they knew me. He was hesitant about advising them to speak to me. Some of them did. My message of comfort to them was and is "Even if everything which can go wrong does go wrong, you can still survive." The expected things were fine, but I was very aware of how complicated and fragile the human body is. It gave me a view of life as shorter. One or two things I had thought about doing but never got round to, I did fairly soon, e.g. I persuaded someone to share with me and buy a small yacht. What part did chaplaincy play? I saw the chaplain on a few occasions, a friend, that was

good. I saw a lay visitor a couple of times and learned to keep my hands out of his reach - after inappropriate squeezing of a very sore hand while saying what seemed like a longer than necessary prayer! I was made aware of the ridiculous and dangerous hours worked by junior doctors. One tried five times to find a vein one night before admitting defeat and apologising that he could hardly see straight. Oddly, I felt sorry for him, instead of being angry at an inadequate and unsafe system.

After six months the ileostomy was reversed, but unfortunately the operation was not a success. After five years I was living again on steroids and suffering their side effects. (How can you have colitis without a colon ?) Ileostomised again and I have come to accept it as better than the alternative!

I'm not sure what I've learned from the experience. Wisdom - probably not! Empathy undoubtedly a bit for those with chronic illness. Experience of the fragility of the body and also at times of the mind when we become to depend on and in an institution. I got to know the Health Service at the sharp end including endless uncomfortable tests after waiting in many corridors. It's not a family condition, I don't believe in fate, nor do I blame God. Occasionally I feel justified in being a little cheesed off, usually I don't think about it, and sometimes there is even a little satisfaction at managing to ski, and sail, and jog and swim and such like which I do more now than I ever did before.

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