

UROSTOMY
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50 years with
a urostomy

Living with a urostomy for 50 years

An account by Eileen Spraggon, a member of UA since 1973, and a former member of the NEC as our Stoma Care advisor.



The majority of urostomy surgery is performed for malignant conditions and therefore life threatening. Continence

problems although socially debilitating are not normally life threatening but my bladder dysfunction was. Urostomy surgery saved my life. My mother told me that my problems started when I was about 5 years old and was labelled as probably being lazy but would grow out of it! When I was seven I remember starting to get pains in my back around the kidney area but the GP treated me for slow appendix and constipation! At the age of nine I passed a large clot of blood in my urine and my mother took me to a new GP, who after feeling a lump in my abdomen referred me to a local General Surgeon. My abdomen was opened and an abscess

was discovered inside a diverticulum (hernia) in my bladder. In those days visiting was very strict and you had to be a patient for one month before even your parents were allowed to visit! Two weeks after my operation the ward sister was off duty and the staff nurse allowed my father in for a few minutes as I was in a side ward of my own. Years later my mother told me that it was the first time she had seen my father cry, after he had seen me. It was ironic as there was a balcony at the end of the main ward and when I was well enough I used to lean over the balcony with the other children and wave to my family in the road outside. Such stupid rules! My father was a tenor in the local amateur dramatic society and I was allowed out of hospital to see him in the lead role in Rose Marie. The lack of bladder control continued and a few boys at school were not very kind with their verbal bullying! I denied my problem so many times – no continence pads in those days!

Kidney removed

Despite having quite a lot of time off school with urine infections I managed to pass the 11 plus to go to grammar school. The uniform was a maroon tunic and unfortunately mine soon developed an obvious faded patch. I had further bladder surgery when I was 13 and again at 15, plus numerous bladder inspections (cystoscopies), and following my hospital experiences my ambition was to become a nurse. I joined St John Nursing cadets when I was 10 and met a lifelong friend with whom I continued on to grammar school and then nurse training. My surgeon at the time said I could apply for nursing training as long as it was locally. By the time I was 20 the incomplete bladder emptying had destroyed my left kidney and it contained a large stone (a staghorn calculus). My friend was on duty in theatre at that time and she fainted when the surgeon said he had to remove the kidney. I was supposed to be her bridesmaid 6 weeks after this! Unfortunately 3 days later I had to have another major operation on my bladder and I ended up with a large rubber suprapubic catheter draining my bladder for 6 months. This was attached to a rubber drainage bag (similar to a hot water bottle) and attached to my leg. At night it was fed into a large glass bottle! There were no disposable appliances at that time. My spirits were lifted when the bridal party arrived on the ward! I also spent my 21st birthday in hospital but the ward staff were brilliant and gave me a lovely party which went on all day!



I had remarked that the best birthday present would be a new bladder. The staff presented me with the inside (the bladder) of an old style football! One day I was so bored and fed up with being in hospital a staff nurse suggested she take me for a ride in her new car when she had the afternoon off. A colleague loaned me her navy gabardine mac which was nurse uniform at the time. We went down the back stairs but unfortunately were spotted by a ward sister from another ward. She reported the incident to Matron and the staff nurse was reprimanded. However when Matron did her daily round the next day she remarked that I looked better with my rosy cheeks from the fresh air!

No stoma care nurses

I managed to finish my nursing training but because of my sick leave did not qualify with my peer group. My remaining kidney was deteriorating so I requested another opinion at a urology unit 50 miles away in Newcastle. After several unsuccessful operations the surgeon said he could give me an ileal bladder (urostomy). My grandmother had a colostomy before she died and I had nursed

patients with ileostomies and colostomies but I had never heard of a urostomy, because in 1964 it was still a fairly new operation. However, I was desperate to save my remaining kidney and return to nursing. The preoperative care at that time included twice daily bowel washouts, enemas, low residue diet and antibiotics for 5 days prior to surgery. How things have changed, when patients today are usually admitted the day of surgery and no bowel prep! My recovery was delayed by some complications which included pneumonia. My stoma care was overseen by the local appliance company as there were no stoma care nurses at that time. The appliance was a rubber bag similar to the leg bag and with a rubber flange. These had to be sterilised with a Milton solution and reused. Friars Balsam was a skin protector and there was Zoff, an adhesive remover, which was quite harsh on the skin. After 6 weeks I was allowed home for the hospital prize giving, and I had won 5 of the 7 prizes including nurse of the year so I could not miss that! Two months later I had to have another major operation for the removal of my bladder as it kept filling up with pus.

I returned to work and applied to train as a midwife, but when I returned for my post-operative checks the surgeon asked me if I would like to work with him so I could talk to patients about to have a urostomy. I had a few admissions to hospital again with complications and one admission coincided with my interview date. I arrived at Matron's office in my dressing gown! So less than a year from my surgery I arrived on the urology unit to take up a staff nurse post on the ward where I had been a patient. It was really interesting – kidney transplants patients were

nursed on that ward and we had a dialysis machine. I arranged to see urostomy patients in the urology clinic to give advice. Later a general surgeon asked if I would hold a community stoma clinic to also see patients with bowel stomas.

New support group

I had joined the ileal bladder section of the Ileostomy Association but realised that a urinary stoma was entirely different to a bowel stoma. I asked permission to go through admission books and gradually built up a portfolio of patients who had had a urostomy operation. I arranged a meeting and this was chaired by Professor Swinney, my Consultant. 150 people turned up including patients, parents with children who had a urostomy and district nurses. We met once a year initially but some of us met informally throughout the year. I was a busy ward sister at the time and on my days off drove 50 miles to see my parents and 4 brothers. I also liaised with stoma equipment manufacturers to try and improve appliances. By late 1971 the Urinary Conduit Association was formed in Manchester. Founder members Valerie Kings and Marjorie Birtles travelled to Newcastle to meet up with me to share ideas, and the Newcastle group joined the Association in 1973.

In 1971 I met my future husband, Neville and we married in 1972. By this time there were several disposable stoma appliances which were not so bulky so I walked down the aisle with confidence! I continued to work as a ward sister for a while and run the stoma clinic but also helped in the family hotel. Because I didn't have a hysterectomy when my bladder was removed I was able to conceive, and I left work in 1975 to await the arrival of our first baby. I





was monitored very closely during the pregnancy as the obstetricians did not have much experience in caring for a pregnant lady who had had her bladder removed and also had a single kidney. The stoma did not cause too much of a problem as I only had to adjust the baseplate aperture as my abdomen expanded. I was told I had made history when they used a drug to induce the birth which they had not used for that purpose before, and our healthy son, Mark was born in April. I took a break from nursing and in 1977 our second precious son, Andrew was born, but unfortunately, 3 weeks after he was born I had a massive haemorrhage and was very ill so we decided against trying for a daughter!

International conferences

I returned to nursing in 1981 and worked on the renal and urology units. By 1990 the stoma care sister who had taken over from me when I was pregnant announced that she was leaving and I reapplied for the post. I was successful and worked as a specialist stoma care nurse full time until 2002.

In 1992 my urostomy was causing problems so I had a complete new one fashioned to prevent my remaining kidney from deteriorating further. I felt privileged that I was able

to empathise with patients facing investigations and urostomy surgery, because of my own experiences. If appropriate I told some patients that I had a urostomy and it did relieve some anxiety when they saw me leading a very busy life. During the time I worked on the urology unit I presented several papers relating to urostomy surgery, bladder dysfunction and bladder cancer, at conferences for the World Council for Enterostomal Therapists. These included conferences in Jerusalem, Brighton, Singapore, Florence, Hong Kong and Munich. At the branch AGM committee members had worked secretly, without my knowledge to produce a presentation called "This is your life". I was totally surprised and was even presented with the red book! Most of my family appeared and the committee had even got in touch with some dear friends in Florida and Dr Desai and his wife flew over just for the occasion. Unfortunately just after my retirement from full time work my husband was diagnosed with cancer and only survived for two years, and I continued to work two days a week until 2007. I have never been bored since retiring as UA work has always kept me busy. Having been a member of the NEC as a Members' representative and subsequently Stoma Care Liaison, I resigned from the NEC at the NAGM in 2011. However I remain Secretary of the Newcastle Branch.

Unfortunately in 2012 I was diagnosed with cancer and had major surgery followed by radiotherapy. The day I was discharged my mother was taken into hospital and died two days later. She was 94 but although her mobility was poor she had all her faculties – only the previous year I had taken her to Spain to see my brother. It was her 10th visit!

Although I was very sad it was a relief as she would only have worried about my health problems. I was just beginning to feel stronger when I was admitted with a bowel obstruction in February 2013.

I had four operations in one session and was taken to Critical Care. The following week I had to be opened up again as I developed peritonitis and an abdominal abscess and two perforations in the bowel – another spell in Critical Care and four and a half months in hospital. I was starting to regain my strength when I developed another bowel obstruction. The radiotherapy had destroyed my bowel and multiple abdominal operations had caused severe adhesions. The only option was to perform a transverse colostomy so now I had another stoma to look after, and I managed to get home two days before Christmas. Again I was starting to regain my strength and independence when I fell and fractured my hip! I walked on it for 2 weeks thinking that it was a muscular problem! As it is impacted it is slowly healing without surgery but it was very frustrating. I also have to start some treatment soon for nodes in my lungs.

I cannot believe that it is 50 years since my original urostomy operation. Where does time go? I certainly know that urostomy surgery has enabled me to have such a fulfilling, active and happy life, and I shall be eternally grateful to the NHS and for the expertise of the surgeons. My family are all very supportive and of course I have many friends in UA. My lovely granddaughter is now 6 years old and my younger son and wife are expecting their first baby in October. I have many reasons to get fit again and joyous occasions to look forward to!