

A Partner's Perspective

Anita Mullen

The journey from diagnosis to surgery and further surgery is often one involving a surreal series of events not only for the individual concerned but also for those closest to them.

My husband, Pat, developed UC-related dysplasia 5 years ago just prior to our getting married. He underwent a planned colectomy with end-ileostomy 3 years ago and a completion proctectomy earlier this year. Between the colectomy and proctectomy he had 2 groin hernia operations, developed adult-onset type 1 diabetes and gave considerable thought to the option of J-pouch surgery. The medical professionals we consulted, the literature searches we performed, the journal articles we critiqued, the patient information events we partook in, the YouTube videos we digested, the pelvic anatomy we revised, the stage production ('Gutted') we watched and the many health-related discussions we had as a couple at the breakfast table, on walks, after long and tiring shifts at work all had an impact on both myself and Pat as a couple and as individuals. We attended 2 national pouch information days but found that it was only the St Marks Red Lion event that held a workshop for 'family and friends'.

The question I asked myself on many occasions was 'In what way can I help Pat?' The answer may seem obvious: 'Support him'. But what does 'support' consist of? I knew it didn't involve telling him what to do or deliberately influencing his decisions to achieve the outcome which I believed to be

best. A lot of the time, it involved respecting and accepting Pat's view. Occasionally, there was unintentional pressure from Pat to tell him what I would do if I were in his shoes. Sometimes it seemed most appropriate to keep my thoughts to myself or to sit on the fence and refrain from giving an opinion but at other times, it was constructive to challenge his perspective. A healthy debate to consider multiple approaches to a problem would remain our priority. My mantra of 'It's your body and it's your life, you must do what's right for you' was, at times, met with exasperation from Pat. Once (perhaps reflecting his own frustrations about the situation) he told me that I didn't support him in the way that he wanted me to. I feel I did my best.

The post-operative phase, which for me largely comprised of brewing cups of tea, trips to the pharmacy for analgesia, antibiotics or sanitary towels (!) and checking Pat's wounds were activities that didn't involve emotion or require patience and were therefore relatively easy to perform. Even Pat's irritability secondary to post-operative pain or lack of sleep or inability to care for himself was tolerable albeit upsetting during the moment. It was the processing of vast volumes of information leading up to surgery and managing the sense of feeling overwhelmed by it all whilst attempting to work out how best to support Pat and then supporting him, that I found most difficult. Of course, I was saddened to witness Pat having to experience and manage the many issues associated with his health - the worry, the indecision, the anticipation, the

postoperative complications. None of it was pleasant for him. None of it was pleasant for me either. Occasionally I felt suffocated by his health issues and at its peak, it seemed like our life was being consumed by them. Would the dynamics of our relationship facilitate or hinder our ability to traverse this chapter of our married life? Would our marriage survive this ambush? And what about our individual lives? Was it selfish to have occasionally thought that I didn't want my life to revolve around Pat's bowel? It was not uncommon for me to experience huge pangs of guilt for having these thoughts; I was conscious of my marriage vows 'In sickness and in health' and as his wife I wanted to look after Pat as best I could. But I placed great emphasis on doing things well and when things didn't go well, I'd

get upset with myself and with the situation I found myself in. This behaviour was of course, unproductive. So, what helped me overcome these thoughts and feelings? Patience, compassion and love not only for Pat but for myself also. Looking after myself enabled me to better look after Pat. Talking openly to each other about our needs and fears also helped. I am immensely proud of Pat because of the fortitude he has demonstrated in the past 5 years. I am equally proud of my own fortitude.

As a partner of someone who has undergone life-changing surgery my advice to others in a similar situation is to share your thoughts with one another. If you can't, consider sharing them with someone else who you feel will be able to support you.



Anita and Patrick.