

## **Nothing up my sleeve. An untold personal story.**

It was nineteen months from diagnosis to his death. Poorly differentiated adenocarcinoma of the oesophagus. The diagnosis was confirmed on the 6<sup>th</sup> April, his 50<sup>th</sup> birthday. He was the eldest of six and a father of three teenage girls. This was not a patient this was my brother. Working in palliative care for twenty years I knew that at some stage my family would experience the loss that the families we care for experience. Not for a moment did I ever contemplate it would be a sibling we would be caring for, I presumed the natural order of things would follow and it would be a parent that would need the care.

The implication of his diagnosis was evident to me but not to him or the rest of the family. My challenge was to stay in the moment and not jump forward to what I already knew was the inevitable outcome. I struggled to sound calm and confident on the phone and was grateful that he couldn't see my face. I explained to him what the next steps would be and told him I would assist him to navigate the healthcare system if that was what he wanted. He gratefully accepted and this reassured everyone. It also helped me have a sense of control and would be my way of "doing something". I wanted his journey to be as comfortable as it could be.

His treatment was planned with curative intent, which he tolerated well; chemo followed by surgery. He maintained his sense of humour but struggled at times being away from his family during his hospital admission. He looked well, maintained his weight and continued to work full time. Life went on as normal. I could feel my anxiety levels rise when he was due for his 3/12 bloods and scans; the threat of disease recurrence always in the background. I would see his oncologist in the corridors and he would reassure me following

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his appointments, bloods good and no evidence of disease on his scans. A sigh of relief and back to relative normality until his next appointment.

There is something to be said about knowing too much.

Sixteen months after his diagnosis he remained well. We were attending the funeral of a father of childhood friends. I was distracted when looking at my brother, wondering what was going through his mind. Did he have a heightened sense of his own mortality? Was he thinking we would be attending his funeral? There was something not quite right with him, his colour was pale and he looked uncomfortable. When I enquired he told me he had been having spasmodic abdominal pain for the last few days. I felt like I wanted to run away. He had an appointment with his GP the following day. I was thinking bowel obstruction and wanted him to return to where he had his first treatment. He wanted to stay near home so it was easier for family. No amount of persuading made him change his mind.

After two presentations to ED he was finally admitted with a bowel obstruction. I felt a loss of control and was distressed by the fact that it took two trips to ED before he was admitted. With his history I would have thought a bowel obstruction would be something that should have been excluded after the first presentation. He had surgery after waiting unsuccessfully for the obstruction to resolve. The surgical team reassured him they had "got it all" and he had nothing to worry about. I asked my brother to tell me exactly what the doctors had told him and he repeated "I have nothing to worry about". In my mind I was thinking you have everything to worry about, as this was the recurrence I had been dreading. After asking the surgical team for the pathology results he was advised to see his oncologist for further explanation.

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He attended his appointment with his oncologist with some trepidation to discuss the pathology results following surgery. He was given a prognosis of three months to three years with another trial of chemo but had to wait six weeks post op for that to commence. During this time my hat changed from nurse to sister.... sometimes hysterical. He said 'by the way the doctor said your suggestion would kill me'. 'Sorry' I apologised 'I gave that suggestion on a day I was being your hysterical sister and I wanted someone to pull a rabbit out of a hat for you'. He smiled and replied 'nothing up my sleeve' (I had suggested a peritonectomy; something I would never advocate for my patients at this stage of disease).

Within a month he was hospitalised again with another bowel obstruction. I knew at this point that his time was limited and prepared my parents and siblings for further deterioration. My father asked if I thought he would see his next birthday, I had to explain to him he would most likely not see Christmas. They could not manage his obstruction medically and I was strongly advocating a referral to the palliative care service. They decided on another attempt to surgically resolve the obstruction. It was 'open and close': he presented with diffuse disease that had progressed in six weeks. The distress was palpable not only amongst family but also within the surgical team. A referral was finally made to the palliative care service.

There were significant family events occurring which my brother needed to be home for. His eldest daughter was graduating from Year 12, his middle daughter had her Year 10 formal, his youngest daughter a birthday and a sibling celebrating a 50<sup>th</sup> birthday. At a family

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meeting with the palliative care registrar where all cards were laid on the table, discharge plans were organised. He wanted to die at home.

It was a time of intense raw emotion, laughter, courage, strength and much love. There were precious moments no words - just a look, a touch, just being present. I feel both privileged and blessed to have been a part of fulfilling my brother's wish to die at home. This experience has given me more empathy and a greater insight into seemingly incongruous decisions some patients and families make on their journey. It is not denial. They just want someone to pull a rabbit out of a hat.

Communication and a coordinated approach to care between teams does not change the inevitable but does make a difference to the patient journey.