

The 'Other Side'.

In September 2018 I suddenly found myself on 'the other side' of palliative care.

My sister called to let me know that the 'gallstones'/'kidney stones' was actually bowel cancer with liver and lung mets. She also appeared to develop Tourette's syndrome during our conversation. "It's not curative" she informed me. But with my experience of working in palliative care for over eight years I sort of knew that already.

It was hard trying to listen to her explain the treatment options without saying to her 'but it's just a matter of time, sis'. My head went into overdrive. The mets were causing the pain, not the bowel cancer. Was she constipated? Had she thought about quality of life? She was always the 'pathetic one' who couldn't watch Casualty with me or stand to have injections. She could never have worked in the health sector like me. For goodness sake she'd only got her ears pierced the once because it hurt.

My heart was in my boots and tears were flowing down my cheeks, but you can't see down phones can you? I stayed calm and agreed with her that life is cruel and hers will be probably shorter than mine. But hey – any of us could be run over by a bus or drop down dead at any time. Oddly that scenario didn't help.

The plan following her oncology appt was to have some chemotherapy at the Hospital that had diagnosed the cancer. She could have gone to a Cancer Care Specialist Centre in the neighbouring city as that was actually her catchment hospital. I talked to her – probably as a professional – about how this is a great unit and they do all sorts of wonderful stuff. As a sister I thought, "you have to go for the best because I don't want you to die just yet". However, her trust was in the diagnosing unit so I respected this and shut up.

I tried really hard over the next few months to be her sister and not let my knowledge and experience intervene. It is so, so hard. Every time she tried a new drug or some other options were mentioned I would talk to a nurse (who bless her is now my personal advisor in all aspects of this journey) and even the Dr's about what this meant. Is too much information a good or bad thing? It's really hard to say. My sister will say it's a good thing because as time went on she'd say what is this medicine for? Should I claim a PIP? I encouraged her to ask for a DS1500 as she isn't curative, however as she works for the DWP she knew what this was and refused.

Having only mentioned it once, she made a will, checked out her life insurance and did basic advance planning. I can't believe I'd let her get away with not already having a will!!!

She cancelled her holidays abroad and we made plans for Christmas shopping in this country in 2019 instead of Germany. Will probably be warmer here.

Work seemed to get a bit better in that for every 'young' person or person with 'bowel cancer' discussed I did not immediately think of my sister. When working with carers I think I had more empathy and understanding and although it was difficult working with two sisters of a patient I really felt that I was a better palliative care social worker as I knew exactly what they were going through. Do we need personal experiences to make us a better worker? Well, maybe not. However, I feel I have matured and grown in my skills and practice by living through my own personal story.

With the chemo not working, a referral for a trial at Manchester became an option. For me as a chemo buddy now and again (It's a 5 hour round trip to see her) I was immediately thinking 'Ooo,

Trafford Centre shops and chemo overnighner'. My sis also thought this was a good idea. I have worked with patients on trials and have to say that most have prolonged life and given a fair quality of life. I was expecting positive outcomes and think I was more disappointed than my sister when after half the trial they discharged her as it wasn't working. On a more positive side, the money she got, paid for her Silverstone trip to watch the F1!

We are now back to the diagnosing hospital for more chemo but know that it isn't the best thing really. My sister has become a little *laissez faire* and says what will be will be. I think I'm living on a day to day basis as I get up at 6.15am every day to check my phone in case she's ill, in hospital or something worse. If I told her this she'd say I was barmy. I struggle to sleep the night before her oncology appointments and I walk around with my mobile waiting for her to text or call with the outcome. Is this normal? Not sure; but I feel it has heightened my awareness of what families and carers are going through which in turn has improved my role as palliative care social worker. I now make sure I check with families how they are feeling about appt's and tests; not just the patient.

I know that it is now a matter of time and that time is probably short. My dad just says 'well, they have to keep offering her chemo because there's nothing else. What else can they do?' I really don't have the heart to say to him that it will stop at some point. Neither does my sister. When I now work with families who are not sharing information with others or in 'denial' I will think twice about what I advise as I have a better understanding behind their reasoning.

My sister is a fighter but will not compromise her quality of life. My struggle now is that my professional head is saying that she needs to think about her funeral and also perhaps accept a Macmillan Nurse and a bit of Complementary Therapy. But how can I say to my best friend and big sis 'What songs do you want played at your funeral?' I'm hoping it's Duran Duran or Frankie goes to Hollywood. They bring back so many happy memories of when she used to take me clubbing (under age). Maybe if I encourage her to have a Macmillan Nurse then the nurse will do all that.

So why am I writing this? It's helping me realise that there are fine lines between work and home. That sometimes you have to remove yourself from certain areas at work. My employers have been amazing at supporting me. It's also to share my experiences of how I have developed and increased my awareness and empathy in the field of palliative care. I have grown through this experience and I would like to say matured as a social worker but my sister would fall about laughing at the thought that I am mature. (Always the rebel living on the edge).

I don't want people to read this and think 'how sad'. I want people to read this and be inspired. As I said earlier, you do not have to have had a personal experience to be a good social worker. All I'm saying is that my experiences have made me a better one. Our personal experiences can inform and expand our professional life, but it's not just experiencing stuff that makes us grow, it's how we interpret and deal with those experiences