The Empty Chair

It is the day after Christmas in Australia—a Saturday. People are waking up to a day of eating leftovers and watching test cricket. In our rural town, patients are getting up to take their spot in the six-chair dialysis unit, eagerly looking forward to talking about their Christmas day. One patient is late, which is very unusual for him. The nurses call his home, only to be informed that he had passed away overnight. Next came the step that the nurses dreaded the most—letting the other patients know that today, there would be an empty chair. Just three days prior, this chair had been occupied by a husband, father, grandfather, university lecturer, car enthusiast, and perhaps most importantly, a dear friend.

Following my own diagnosis with chronic kidney disease (CKD) and the commencement of peritoneal dialysis seven years ago, I have visited the local dialysis unit once a week to take flowers and to talk to the patients and staff. I started this as I felt isolated at home, knowing no one else who was on dialysis at the time. Over time, we have formed deep bonds, connected by sharing similar, but at times very different journeys. We celebrate together when someone receives a transplant, we attend funerals together when one of us dies, we have lunches together, or merely a chat over a cup of tea, spending time talking about our fears and hopes. There is a sense of understanding, camaraderie amongst those of us receiving dialysis, a knowing without verbalizing how we are going. I have kept these visits up after my transplant, knowing that one day I too may need one of the chairs. Sometimes I think it would be easier not to develop friendships with those in the unit, to avoid the pain when we lose someone, but for me it is essential to my growth and learning on my journey with CKD, to support and be supported by people who understand. It is always so hard to go into the unit after one of my friends has died, the empty chair ever present and no matter where you are in our small unit, the emptiness is seen and felt.

Seven years have gone by since I commenced dialysis. Since then, I have been to eight funerals of close friends with kidney disease, each from a different walk of life, of all ages, and each at a different stage of the disease continuum. Each has left behind an empty chair, be it in a dialysis unit, at a table in a family home, or a desk at work. There are no words to describe the grief of those who are left behind to deal with the loss of their loved one. Nothing could have prepared me for the grief that I would feel for people who I did not even know prior to starting dialysis, my “kidney family.”

I have dealt with death in many forms in my own family, including the recent death of my older brother from bowel cancer and my mother from breast cancer. My experiences with both of those deaths were very difficult. However, the numerous palliative and support services available to me helped me cope with difficult times. This is in stark contrast to my experience with close friends dying from kidney disease, where we have limited assistance offered, and it’s usually the nursing staff or social worker who provide some support, both of whom have been deeply affected by each patient’s death too. Professional psychological support was either offered to the staff of the dialysis unit, nor to fellow patients. This has been particularly difficult for those of us in rural or remote locations, where we do not have ready availability of psychologists attached to our renal services.

I consider myself one of the lucky ones. I am now the proud owner of an amazing living donor kidney, but I am still at a significantly higher risk of death than my non–kidney disease counterparts. Despite the fact that kidney disease is fraught with death, loss, and poor outcomes, this area lags behind other areas of medicine, such as oncology, in providing psychological support to patients, families, and staff. We need to increase the provision of psychological support in nephrology and urgently need research to support patients’ ability to cope. Mortality rates are discussed at great length, however, grief is not. We need to encourage the doctors and nurses looking after us to talk about the illness experience of kidney disease and its effect on our "kidney families."

We need to talk about the empty chair.

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