

Vignette

A Christmas Dialysis Vignette

Every Christmas, a card with a touchingly wry message from the patient arrives, reminding me of a 'near miss'.

A few months before he retired my senior colleague, who had looked after her and her father, introduced her to me hinting that a very careful approach would be needed.

She has adult polycystic kidney disease. Problems had started early—at the age of 21 she had developed a left renal abscess, which had been drained. She was an only child and had seen her father reach end-stage renal failure at the age of 52, be established on home haemodialysis for 2 years before having a transplant. He died at the age of 61. She had been well for 15 years after the abscess drainage, but then developed haematuria, loin pain and renal impairment. End-stage renal failure was approaching in 1995—she was 41. She had dreaded this for 20 years.

At our first meeting she told me that she would not be entering the renal replacement programme preferring a short high quality life to the prolonged misery, as she saw it, of dialysis. She had deep and unresolved reservations about renal transplantation and immunosuppression. She was a professional woman, with a demanding job and irregular hours but made up for it with a full social life and love of food and wine. She was surprised that I did not argue. I had been warned that this was her fixed decision. I told her that I respected it but did not really believe she would stick to it. She was adamant that she would.

"Even the most determined patients change their minds when the time comes."

"I won't."

"They all say that."

"I will be the exception."

"They say that too."

Impasse, but it did not yet matter. This was the first mistake—she was a lawyer and liked to win arguments.

Three weeks later it did. She had been admitted to a local private hospital with another cyst haemorrhage, uraemia and pain. Her GP requested transfer to the renal unit. I suggested local palliative care, as transfer to a dialysis facility seemed inappropriate. This was the second mistake—to leave her there would lose us the opportunity of changing her mind. There were several phone calls before transfer was arranged when it was argued that the private hospital did not have the expertise to manage terminal renal failure.

She requested dialysis and expressed amazement that I was neither surprised nor censorious. "I was at least expecting you to say, 'I told you so'."

She had a bilateral nephrectomy and started treatment. My feeling of vindication was premature.

She was an angry and unhappy haemodialysis patient, did not feel well, found the disciplines intolerable and resented scolding about phosphates and weight gains. The possibility of a transplant from her elderly mother was explored. This was the third mistake as the chances of her being fit were very small. She was not a suitable donor. There was more disappointment and resentment at less than perfect communication on our part.

She decided to stop dialysis. I begged her not to. She was impervious. In desperation I phoned my retired colleague who was himself facing death from cancer. He spoke to her at length and eventually persuaded her to continue. After missing a few dialyses she returned grudgingly to the dialysis unit for treatment. She explored switching to another unit for her transplant and asked to come off our cadaver list.

An excellent matched kidney came up. Luckily somebody ignored her 'suspended' status. She was phoned by the duty nephrologist and asked whether she would consider accepting it. She did and it has worked perfectly. She is back at work, full-time, off steroids and looks wonderful. While admitting charmingly that she was wrong she told me politely but pointedly of our lack of understanding of her views and the two-way breakdown in communication. The positions she had adopted were not fixed but pleas to engage her fears and anger at her disease.

I have often reflected how close we were to losing this precious and productive person and wondered how common a problem this is. I at least have learned that it is better to 'lose' the argument than the patient. The Christmas card says, 'Thank you for another year'.

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