EDITOR'S CHOICE

The brilliance but horrendousness of dialysis

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"There was death at its beginning as there would be death again at its end." So begins Nicholas Evans's bestselling novel, *The Horse Whisperer*. Evans could be forgiven for wondering whether his own death was on the cards in the days after he and his wife ate some deadly mushrooms four years ago. "We had black diarrhoea and nausea and retched every few minutes until all that came was blood and bile," he tells us in his Patient's Journey article (doi:10.1136/bmj.e5262). Their renal function almost completely disappeared, and they were saved by haemodialysis and ultimately renal transplantation.

It's a great read with a happy ending for Evans and his wife, but that's not enough to earn its place in the journal. What it provides is a striking account of "how physically and mentally overwhelming his 'crash land' on to dialysis was, going from health to organ failure in a matter of days," in his medical team's description. It's also an account of the wretchedness of dialysis and the ultimate deliverance that a donor kidney brought (in Evans's case from his daughter). He recently discovered that six friends from his dialysis unit had died in the preceding year. He says the average life expectancy on dialysis is five to eight years, "and as I now know, being on dialysis isn't really a life. It's not even half a life."

In her very different patient journey, Renata Carey provides another view of dialysis, although Evans would endorse her summary judgment: "dialysis is brilliant, of course, but deeply horrendous" (doi:10.1136/bmj.e4492). He would recognise "the first world war scenario" on the dialysis unit: "patients suddenly

appear with amputations; and very often with heavily bandaged feet, rapidly followed by crutches and then wheelchairs."

Older than Evans, and with multiple pathologies, Carey experienced the slow decline of renal function that should have meant she was better prepared for each new phase. Yet each one came as an unwelcome shock. Discussions about possible donation from her children—Evans's salvation—left her angry:

"I gave birth to my children; I nurtured them; I tried with all that is in me to let them have fulfilled and happy lives. They might need kidneys for their own children; for their wives or husbands; they might have accidents that destroy their kidneys."

Carey seems supersensitive to the attitudes of the healthcare staff around her, and documents how they could come across as more caring. The fairness of her comments is not really the point: it's how she felt. As the chief executive of Macmillan Cancer Support says in another context, hospitals need to give patient experience and non-clinical needs as much priority as medical activities, because patient experience is as vital as treatment to quality of life (doi:10.1136/bmj.e5864).

The dialysis machine is, as Carey asserts "a fantastic invention." But patients' experience of dialysis goes far beyond a piece of kit that works as intended. In that respect, dialysis could serve as a metaphor for many of medicine's high tech interventions.

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