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A PATIENT'S JOURNEY

Kidney dialysis—the need for humanity

Renata Carey provides a patient's perspective on chronic kidney disease, being considered for transplantation and starting dialysis

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

From my perspective as a patient, dialysis can appear to lack imagination and kindness. My kidney failure was diagnosed in 2005. At that time, I was on another journey, one of indescribable and agonising sadness. My husband was dying. For many months I cancelled appointments. Eventually I went, not because of any symptoms but because I thought it best to find out what I should do. I was 74 and was referred to the low clearance clinic.

This was a kind and decent set-up with excellent nurses monitoring the gradual deterioration of people's kidneys. Dialysis was never mentioned. Some time later came the first appointment with the consultant. Now a transplant was proposed: I was put on the transplant list. I started attending the low clearance clinic in 2007, and at the end of 2009 the superb consultant said that dialysis must now begin.

So dialysis began in January 2010. It was particularly unfortunate that the first thing I passed on my way to the new dialysis unit was the mortuary: a sad low brick building with lots of little windows—maybe for the corpses to breathe better. Then followed a tiring uphill climb to the unit. And when at last I got there, a closed door greeted me. "Any chance of you kindly opening it when you arrive at 6.30 am?" I asked one of the nurses.

"We change into our uniforms, we've got all the machines to get ready, we've . . ." "But wait a moment," I pleaded politely. "It's freezing out here in the dark in the winter. We would only go into the warm waiting room—obviously not into the machine rooms until we're allowed. We'd just sit there warmly till everything was ready." End of conversation. And how I did hate having to suggest an idea to "someone higher up."

Other things were much more complicated to suggest or complain about. Kindness, thought, imagination—all these should have been the order of the day. But those depended on the personalities of the nurses and doctors involved. The kidney consultants and nurses at the hospital before dialysis were mostly excellent. But the dialysis doctors were from a different world—both the consultants and the staff who rushed around keeping an eye on patients' blood results and general progress. Fantastic invention that the dialysis machine was, how hard it must have been for those doctors not to be in an active, positive, curing role—instead they were watching their patients, immobile and attached to machines for four or five hours, three times a week, patients who are hardly over the moon about that. Not quite true, that last bit: a GP had once told me that one of his patients who had at last received a transplant actually missed the jolly camaraderie of it all and the routine of coming for dialysis.

It is not a good idea to say to a patient, as the dialysis doctor said, "I'm being very honest. I mean, I'd never have put you on the transplant list: you're much too old—you would probably die on the table. People always think all be fine when they've got that kidney. But indeed not, masses can go wrong."

"Can you take me off the list?" I inquired gently. "Unfortunately not. But your consultant could." *My* consultant? Yes, he was, I supposed. It was at my last consultation that he'd said "I see you have two children." And I sensed what was coming. "You know live donors are far better than dead ones," he said, adding, "Can you ask them if they would give you a kidney?"

"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. Do you have children?"

"Yes I do."

"Then think!"

This conversation was not a good way to embark on a relationship—but by god I was shocked by his suggestion.

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And then there were the masses of other machine people. Vaguely, one said good mornings into the air on entering the waiting room. Apart from that, I probably conversed with only three patients, of different nationalities, all of whom gave me interesting lectures on the history and politics of their countries.

And now there is a new development: self care, which they try to foist on everyone. Ghastly for patients to have to think “dialysis” all the time and struggle with tricky technical procedures (“leave it to the professionals” we might prefer). And the end aim—to have our own machine at home. At home alone, within four walls and with a machine and bags.

There are other things that I could mention. Firstly, I feel we should be forewarned that eventually we stop passing urine; happily it hasn’t yet happened to me. But the idea is pretty horrid physically and psychologically. And secondly, what I call the first world war scenario. (The students I tutor one to one are often doing projects on this war: the terrible slaughter, the trenches.) Anyway, throughout dialysis, patients suddenly appear with amputations; and very often with heavily bandaged feet, rapidly followed by crutches and then wheelchairs.

To summarise: dialysis is brilliant, of course, but deeply horrendous. The people running it must be selected for heart and intelligence and imagination. Above all, they need heart and humanity.

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A doctor’s perspective

Renata was first referred to the renal clinic in 2005 with a previous history of a hemicolectomy for carcinoma of the bowel, type 2 diabetes, ischaemic heart disease, and deteriorating kidney function. She had been noted to have hypertension and abnormal kidney function in 2001, but these had been appropriately managed in the community and her care was transferred to me in the context of her renal function and proteinuria. The initial assessment was of a well woman with chronic kidney disease stage 3-4, presumably caused by her diabetes, hypertension, and atherosclerosis. It became apparent that she needed coronary artery bypass graft surgery. She had the surgery, successfully, and for the next two years she attended routine clinics where the focus was on treating her hypercholesterolaemia, hypertension, and monitoring of her renal impairment.

In 2006 Renata lost her husband, which deeply saddened her and she was very reluctant to contemplate dialysis and initially not keen to consider any active treatment. However, she began to explore the possibilities of transplantation and was assessed for this. In our practice at the time it was extremely unusual for a patient in her 70s with diabetes to be considered for transplantation because of the high risk associated with the procedure and the scarcity of deceased donor kidneys. However, her recent successful bypass surgery, which she had tolerated well, was very much in her favour, as was her remarkable level of fitness, enthusiasm, and engagement in the medical aspects of transplantation. There were no obvious live donors that she was willing to consider, and after a few additional tests, her name was added to the transplant list. However, as part of an agreed back-up plan, a forearm fistula was formed.

Over the next two years, without any offers of a deceased donor kidney, her renal function gradually and predictably declined, and towards the end of 2009, we felt that her symptoms of malaise and fatigue resulted from her renal failure, and she was urged to start haemodialysis three times a week. This started in January 2010.

Diabetes and hypertension are very common causes of chronic kidney disease and renal failure, and Renata’s history will be echoed by thousands of other patients with diabetes and renal impairment.

Mark Harber, renal consultant

Useful resources for patients and healthcare professionals

- British Kidney Patient Association (www.britishkidney-pa.co.uk)—A UK registered charity that gives information and advice for those with kidney disease, grants to help patients and families needing financial help with domestic costs, hospital travel, education, and holidays, and financial support to UK kidney units
- British Renal Society (www.britishrenal.org)—Promotes patient centred multiprofessional care for people with kidney failure and their families and carers; advances education about renal disease and replacement therapy in the UK; and helps fund multiprofessional research into kidney disease and management
- National Kidney Foundation (www.kidney.org)—A US voluntary, non-profit organisation dedicated to preventing kidney and urinary tract diseases, improving the health and wellbeing of individuals with kidney disease and of their families, and increasing availability of organs for transplantation
- Kidney Health Australia (www.kidney.org.au/)—A not for profit organisation focusing on improving kidney health and developing initiatives that reduce the incidence of kidney disease in Australia