End-stage renal failure - a long term condition

Malcolm, expert patient

MALCOLM

Unless you've actually been a dialysis patient, you might be a consultant, a nephrologist but if you've not been a dialysis patient you don't really know what it's like. I suppose it's like riding a bicycle. You can explain to people what it's like to ride a bicycle but if you haven't ridden a bicycle you just don't know what it's like.

The patient is supposed to be autonomous and is supposed to have some say over what happens. One should be knowledgeable about what goes on, and having had a medical course as part of my dental studies, then I do understand a bit more about what's going on than a lot of patients do. I look at my blood results and I know pretty well what they mean. But, nevertheless, I feel that I have to give way to the doctors and nurses, and let them get on with the job, and not tell them what to do, although sometimes I have to say well, you know, if you don't mind I'd rather you did it this way but not very often.

It is important to monitor what's going on with one's health, no matter what the condition is. I think also a lot of us professionals these days tend to get on the internet as soon as possible, and tend to check up what's going on, but I just think that's the way of life at the moment, I think that's the sort of responsibility we all have. Life is much more complicated these days, and one has to be aware of what one's treatment is. One shouldn't overdo it, of course, then one can get sort of paranoid but I think that is a responsibility of the individual to know what's going on with his treatment, and to keep a check on it.