

Patient B

Patient B is aged 40 years and lives with her husband of 12 years. They have no children. Since starting home haemodialysis she has been able to work part-time running children's workshops. Going out to work is very important to her quality of life. When hospital dialysis prevented her working, she felt her life was just about dialysis. She also enjoys long walks with her husband, socialising, going to the cinema and theatre, and playing the guitar.

She was on hospital haemodialysis for 15 years and had three failed kidney transplants before starting on home haemodialysis 5 years ago. She recalls the years of hospital haemodialysis with considerable negativity. She generally felt poorly and was often sick. Dialysing three days a week meant going from Friday to Monday without dialysis which left her feeling very ill on the Sunday and Monday. She had to completely 'write off' these two days. Most Sunday nights the nausea would reach a point where she felt she was going into kidney failure, being unable to breathe or see very well. Often she had to sleep sitting up which was very depressing. Monday's dialysis would result in cramp and nausea and she felt completely flattened. She did not recover till the Tuesday.

She first heard about home haemodialysis 8 years ago from her consultant. She was told it was a treatment option that would be gentler on her heart and so potentially offer her a longer life. There would be more of a gentle wave as opposed to massive peaks and troughs in her blood pressure, and uremic and creatinine levels. Her consultant also said the nausea, restless legs and fluid gain she suffered from should lessen.

She remembers very quickly deciding she would like to move to home haemodialysis. She felt overjoyed that after all the years of treatment there seemed a way of living life differently and with hope of longevity. She thought it might give her more freedom, and a bit more say in her treatment. What she calls 'hospital politics' was also important to her decision. She used to be given toast and a cup of tea, and then after a couple of hours on dialysis, crackers or maybe a sandwich. Then they

introduced new arrangements and she only got a cup of tea and a biscuit which she thought really poor since she was often in the hospital up to 6 hours. The hospital became more about rules and regulations than personal care, making her feel pushed into a corner as 'patient 4324' rather than a person.

However she had to wait a further 3 years to start home haemodialysis. Initially it was not available through her hospital trust and then when it was possible, her cottage was considered too small for a dialysis machine and all the stores. Therefore she and her husband moved to a slightly larger home specifically to be able to get a dialysis machine.

Although determined to go onto home haemodialysis, she worried how it might affect her marriage. Hospital haemodialysis was time consuming and restricting, but once she came home she was free and did not have to think about dialysis. She and her husband were able to go out many evenings. Knowing the dialysis was going to come home with the machine in the house, that her husband would have to watch her put needles in and be the one to give her saline, made her concerned about how he would handle the change and responsibility. However nurses at the hospital discussed what it would be like with both her and her husband, and the two of them had long conversations together. She also listened to his view that no matter what he would sooner have her at home than the horrible Sunday nights with a dreadfully poorly wife which he dreaded each week.

She thought the home haemodialysis training very good. It lasted about 7 or 8 weeks. She found it fairly easy since in the satellite unit where she was beforehand, she had lined her own machine and done a lot of self-care.

She is very pleased she moved to home haemodialysis. She now feels in control of her treatment. She has the 'say so' if she dialyses, when she dialyses, for how long, and how much fluid she takes off. Having choice and not being restricted by hospital rules is a hugely positive aspect. She does not have to get up early or hang around waiting for hospital transport. She has a more normal and everyday life. No where near as good as having a kidney, but the best of the treatments she has had.

Very importantly for her, she can now eat healthily including things like tomatoes, spinach and tofu which she could never do before. She particularly remembers having her first pasta meal with lots of tomatoes, chillies and mushrooms. Before would have a little taste, never a whole dish. It felt daunting and she thought she might have a heart attack. But no, it was fabulous. It was like being reintroduced to food again after the restrictive renal diet. She started cooking and became fascinated by all the food she had stopped eating, making lots of Thai and Chinese meals and her own soups.

To start with she dialysed 6 days a week, 2 hours a day. Her phosphate and potassium readings came down very quickly, her blood results became normal. She felt much better, did not have restless legs, ate more and was nutritionally better off. She was able to go out to work and she and her husband did more together. Then life became too busy not to dialyse and she has ended up doing 7 days a week.

Being on home haemodialysis has changed the relationship with her husband. On the positive side, she thinks he sees her less as a patient because she can go out to work, bring a bit of money into the home and talk about normal things. They spend more time together and she feels they are closer. If she is on the machine he will bring her tea, toast, a hot water bottle, whatever she likes and come to sit with her. They may watch a film together or go on the Internet. However, she is also aware of being more reliant on him for care and support. They both work during the day so their evenings are now dialysis. She ends up in her pyjamas and they become more carer/patient than husband/wife.

Another difficulty is she can sometimes feel quite isolated. On the unit she could just say to another patient, 'I'm having a bad day, how's your day?' She feels there should be some sort of home dialysis chat line. She can phone the home dialysis nurse, but it is not the same as talking with other patients, and the nurse only works part-time. She also thinks the technical support is not very good. She can only contact the technicians between 7.00am and 5.00pm. At other times she can phone the main hospital dialysis unit, but they are not always able to help. She feels she does not have enough back-up. Despite these difficulties she would never want to go back to hospital haemodialysis.