



## **End-stage renal failure - a long term condition**

*Malcolm's story*

### **MALCOLM**

My name is Malcolm Lawrence. I'm a dialysis patient. I've been on dialysis for four-and-a-half years. I'm on dialysis because both my kidneys failed. My first kidney had a benign tumour called an oncocytoma 17 years ago and had to be removed. The second kidney, over a period of 12 years, gradually failed which meant that at the end of those 17 years I really couldn't really exist without going on to dialysis. Dialysis is a way of filtering the blood externally, doing the things that the kidney should be doing, but isn't doing. If you've not been a dialysis patient you don't really know what it's like. There are plenty of other illnesses around but I can't think of anything where you have to have this regime on a regular and very necessary basis.

### **MALCOLM'S WIFE**

Malcolm's been on dialysis for over four-and-a-half years. You've obviously got used to the dialysis and accept it, and don't want it to rule our lives, but essentially it does, to a certain extent, it rules our timetable because Mondays, Wednesdays and Fridays obviously we can't make any major plans on those days and, in fact, when Malcolm goes to dialysis I choose those days to do my own things.

### **MALCOLM**

I have dialysis. I have what's called a fistula. This is when a vein is joined to an artery in your forearm which gives a good site for needling. I put anaesthetic cream on it and take it down, and then I have some lunch, and then I get to the unit about quarter to one. So here I am on the dialysis unit. I've been here about an hour today and my whole session will be four hours, not including putting me on the machine and putting me off the machine. This is the great dialysis machine here next to me, and this is the filter which is red as my blood is passing through it. The blood goes through the machine and back into me, and out again, and here you can see the two needles that have been put in. Being on the machine is perfectly fine normally, but one or two things that occasionally happen – sometimes blood pressure drops, and sometimes one gets cramp – so these are very infrequent. Most of the time it's really quite nice sitting here. They keep the temperature well controlled and the seat's quite comfortable, now that I've brought my cushions in, and it's really just a matter of whiling the time away. The main problem of being on dialysis would be perhaps the next day you might feel rather tired and a little bit strange as well, but actually being on the machine, as far as I'm concerned, is quite a passive thing. I feel very fortunate I'm here. It's only a 20 minute

journey by car when I drive here, the unit is very, very efficient, I'm always seen within half an hour of arriving, so one must count one's blessings. You can view going to dialysis as working for a few days a week, doing a job that you had to do. If you see it in that light it becomes in a way less threatening, you know. At the weekends we do things that other people do, I suppose. I think, hopefully, we live a fairly normal life outside of dialysis. At the moment, although I'm 73, I'm fairly fit, apart from my kidney problems. I'm able to drive myself to dialysis and I'm able to make the most of it, and read and do stuff like that. I've got a little routine of exercise I do every morning. It takes me about 10 minutes which, I hope, keeps me fairly fit. I've never been an athletic person. I used to jog but my knees aren't so good these days, so I make sure I go for a walk most days. Some days my wife has to drag me out.

### **MALCOLM'S WIFE**

Obviously I do worry about his general health and what it means being on dialysis, and the various side effects of all the medication that he's on. Dialysis is essentially part of my life as well as his.

### **MALCOLM**

As well as being on dialysis I take quite a lot of medication. Most important we take Renagel, which is a protein-binder. I have to take those every time I have a meal involving protein, which is most meals. Apart from that I take other tablets. I have to take vitamin tablets and I also take statins, and patients who are on dialysis tend to have trouble with their parathyroid gland and so I have to take tablets for that as well, so I've got quite a box of pills and I've got a very methodical way of doing it, so I don't forget any tablets at any time. I hope my friends won't be offended, but no-one has ever said to me now, what exactly happens when you're on dialysis, what goes on, you know, what's it like? But I suppose it's natural, I think, to shy away from things that one doesn't like. I don't really mind, I mean because it helps me to compartmentalise it, you know I just put it to one side, the same way that they're doing, so they're putting dialysis in the corner, as it were. Me and my two friends, we meet here once a week to have a meal at the Café Rouge, and discuss old times and often any health. I must be careful of the food I eat. Before I have a meal I must take what are called protein-binders. I take two of these tablets that I'm going to take now, with a bit of water. Also I must be careful not to drink too much water because one's water is very restricted when on dialysis. So now I'm going to enjoy my special meal of grilled salmon and boiled potatoes and beans. We have to go on a strict diet. This is because dialysis doesn't do everything. For instance, I'm not allowed to eat things like tomatoes and mushrooms, and spinach and chocolate, and nuts, and all the things that I like, which is probably why I lost so much weight after I went on to dialysis. You know sometimes you feel I'd love to have a great big glass of Coca Cola, especially with ice in it, but you just get used to it. One has to get used to it, one develops a

sort of philosophy of life to say well these things aren't so important, but I must say when they pass the chocolates round at the end of a meal you do really feel like one, you know.

### **MALCOLM'S WIFE**

Whereas previously we would obviously often have gone away for weekends and had maybe two or three holidays a year, because we've got family abroad, that obviously is very cut down now, and we do have to take his condition into account with everything because we can't do things unplanned.

### **MALCOLM**

You have to make sure wherever you go there is dialysis available. I've been to Israel and I've been to America, and I've been to other places in this country. If you go on holiday you like to feel you're on holiday and to have to interrupt it, you know three times in a week, is not ideal. It means I can't see my son in Israel as much. We have been out there a couple of times but, because of all the difficulties of arranging dialysis, I haven't been out there as much as I would like.

### **MALCOLM'S WIFE**

You're suddenly going from a free, independent person to somebody who's only functioning, although very gratefully, due to medical technology, and all the time, so it's not a, it's not like an operation that you have once and it's finished with. When you're on dialysis, unless there's a transplant, it really is for life.

### **MALCOLM**

I am on the transplant list, which means I could get a phone call at any time - because someone has come off his motorbike on a Saturday night and got killed, it's tragic really - but it means his kidneys match up with mine, I'd have to rush over to the Handsworth Hospital and get that kidney transplanted into myself, or one of the kidneys transplanted into myself. It's a funny thing to be living with hope, but that hope is dependent on somebody else being dead. Now I also live with the possibility that I will never get another kidney, and therefore I also have to be reconciled to the fact that being on dialysis is something I've got to live with for the rest of my life. Now that's okay if you're feeling well but, should I have any other illness, it made life more difficult, then the whole business of going to dialysis would be compounded, so that really is my sort of big fear. I think one can get too worried, you know you can read the mortality rates of people on dialysis and think, you know, how long have I got to go? So I tend to look things up on the internet and to read magazines and things, but I tend not to overdo it because I think sometimes too much learning can be a dangerous thing, you know. My philosophy towards the condition is to realise that it's keeping me alive. If I wouldn't be on dialysis, I would have been dead five years ago. That sounds very dramatic, but it's true, and I think one has to be positive and realise there are other things in life apart

from the food that you eat, and having a completely free week when you don't have to go anywhere. I mean one realises, one begins to develop a different view about life, and life is more important, and time is more important. Life becomes more vital, as it were.