

Big D and Me ~ Briefing # 3

Healthy dialysis techniques for people whose kidneys have let them down



Dialysis: from Shock to Acceptance

At a logical level, most people come to terms with needing dialysis reasonably quickly. They can handle the needles and the hours in the chair; they feel healthier and have more energy; they understand that they need dialysis to live.

But at an emotional level things are often very different: we all mourn and resent the loss of our health and freedom.

The Dialysis Grief Cycle

We have all heard of the (Kübler-Ross) Grief Cycle. Normally shown as five stages, I think the extended version is closer to the dialysis experience. Just so you know that you are not alone, but on a well-trodden path, in good company, I've added a little about my journey to emotional acceptance to the description of each stage.

1. Shock: *Initial paralysis at hearing the bad news.*

I was in shock at starting dialysis for a relatively short period, because I had about 20 years to get used to the idea. My kidneys were damaged in an accident and they slowly lost function until my first dialysis day arrived.

2. Denial: *Trying to avoid the inevitable*

I was in denial for about 5 years before I began dialysis. I secretly hoped that it was all a mistake, that my kidneys would miraculously recover, or that biomedicine would grow me a new one and I would dodge the dialysis bullet. That didn't happen. When my wife offered me her kidney I thought my denial had paid off. Sadly, the transplant failed, so it was dialysis for me.

3. Anger: *Frustrated outpouring of bottled-up emotion*

My anger lasted off and on for many years, not only because my kidneys had failed me and my life as I knew it was over, but because I had also wasted my wife's precious gift and exposed her to potential kidney problems for nothing. While I was obviously angry in the early days, it has gradually faded (I am still upset, but she's OK about it). But I was not above sending messages of anger or denial: coming in kilos overweight, ignoring fluid restrictions and diet, forgetting binders, OD-ing on salt. But eventually I worked out that the only one on the receiving end of my anger was me.

4. Bargaining: *Seeking in vain for a way out*

I talked with every specialist, read everything I could, trying to find a way out. My wife's kidney was part of that process. But when it comes down to it I didn't have much to bargain with.

5. Depression: *Final realization of the inevitable*

For people like us, getting depressed about kidney failure and dialysis is like constipation: you're never absolutely free of it. I still have days when I get a little miserable or angry about the time it takes or the dietary restrictions, but it passes. It's not a permanent part of my life.



6. **Testing:** *Seeking realistic solutions*

This is another stage that doesn't stop: I'm always looking for a back door: new things to make dialysis easier, more effective or more liveable. Like researching new transplant or donor options, new technologies (portable dialysis machines, or wearable or implantable artificial kidneys, or the latest stem cell research); or changing what I do – a new diet, different dialysis techniques, different lifestyle approaches, new hobbies or travelling to different units.

7. **Acceptance:** *Finally finding the way forward*

Yes, I got here, but it took a long time. Sometimes it was one stage forward then two back. But I got here in the end.

Everyone I know on dialysis is working their way through this cycle. Some admit it, others are in too deep. Some of us go fast, others slow (if you think you're different and it doesn't apply to you, you are still at stage 2!).

Getting to Seven

I have been dialysing for 18 years, and I can safely say that it took more than half of those to get to Stage 7. I touched every base on the way, sometimes several at once, and I still dabble in Stages 5 and 6.

The secret of success is to agree to re-balance your life (again). You've done it before: when you left home, when you got a job, took out a mortgage, found a partner, had kids, even grand-kids. All of those events demanded change and growth, and you're up to it this time too.

That doesn't mean you can't curse, rage, weep and even whine a little (best done in private). It's part of the process and can be quite satisfying. Just not too much. Move on.

Knowledge is Power

Dialysis is a moving feast. Techniques and technologies change. Fast. And what you do matters. Information is the antidote to fear and the key to acceptance. Get to know and understand the two laws of dialysis:

- For every action there is always a reaction
- Nothing good happens quickly (but bad things can hit overnight).

Read up on the dialysis basics (check out BigDandMe!): How can I avoid too much fluid? Why avoid salt? What happens when I don't have enough fluid? How can I manage my blood pressure? Stop my bones decaying? How can I get more energy and stop being so tired? How do I shorten my recovery time, get rid of restless legs, get some sleep? Can I travel?

Experiment, notice, react. Find your best operating level and keep tweaking it.

The key is to accept and use dialysis as your lifeline, but don't build your life around, resenting it. It's just another piece in the jigsaw that is us.

For the time being at least, this is the new you.

FOR MORE INFORMATION, HELP, ADVICE AND SUPPORT GO TO <http://bigdandme.wordpress.com>.



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