

To the "Big Apple" with a "Big Machine"!

The 18th August marked a very memorable event; it was my husband's 30th birthday. We had decided "back in the day", when the age of 30 felt a lifetime away and long time before the unwelcome arrival of renal failure in our lives, that we would celebrate this momentous occasion in New York.

Thankfully the Control freak nature of my personality is a beneficial attribute when it comes to organising a holiday as a Peritoneal Dialysis patient, well that's what I tell people anyway! So the planning began in early April..ohh and to add to the adventure...it was going to be a surprise, as hubby had accepted that due to my "situation" a trip across the Atlantic was off the agenda.

So flights were booked (Aer Lingus), insurance applied for and obtained (Worldwide Travel Insurance-making sure I had disclosed ALL my medical problems), hotel booked (Hotel on Rivington-FAB!), Pharmacy contacted, delivery of fluids arranged, transformer ordered from Baxter's and just the small matter of a few clothes and we were ready to rock.

Himself was taken to Dublin under the cover of a Rolling Stones gig (not a great concert, but that's another tale....did anyone else see a Zimmer frame at the side of the stage!)? So off to Dublin Airport where the staff of Aer Lingus could not have been more helpful. An Impending pilot strike meant the flight was chocablock but with a word in the ear of a friendly member of staff, I was checked in via their premium service and allowed to bring my machine to the gate, where I actually watched the Aer Lingus representative put the machine in the hold. I carried all the accoutrements necessary in my hand luggage with a letter from the pharmacy and my consultant to prove I wasn't a terrorist threat!

On arrival in JFK, machine et al came off the conveyor belt and I could "relax", machine had arrived..let the holiday begin!

Frequent emails to the hotel (control freak remember) meant I knew that all the boxes of fluid would be waiting in my room, and there they were 16 boxes of Dialysis fluid looking out at Manhattan from the 18th floor waiting on me. Ohh with a box of cassettes too as the connection's were different than home.

The machine got set up on my designer bedside table which even had a hole in it which the bags of fluids fitted into perfectly, it was meant to be! Fifteen minutes later, we were ready to go out on the town for a beer and a "slice" (my Dr and dietician should probably not read on but well I was on holiday!)

Ground Zero, helicopter ride over Manhattan, Times Square, Top of the Rock, the Rainbow Room and that was only day 1. Our feet hit the ground running on the Sunday and did not stop till we got home the following Saturday. The rest of the week involved limo rides, shopping, boat tours, bike tours, eating an unhealthy amount and even meeting a famous movie star (Mathew Modine of Full Metal Jacket fame)

I slept like a log in the hotel every night, and there was literally not a peep out of the machine once. The new connections on the cassettes were the only thing different from home and they were absolutely fine.

Getting the machine, transformer and medical supplies back through security in JFK went like clockwork, getting my years supply of clinique makeup in zip lock bags through security proved a little trickier.

I quite literally "had the holiday of a lifetime", and have the credit card bill to prove it! Spending my husband's 30th birthday with him in New York was a dream come true, granted when we planned the adventure back in our hedonistic student days, I never thought we'd have to bring a blooming great machine with us for company, but "have machine will travel"!

I know going to far away climes when you're on PD isn't everyone's cup of tea and it is certainly not the way anyone would wish to travel, but with a bit of organisation, forward planning and a good dose of "control freakiness", the option is there for those who want it. And well there is a certain amount of method to this madness.....2 years until I reach the big 30, so himself had better start planning.....

I have to give a special thanks to the Renal Pharmacy and the PD unit who were a tremendous help and support in organising the trip and I am truly grateful for this.

Orla Smyth

Renal Review Implementation Group Update

The Renal Review Implementation Group was set up by the department of health to guide the development of renal services in Northern Ireland. The group meets several times a year to discuss problems in the service and to find solutions. Consultant nephrologists, Professor Peter Maxwell and Dr John Harty, serve on the implementation group together with representatives from the renal hospitals. NIKPA also has a representative on this implementation group. We are there to voice the views of kidney patients in Northern Ireland. The members of the group are very committed to working together to ensure provision of dialysis and transplantation to all who need this care.

I attended the last meeting, which was held on June 18th 2007. The following are some of the more important matters that arose from the meeting:

The publication (December 2006) of the UK Renal Registry, which compares the performance of renal services in the UK, shows that Northern Ireland came out very well; we were in the top 13 of the 50 units that returned data to the renal registry. We also came out on top for dialysing a lot more of adult population compared to other renal units in the UK. This was recognised as being due to the professionalism and dedication of all the renal staff in Northern Ireland.

Also on the agenda were the expansion of haemodialysis stations at Daisy Hill Hospital (to commence in January 2008) and the proposed expansion of haemodialysis stations for Omagh Hospital. Although the major concern was the priority and the need for expansion of haemodialysis services at the Antrim site.

Since this meeting the expansion of the Antrim site has become more urgent. Many more Northern board patients are starting dialysis. Antrim renal unit is already over subscribed. New patients with Coleraine and Ballymoney postcodes have to travel to Belfast City Hospital for dialysis and this in turn involves displacement of patients from BCH to dialyse in Ulster Hospital Dundonald. Patients have been complaining and this has been noted.

NIKPA's stance on this is that no patient should have to travel long distances to dialyse and that pressure should be put on the NHSSB to release immediate funding for the expansion of the Antrim site. A letter has been drawn up by NIKPA and sent on behalf of the patients to Mr McGimpsey and the director of the NHSSB detailing the urgency of this situation and also suggesting that the Minister meet with the renal patients in Antrim and Belfast renal units to talk to and hear for himself the problems haemodialysis patients are faced with.

If you have any view relating to this or other dialysis issues you can log onto are Discussion Forum found at our website www.NIKPA.org.

Linda McDowell

The Opt-Out Option

Presently in the UK we have a system of opt-in organ donorship whereby people who are willing to donate their organs after death sign on to the Organ Donor Register. Recently the Chief Medical Officer Sir Liam Donaldson recommends moving to a system of presumed consent (opt-out option) where everyone is on the donor register unless they choose to remove their names. This would mean that more organs would become available for donation.

If you wish to give your support to the opt-out option you could sign the online petition on the Prime Minister's Downing Street website at <http://petitions.pm.gov.uk/Dialysis>

Have your say

Visit The Forum at

www.NIKPA.org

Reasons to Dialyse at Home

Home Haemodialysis, in its current format, has been running successfully now for 4 years. To date, there are 15 dedicated and determined people who, 3 – 5 times per week, connect themselves to a haemodialysis machine and effectively self-treat. Of course, in the background, medical staff are monitoring treatments and blood results, technical staff are monitoring and maintaining dialysis machines and somewhere in the mix, nurses, dieticians, pharmacists etc, are offering support as far as is practicable to the independent souls out there "just doing it".

Why would anyone give up the peace of mind and support of hospital dialysis? Of course, no-one does dialysis for its own sake. It is a means to an end – offering some benefits of a feeling of well-being and, hopefully, a relative degree of normality in life. But why would anyone want to leave the relative safety of hospital? It's like a trapeze artist without the safety net.

You may say to yourself, "I would miss the craic". And you may be right too. However, as with most things in life, change occurs. Your neighbour, with whom you probably spend more time in conversation than your wife (or husband) during the course of your 3 dialysis sessions each week, may move onto a different shift or they may receive a transplant. Change invariably happens.

Many of you will say to yourselves, "Why would I be bothered with the hassle and responsibility? Who is going to prepare my machine at home?" You may feel with some justification that it isn't your responsibility to do this task. No-one can force you to do them against your will. Other questions that might arise are, "What happens if there's a problem with my machine or what happens if I'm unwell? How do I get my bloods sorted? Who's there to give me some support?" These are common problems and genuine issues for everyone and not everyone on dialysis will be able to deal with them. For many of you, even thinking about them may cause feelings of panic and anxiety. You may feel that coming to terms with your kidney failure and its attendant complications such as fluid restriction, diet, drugs etc, is more than enough to be going on with.

If you do feel that dialysing at home will only add to any worries you may have, I have good news. If you're already dialysing in (or under the care of) any one of the excellent dialysis units in Northern Ireland at this time, you're already in the most capable hands. There are caring, skilful nurses and skilled, capable medical staff who will do their utmost to keep you well. They will also help you deal with your medical condition and any associated issues that could cause you concern. I would encourage you not to intensify further any anxiety by taking your haemodialysis treatment home with you.

However, a few of you will look at these questions in a different light. You may consider these as challenges to be met, to be overcome. You have the reassurance that many of your peers have been there before you and have successfully prevailed over these issues. Of the current cohort dialysing at home, they age from 18 to 71 years old. They live in diverse parts of the province from South Tyrone to North Antrim; from South Down to the conurbation that is the Greater Belfast area. They all have different lives with different aspirations in life. Even their reasons for dialysing at home are different, but all equally valid.

What does home haemodialysis offer them and what could it offer you? To summarize:

- Flexibility – dialyse when it suits
- Optimize your health
- Less travelling to hospital for dialysis treatments
- Spend time with family
- Control of your treatment - independence

If you feel that you would like more information about dialysing at home, please contact me by email or telephone. I will arrange to send out some written information to you and your family and, following that, I will contact you to help answer any other questions that may arise.

Gary Gamble
Home Haemodialysis Coordinator
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Tel No: 07753851689 .

The Journey Home

My experience of Home Haemodialysis

Dialysis for me started in earnest on 24th December 1999 (Christmas Eve). Having been relieved of excess fluid and toxins for the first time in several years I remember feeling great (like the "bionic man") on leaving the hospital and thinking this dialysis business is easy. In August 2001 I was fortunate to receive a Kidney transplant. However due to an unforeseen fault in the transplanted kidney, it had to be removed after about a week which meant I found myself back on dialysis. The experience however has in no way put me off, and given the opportunity if it arose I would have no hesitation in going for another transplant.

Two years later: Attending the unit three nights a week in the evenings after work I found myself with more energy and greater well-being which meant that I could keep on working at my job and was once again able to participate in social events with my family. I arranged to go abroad on holiday with my family for the first time in approximately five years. This was achieved by having treatment at a dialysis centre close to my holiday destination, following discussion and agreement with my Renal Consultant at the BCH.

Home training: In September 2003 I was invited to commence training for home dialysis. This entailed learning how the specially designed Home Haemodialysis machine functioned, how to line it, and how to needle your own fistula. The thought of needling was the one thing that frightened me and was possibly putting me off the idea of "home haemo". However after the first successful attempt I realised it was not that difficult (or painful!!) and that it got easier with more practice. I was now capable of "flying solo" and it became clear to me that having my own dialysis machine at home would provide me with many positive advantages including:

- the flexibility of being able to have treatment at a time of the day which suited me - either in the morning, the afternoon or the evening.
- the opportunity to go out socially in the evenings where before, I would have had to attend my fixed slots at the Unit.
- less travel to and from the Unit late at night.
- the opportunity to increase the number of hours and days on which I did dialysis - the extra hours giving me a better dialysis treatment.
- the fact it would free up my slots at the Unit for someone else to receive treatment.

A machine was then very quickly installed by the Baxter company who covered the costs of plumbing, wiring, painting and special flooring over three days with no mess or inconvenience in a spare bedroom at my home. Initially, a nurse attended each morning to keep an eye on things while I put myself on. Then came my first day on my own. I remember sitting with a needle in my right hand for two or three minutes before plucking up the courage to proceed. Since then I have not looked back. Needling has got progressively easier and the flexibility of having the facility at home has been great. I now do dialysis for approximately four hours a day, five days a week and administer my own epo, and iron infusions. By doing dialysis five times a week my overall feeling of well-being has improved as the toxins and fluid do not get the same opportunity to build up due to the additional regular treatment. This has allowed me to do more with my family and to spend more time at home which would otherwise have been spent at the Unit or travelling to and from it. Dialysis supplies are delivered to the house and the machine is regularly serviced by Baxter's technicians, with advice being immediately available by telephone. Dialysis results are monitored closely by my consultant and the nursing staff, who keep in regular contact. Gary Gamble has recently been appointed as the specialist nurse to monitor and promote Home Haemodialysis. I can honestly say that I have benefited greatly from the opportunity to receive treatment at home and I would thoroughly recommend it to anyone who feels it could benefit them also. Finally, I would like to take this opportunity on behalf of all the Renal patients in Northern Ireland to thank all the Doctors, Surgeons, Nursing and Renal Education Staff who help to keep us well and who help to provide us with a better quality of life.

Colin Thompson Home Haemodialysis patient

