PERITONEAL DIALYSIS
WITH
2 LITRES OF DIALYSIS FLUID IN MY STOMACH
ANITA’S STORY
It was summer and a wonderful time. I had moved into my new flat, had just met Stig and was very much in love.

I was also well under way in my first job as a graphic designer after finishing my training in the USA. The work provided me with a number of exciting challenges and I worked from early to late. Insisted on it.

It was at that time that I began to complain of a severe headache. I thought that it was due to the pace of life, stress and my work. It seemed silly to go to the doctor. In any case, he would just ask me to work a little less.

It was one of my colleagues who finally decided me. One afternoon at work he mentioned that I didn’t look very well.

When I took time to think about it, I was in fact very tired.

VISITING THE DOCTOR

I arranged an appointment for a check-up and went a few weeks later. All the usual tests were done at the doctor’s. When the doctor measured my blood pressure, he was startled. He measured it again. No, it was still high. He asked me to lie down on the bench and relax a bit before he measured it again. Too high.

The blood tests showed that my creatinine values were also unusually high.

Creatinine?

The doctor explained that creatinine values, among other things, show something of how well the kidneys are working. A normal creatinine value is between 80-100 depending on one’s age. The higher it is, the worse.

Mine was 234.

Little did I know that creatinine was to become a firm friend in the long period ahead.

My doctor rang the kidney department at the hospital. I heard him say:

... you know I have a patient here that I want to refer for investigation immediately.

It was strange to sit there and suddenly be referred to as a patient. I wasn’t ill anyway. I was simply there at the doctor’s to convince myself that I was healthy; to be told that I should be taking things more calmly at work.

I had never been seriously ill. A slight ear infection and a thick, pink medicine when I was little, but apart from that I had been healthy.

I was a little distracted when I returned to work after we had talked about my going to the hospital the following morning. I was confused. Would I become hysterical? Depressed? Or was it OK to feel that everything was simply unreal?
ADMISSION

When I arrived at the hospital the following morning I was given a bed by the window. The nurses who looked after me were very pleasant and explained to me that over the course of the next few days I would undergo a series of tests. X-ray, ECG, blood tests, blood pressure measurements, kidney biopsy, and many others whose name I did not grasp. It would mean a little waiting, so there was nothing to do but take things calmly.

I sat there on the edge of the bed and was apparently ill in some way or other. The room was sad as I had expected. Sad possibly because it is supposed to be sad in a hospital. White coats, sterile gloves and medicine trays. And not least, sick people.

I took a trip down to the kiosks and bought myself some magazines, a newspaper and two pounds of mandarins. I love mandarins. They taste delicious, smell fresh and have a warm colour. I laid them in a pile on the bedside table and illuminated them with the bedside table lamp so that there was a small snug feeling in my corner. I put on my woollen socks, selected some reading material, began to peel the first mandarin and went off into another world for a brief period.

A hospital is a strange place to wake up in. Because the people who were there in the evening when you went to bed are not the same the next morning when you wake up. New patients, other nurses and different doctors. It all seemed rather disorganised. I couldn’t understand how they kept tabs on what, who and where, and in which folders everything was filed.

Out in the corridors it was full. I was a little surprised about the fact that I had been given a place in the room, since I was well to a greater or lesser extent. People who looked really ill were lying behind a screen in the corridor.

The days dragged slowly by. They consisted of meals, injections and waiting. The evenings passed even slower.

Sick people go to bed early. Yet another sign that I could not possibly be ill. I sat up alone with my knitting until the announcers on the TV said goodnight and the evening’s bedtime images came up on the screen.

It was quiet and dark in all the rooms with dimmed lighting in the corridors. I could hear the sounds of people sleeping, nursing staff whispering and now and again shuffling through the toilet doors while I was sleeping.
MEETING WITH AN UNKNOWN WORLD
KIDNEY INFECTION

When all the tests had been performed, the doctor told me that I had had a kidney infection. Possibly it had occurred as a result of a throat infection. Could I remember if I had had one?

Well. It was a little difficult to remember exactly... but could I have some medicine just so that I could get well again?

The doctor told me that the kidney infection had caused permanent scarring to the kidneys. This scarring would become worse with time. At some point in the future I would need to have new kidneys.

A transplant. But I did not need to think about that yet because that would possibly not be for another ten years. For the time being I would have medicines to control my blood pressure which was a little abnormal after the damage to the kidneys. And therefore I would have to come for regular tests so that they could follow developments.

I was not told that much in the course of the 15 minutes I was in the doctor’s surgery.

The questions came thick and fast after I had gone out of the doors. Transplant? I hardly knew what that was. Transferring organs from one body to another. Whose organ would be put into my body?

Why could they not transplant a kidney immediately? Then it would be over and done with. Were there things the doctors weren’t telling me?

Perhaps it was just as well not to ask so much. This transplant would in any case not take place for many years. I felt healthy and I was afraid that the answer would make me ill.

Outside the sun shone. I opened the door, walked out and hoped I would forget.

CREATININE

At regular intervals I was dragged back to the clinical world.

Tests. Particularly that figure, which just kept increasing in value.

274, 335, 387...

It started to be tiring to go up steps. It was hopeless watching films on the TV. I invariably fell asleep halfway through and never managed to get to the end.

428, 503, 532...

The nights started to become irritating. It was difficult to sleep, my legs itched. Now and then I had to get up and stamp hard on the floor, quietly. After all it was in the middle of the night and others were sleeping.

My appetite disappeared. A simple way of losing a few pounds perhaps, but now it was a matter of keeping what pounds I did have. I did not enjoy the food I was eating. I felt sick simply from forcing it in and
swallowing at full speed while desper-ately trying to think of something totally different from food.

I was 28, would soon be 29. The creatinine was more than 600, I worked 50% of the time, was tired and forced to admit that in fact I probably was ill.

The creatinine had passed 700. My kidneys no longer did the job alone. They needed help.

New and difficult questions sprang up. The most difficult of all:

Do you have a donor in your family?

**DIAGNOSIS:**
**CHRONIC RENAL FAILURE**
ORGAN DONATION
ASKING

At the hospital, it was easy to talk about organ donation, but with my family it was more difficult. I was afraid that they would feel pressurised. If they were to say no, I would understand.

To make it easier, the doctors at the hospital offered to talk to my family. But in my case I felt it was not the right way of going about it. Illness was not exactly the pet subject at family suppers, apart from polite questions and simple answers about my situation at the time.

I was in a hurry to have an answer so I would have to approach the subject more concretely. I talked about what a transplant involved and how I had now come to be placed on the waiting list to have a new kidney, but without hinting at the matter of a donor at too early a stage.

I wanted to let them have time to think about the problem themselves. I obviously hoped that if one or other of them were willing to donate they would contact me rather than my having to ask anyone directly.

Later they did make contact, one after the other, each in their own way. Whatever the outcome, however, my body needed help. I was to start on dialysis until we had found a donor.

But first of all I had to decide what form of dialysis I wanted to use.

FINDING A DONOR

Stig, my partner, was happy to donate, but had the wrong blood type.

If I was lucky, my parents or brothers and sisters would have a kidney that was suitable.

If I could not get a kidney from my family, I would be placed on the waiting list to receive a kidney from someone who had died.
DIALYSIS

-A METHOD OF CLEARING WASTE SUBSTANCES FROM THE BODY
CHOICE

I read what I could get hold of in brochures and articles. At the beginning, haemodialysis appeared to be the best solution. I think that was mostly because I didn’t want a tube in my stomach. It made me feel sick. I would rather not have anything to do with that sort of hospital thing. For that reason it was probably simplest to be connected to a machine, wait for a few hours and then go home and have the next day “free”.

However, I had a chat with nurses on the PD ward. I saw the tube and the bags. The principle of PD dialysis was explained to me. I was surprised to hear that the liquid which came out of the stomach was clear. I had imagined that it would be dirty and bloody. I read an article about a Swedish lady who went on bicycle trips, which illustrated the possibilities of PD for me. When she was on long cycle trips, she would take a break when it was time to do an exchange.

She attached herself to the bag, placed it in the handlebar basket while she herself laid down in the grass beneath the basket and enjoyed the sunshine. It sounded almost a little romantic.

I was fascinated by the possibilities. I could control everything myself, I could make myself more or less independent of the hospital. I could travel away for several days. I could continue to work. Every day if I wanted. The PD staff of the hospital were never more than a telephone call away.

I liked the thought of being able to live as normal a life as possible and went for PD.

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HAEMODIALYSIS

Haemodialysis removes waste substances and excess fluid from the blood by means of a dialysis machine. You are connected to a dialysis machine in the hospital three times a week. Your blood is channelled out via a needle, for example in the arm, then passed through a filter before returning through another needle. Usually this takes about four hours.

PERITONEAL DIALYSIS (PD)

Here your own peritoneum is used to remove the waste substances from your blood. A dialysis solution is left in your abdominal cavity to collect waste substances and excess liquid until it needs to be exchanged for a new one. In order to have access to your abdominal cavity, a small, smooth tube (catheter) is inserted surgically with a few centimetres protruding outside the body. The catheter is used to connect you to the dialysis bags so that you can exchange the old fluid for new. The fluid must be changed four times daily. Each exchange takes about 25 minutes. You can choose between doing it manually yourself during the day or being attached to a machine at night which exchanges it for you automatically.
CATHETER

- There’s a biro here so that you can mark where you want us to position the tube.

The surgeon who was due to perform the operation shook his head a little doubtfully when he saw where I had placed the mark.

- Isn’t that a little low down there? We usually position it nearer to the navel.

- Yes, but isn’t it possible…?

- A bare tummy is the fashion now, said the kidney specialist who was present at the operation. – We’ll put it where Anita has marked. So he patted my head and left the operating theatre.

It was a simple operation under local anaesthesia. It took perhaps half an hour.

The tube was hidden under bandages which were taped fast to my stomach. It was perfectly OK, I felt no special need to look at it more closely.

But when the nurses needed to check it a few days later, I had to have a look. I was positively surprised that it looked so good. A tube protruded about 5 centimetres - without any wound, blood or scar. Later it was attached to a long tube with a screw top so as to make it easy to connect the bags.

In a way the tube was the first physical evidence that I was ill.

At the beginning I thought the tube was slightly nauseating and it took a little time to get used to having such a direct opening into my insides.

In order to make the tube less frightening, both to myself and to those about me, I was happy to talk about it; where it was inserted, and to show it if anyone wondered what it looked like. I got mixed reactions.

- No, said my mother.

Others were more interested.

The tube had to grow in before we could start the dialysis. For the first few days I could feel the tube in my stomach, like something foreign in there. Now and again it was very painful. I wanted to pull the tube so that it was clear of what it touched.

It was lovely to feel the fluid filling up my stomach the first time. The tube lay and moved. The discomfort was gone. But I felt a little bloated.

2 litres of fluid in my stomach. That must take up a lot of space. For the first few hours I felt a little padded out. I felt it pressing against my lungs. I imagined that it was a little more difficult to breathe, but that passed. Soon I only noticed the fluid if I turned over suddenly in bed. It slopped about a little inside me.
A SIMPLE OPERATION UNDER LOCAL ANAESTHESIA
LIVING WITH PD

DIALYSIS FLUID
Bag containing 2 litres of dialysis fluid which is used to replace the old fluid that is removed. The bag is placed or hung higher than the stomach so that it can run out without help. It takes about 10–15 minutes to empty, depending on how high up the bag is hanging. In the course of one day you exchange the dialysis fluid four times.

CONNECTION
This is where you connect the catheter to the dialysis bags. You first open the empty bag so that the old fluid can run out, you then close the tube and open the bag with the new dialysis fluid.

DIALYSATE
Empty bag which is filled up with used dialysis fluid. The liquid is clean and odourless. The bag is placed on the floor or hung low down so that the liquid can flow out by itself.
TRAINING AT THE HOSPITAL

Hot plates, caps, bags, scales, clips, hooks, masks, disinfectant spray, soap and stands were some of the equipment which stood there ready when I started my training at the hospital.

At the beginning there was always a nurse present. During the connection and disconnection, she made certain that things were done in the right order. First of all the bag had to be positioned correctly, then I had to wash and disinfect my hands, then take the cap off the tube opening and the mouth of the catheter.

The first time I sat entirely alone I was still a little shaky but afterwards I began to feel totally confident. I thought that it was good to do the exchanges alone.

FIRST CHANGE AT HOME

After a few days I returned home with equipment and dialysis fluid for the next few months.

In the bathroom, I put up shelving for all the equipment, sat on a chair and chose a pile of reading material. Everything was ready. My partner needed to stay in the bathroom with a face mask during my first home operation. I was a little shaky, but at the same time a little proud.

PART OF EVERYDAY LIFE

I had to do four exchanges daily. It took me about 35 minutes to do an exchange. At the beginning I was very careful that it was exactly 4-5 hours between each exchange. And that I washed my hands several times to be sure that everything was clean. I used a face mask and invariably sat on the chair in the bathroom until I had finished the exchange.

But afterwards I began to use the bathroom only for connecting and disconnecting. I continued to ensure that everything was clean and dry, but subsequently I dropped the face mask. I took the bag with me into the living room, kitchen or work room, as necessary. There were hooks hanging here and there on which to hang the bag. Now it was the bag which had to adapt itself to me and my needs and not vice versa.

At the beginning I got up an hour earlier than usual in order to have sufficient time for the morning exchange. But afterwards I would just get up in a half-sleep, connect to the bag in the bathroom, go back to the bedroom, hang the bag above the bed and lie down again. In that way I got a few extra minutes in bed before having to get up.

AT WORK WITH PD

Before starting dialysis I had previously had a short discussion with my colleagues about what I was going through. I tried to explain what had happened to my body and prepared them for what possibly was awaiting them.
At work I had a minimum of dialysis equipment, but enough so that I could exchange the bag there in the middle of the day. I connected and disconnected in a little room, went back to my workplace, hung the bags up and continued to work. Both customers and colleagues went past but it was rare if anyone noticed me sitting there with my bags.

**A DESERVED REST**

I often felt that changing bags was a pleasant break during the day. Even when I was on dialysis my creatinine levels continued to be over 700. I became very tired and the exchanges in a way gave me an excuse for relaxing a little on the sofa. In addition, changing bags was a brilliant excuse if you were in company or at a party which was starting to become boring. It then became suddenly extremely important to exchange at the right times.

If I was away one day I took the dialysis bag with me wrapped in a hand towel, together with a hot water bottle to keep it at body temperature. Then I was able to do an “external exchange”. Or I would do two exchanges rapidly one after the other and could have a longer break in the middle of the day.

Now and again I would have a bad time and get a little behind schedule. Then the exchange took too long. So I would hang one bag on my belt while holding the other as high as possible above my head at the same time as I ran around and made myself ready.

**OK FOOD AND NO-GO FOOD**

Cashew nuts. I loved cashew nuts during that time for some strange reason or other. I simply had to have them. Probably because they were on the list of my “no-go” foods. Diet is important when you are on dialysis. The most important thing is to control protein, phosphate, salt, potassium and fluid. Because I was using PD dialysis I had no
restrictions on fluid intake.

I managed largely to keep away from cashew nuts, but now and again, or perhaps a few times, I would buy a little bag. I enjoyed every nut.

At the beginning it was a little stressful with the diet, it was difficult to produce meals which did not contain this or that. But later I prided myself on having a greater awareness of what I was putting in my body.

A REMOVAL VAN FULL OF BOXES

Each month a new supply of equipment and dialysis fluid was delivered. Four bags daily for 30 days makes about 250 litres of fluid. It looked as if I was moving in each month.

Everything that comes in, must go out again. The dialysis fluid was both clean and odourless so that it was emptied into the basin after use. But there was not enough room for all the cardboard boxes in the dustbin. We had to have these taken away at regular intervals. I had the impression that at times we were afloat with boxes everywhere. Full and empty.

WITH PD TO BARCELONA

The summer was approaching and holidays had to be planned. I had heard that the suppliers of PD equipment could also deliver dialysis fluid to other countries if you wanted.

I wanted to go to Spain. In three weeks. Certainly out of a little bravado just to prove to myself that I could if I wanted. I checked with the hotel that they could take supplies of dialysis fluid. That was entirely in order. But I don’t believe they had expected the quantity which arrived a couple of days before us. More than 180 litres divided between 25 boxes.
I packed a suitcase with the equipment I needed, including a couple of bags with dialysis fluid in case the flight was delayed. I took the necessary papers and the telephone number of the PD department with me.

It was hot when we landed. We were to stay in a little town just to the north of Barcelona.

Sea and sun. It was lovely to sit under the parasol and see life on the beach. To feel the heat from the sand and think that life basically was quite wonderful.

I was a little envious of those splashing around in the water since unfortunately I was prevented from bathing because of the catheter entrance. But showering was totally OK. For this reason the showers, specially those close to the ice-cream kiosks, were used studiously.

BUILD-UP OF PANIC - EVERYTHING IN ORDER

One afternoon, while I was sitting studying a group of ants that were walking along the rail during a change of bags, I happened to look down at the bag which was about to be filled up. The fluid was more or less entirely white; it was no longer clear as it should have been, but more milky. I soon realised what it was, but even so was a little worried. During my training I had been told about the risks of infection in the abdominal cavity. And the symptoms. I rang the PD department at home and we agreed that I should start a course of treatment. I had a pack of medicine and all the necessary equipment and had been given instructions as to how I should add the medicine to the dialysis fluid. It was a satisfying experience to master the situation. I was a little weak the first few days but was soon back to my normal dialysis state.

The days were spent reading the daily newspapers, eating good food and going on trips to Barcelona. Often for a whole day. Then it was a matter of finding my own place to change the bag. What could be better than a quiet park right in the centre? There were remarkably few people who noticed the bag.

On the beach it was really good to go about in a bikini, no one could see the tube which ran along the top of my bikini bottoms.

After masses of sun and lazy days we returned home rested to an autumn of new challenges.
Bag exchange on a park bench in Barcelona.

Enjoying seaside life from a paddle boat.

Here I add medicine to the dialysis fluid under temporary conditions.

Bag exchange on a park bench in Barcelona.
LOVING AND
BEING LOVED
WITH A TUBE
IN YOUR STOMACH
After the operation I was a little afraid that my partner would think that the tube in my stomach was horrid and that the bags and the equipment were a little nauseating. I even thought myself that it was a little near the bone. But I was lucky. He was in fact very interested. I did not feel I had to hide the tube every time my stomach appeared.

STIG EXPLAINS

To begin with it was difficult to grasp that Anita was sick. She never complained, worked a lot and at home we talked little about her illness.

It was only when the subject of children came up on one occasion that it really struck me that Anita was ill and that her illness would have consequences for us both. I was also part of this.

What about children?

I had never thought that carefully about it. I had imagined that one day I would become a father. Now that was no longer obvious. Could Anita have children with damaged kidney function? Or was it possible after a transplant? Was it important for us to have children?

That made me become more interested in what chronic renal failure meant. I read the brochures Anita had at home, surfed the Internet to find out more and tried to help in the question of which form of dialysis she should choose.

When Anita decided on PD, it was not so frightening that she should have a tube sticking out of her stomach. I had previously both seen and touched the tubes and dialysis bags. I was in fact more fascinated about the method and how well the surgeon had inserted the tube into Anita’s stomach than repulsed by it.

Even if we have to wait for children, that does not mean that we have finished with sex. Our sex life continues as before. We take no special precautions as regards the tube, but keep an eye on where it is at any time.
Two years after I was diagnosed as having chronic renal failure and having been on dialysis for half a year, I received a kidney from my father.

I often think about my new kidney. I can feel it low down in my stomach to the left of centre. We are, as it were, a team. It is strange to have an organ that is almost twice as old as I am.

Probably needless to say, I am very happy that it is there.
LNT.
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