

Julie's Story Transplanted 1985

Julie's story written at age 21 (1991)

As a little girl I remember vaguely how things used to be. Everything seemed to ordinary to me but as a child I don't suppose you have any worries, the only worry I had was having to come home from school to mince beef and mash potatoes, I was such a fussy eater. I hated vegetables, gravy, mashed potatoes; in fact there wasn't a lot I did like. I used to hate Sunday it was almost guaranteed that my mum and dad would have an argument about me not eating my Sunday Dinner.

Later on I started coming home from school quite regular with what I thought was just a tummy pain. My mum and dad began to get worried with my eating as I was quite skinny but yet my stomach was so large. They took me to the doctors a couple of times and the doctors gave me medicines to try and help my appetite. I remember one medicine quite clearly it was green and it was disgusting. I can honestly say I would rather have eaten mince beef than drink the medicine; I suppose maybe that was the idea.

After realising the medicine wasn't doing any good anyway I was taken back to the doctors. I think my mum and dad were shocked when they were told it was malnutrition that I had, I support really it could have looked like that and I was asked to come back down to the surgery for a blood test, that was an experience I didn't want to go through again, little did I know at the time that I may be having them for the rest of my life, in fact the next one was to come sooner than I thought because the next night there was a knock at the door. It was the nurse from the surgery, she said my blood had clotted and could I please have another test done the next day. Of course my mum and dad agreed despite how I felt about having needles stuck into me. Unfortunately I was too young to have any opinions to matter. Later on it was found out that my blood hadn't clotted they just couldn't believe what they were seeing in a young girl's blood so they needed a second test doing to make sure it was right. Unfortunately it was and I was transferred to a specialist at the hospital. Dr Hunter a very nice lady doctor examined me. Within five minutes of examining me she knew what was wrong and admitted me straight into hospital, yet another new experience. I wasn't too bad until my mum had to leave to fetch me some things from home, I remember I cried because I didn't want to stay there with strange people.

Well this is where it all started. I had test after test done, all the doctors wanted to examine me. I hated all those blood tests. I never thought I would get used to them. I cried nearly every time one nurse told me I shouldn't cry. I should be used to it by now she said, how could she say that how would she like to have a blood test every day I thought.

Things began to get worse. I began to deteriorate. I spent more and more time in hospital. I remember one time I was put in a little room of my own

and any visitors had to wear a white gown to come in, that scared me a little.

Eventually Grimsby doctors realised that there was nothing more they could do for me so they referred me to a liver specialist in Sheffield. I remember my first liver biopsy. I don't know whether things have changed since then or whether maybe I was just too young to have it done while I was awake which is what they do now. I don't remember all about that hospital but I remembered being transferred yet again to an adult hospital, still in Sheffield, the Royal Hallamshire. It was horrible, full of old men and women, by this time my stomach was extremely large. The doctor couldn't believe my skinny little body would be able to carry such a weight. Well by the time I was fifteen they realised my only hope was a liver transplant. I was suffering with hepatitis, a very infectious liver disease.

Time again to be transferred, this time to Birmingham Queen Elizabeth, where there were more tests to see if I was well enough to go through such an operation. They had to try and really build me up so I could fight through the operation. Everyone helped - I met my surgeon who brought some doctors round from Scotland to have a look at me. They had no confidence in me at all. They really didn't think they could help me. I am so pleased someone had confidence enough to give me the chance. Bill Essex, the transplant co-ordinator was great, he made me laugh and got me a teacher so I had things to keep my mind occupied. I was very much a fan of Shakin Stevens at the time and a patient's daughter got her son to get me some tapes and she organised a visit for me, unknown to me at the time. I was discharged for the weekend, the day before he was going to visit. I may as well have been there too because I got home and though the night was taken back into hospital after a haemorrhage. They gave me blood for a couple of days in Grimsby and as soon as I was strong enough took me back to Birmingham.

That's when I half started to give up. I wouldn't eat but that was because I didn't like it. I wasn't allowed any salt in my food, not even in the cooking of it, it tasted terrible. I am so glad my mum and dad were there to help me along; they rented a flat at the back of the maternity ward so they could stay with me and eventually my two sisters came as well. My brothers had a place of their own back home and could not really afford to leave but they kept in touch regularly. Our next door neighbours at the time, Jenny and Barrie were great; they sent me letters and sent down my favourite Spaghetti Bolognese for me. There was even a nurse on the ward who used to bring in soup when I was allowed to have it.

I began to feel very weak; I just couldn't be bothered to fight. When I was asked once if I wanted the operation I said 'No' I don't think I really meant it. I was just so fed up at the time.

I thought my dad was getting angrier every meal time when he tried to make me eat something and I wouldn't. I realise now if he hadn't forced me I might never have been strong enough to pull through. I remember

eating lots of Rice Krispies and having the odd treat of an Indian meal. I think they would have let me have anything in the end as long as I ate to build up my strength.

I went into a coma while I was waiting. I bet that scared a lot of people but luckily it only lasted a day, and as far as I knew I'd been asleep, except I started saying stupid things like asking my dad to wash my face with a cup and go behind the bed and drink the milk. I also had hold of his hand but it felt like he was holding mine really tight and I kept telling him to let go of my hand but he couldn't because it was me that had hold of his, my dad had to pretend to do these things.

My dad also played a little game with me. There was a club on the grounds where he could go to get away from things for an hour or two but I had to sign his pass to let him go by running my finger across his hand, if I didn't sign it he wouldn't leave me.

I was really well looked after. There would be someone there for me from when I woke up in the morning to when I went to sleep at night. Eventually the time came and we were told that it was possible they may have a donor, but we weren't to build out hopes up just in case there was a let down. Nevertheless they stopped me eating and drinking. I began to get scared then a few hours later we were told it was off, the donor wasn't suitable. I didn't know whether to be disappointed or happy that I didn't have to go through with it at the time.

Some more time went by, exactly how long I can't remember the tests went on and I seemed to be permanently on drips either feeding me or giving me blood. I began to get weaker and was feeling more tired. Eventually another donor came along and this time it was for real. I remember asking if I could have a cup of soup first before I had to stop eating and drinking, but they wouldn't let me. I hadn't eaten much that day and just because I knew I wasn't allowed anything, I was hungry.

They gave me my pre-med a couple of hours before my operation which was going to be in the early hours of the 23rd April 1985. I began to see the worry in my mum and dad's faces so I knew I had to be brave for them, just as they had to for me.

Then the time came for them to wheel me to the operating theatre. My mum and dad came as far as they could with me holding my hands all the way. I still managed to keep on my brave face, but deep down I wasn't really as brave as everyone thought. I was scared stiff not knowing if I was strong enough to pull through and not knowing if that was going to be the last time I saw my mum and dad. The operation lasted 6-9 hours. I can't remember exactly but that was the easy part. I can't really remember my first reaction as I woke in intensive care, as I was on a life support machine they gave me a pen and paper to communicate with. I hated the life support as it does your breathing for you and every time they switched it down so that you could breathe a little by yourself, I always felt as if I

wasn't going to be able to breath. I remember seeing one man pull his tube from his throat. I was worried about him so I wrote on my piece of paper what he had done and attracted someone's attention to let them know. Fortunately because they are on constant watch they already knew. Eventually I came off the life support machine and was breathing on my own; it felt good to be able to talk without having to write everything out.

I started eating slowly, I was off my no salt diet but the food tastes strange having salt in it again, it took a while to get used to it, in fact I had to get used to doing everything again, breathing, walking, eating, going to the toilet - that was the worst thing. Every time I tried to go I'd sit on the toilet for ages trying then when I couldn't I'd cry my eyes out knowing they would put a catheter back in. It was just like being a baby again learning how to do things. I had so much help from my family and the staff I think I would have given up without their help. It seemed to take so long for me to get back on my feet properly but they eventually stated to let me go out for a couple of hours. I can remember one day I don't know whether I had overdone things or not but my mum and dad had a flat across from the hospital and I had gone over there for the day, we had relatives visit and it seemed crowded. When I got back to the ward that night I had some sort of fit. I personally don't remember anything of it except having drips in the next morning. Someone told me what had happened. After that I had my ups and downs but when it became more on the up they let me move across to the flat with my mum and dad but I had to visit the hospital every day, once things got better and I was coming only once a week we moved back to Immingham. At home all the neighbours and friends and family had put on a big welcome home party, I was picked up in a white Rolls Royce and taken to the party where there were loads of people to greet me with presents and flowers. I had a lovely time and it was good to know I had so many people praying for me.

Things went well for me after that. I finished school then I went to Boston on a YTS course training to be a stewardess at sea. I did a fire fighting and sea survival course and then did maybe two weeks at a time at sea on different ships. I went to Denmark, Sweden, France and Germany and really enjoyed myself.

After my two years were up I went to work for McDonalds and soon climbed up the ladder there. I was training for Floor Manager but I was offered a job with Sealink Ferries which I left McDonalds for and then did not end up goings that's when I started at Gateway and did work as a part-time barmaid for a while, but both jobs got too much so I stuck to Gateways. There was a time in between when I was very badly ill again and was put on the transplant list for a second time but fortunately thinks took their own course and cleared up. I am now very fit and well, enjoying life to the full and still hope to make a career as a stewardess at sea.

This is not my whole story as I'm sure doctors and family could tell you but this is what I saw and remember.

I'd like to thank all the doctors, family and friends, without their help I don't think I would be alive today.

Julie's update 16th June 2002

I am sending a copy of this story to Birmingham Children's Hospital to help children and families feel positive about getting through liver transplant, there is life at the end. I am now 32 years old. I am a personal account manager for Lloyds TSB and have just had my first child, a little girl called Jasmine who is 3 months old. Pregnancy also went normal and Jasmine is healthy.

Hope this helps

Love

Julie