



SIMON'S
STORY

A DECADE OF DARKNESS

Diabetes can ruin your life. | Simon's Story



Me + Diabetes
A blog about
my journey

MY LIFE WITH DIABETES

My name is Simon, aged 45, and I did not manage my type 1 diabetes. I allowed my diabetes to become **out of control**.

Now, in 2015, I live with my health problems which are mostly caused by that abuse.

I have learned that you have to follow the rules and be determined not to let diabetes destroy you. A positive attitude is essential.

My mission is to use myself and my experiences to show people what can happen if they are diabetic and do not follow the disciplines and advice of the medical profession who support them.

My objective is to prevent patients from making the mistakes I made and thus avoid the many painful and restricting conditions that can occur.

To do this I am prepared to work with any group who feel that I can help them and their patients.

I have attended some meetings and spoken about my life with diabetes. The Swindon CCG has created a video interview of me on the website

www.swindondiabetes.co.uk/support/simons-story

I am now committing this story to print.

Simon

MY PROBLEMS

1988	Diagnosed with Type 1 diabetes – insulin dependent
2003	Problems with eyesight, several surgical procedures
2005 March	Diagnosed with kidney failure earlier and now started dialysis at home each night.
2006 Nov	Became blind with zero vision, still on dialysis. Many infection issues. Need transplant.
2007 Dec	First call for transplant - aborted
2008 Jan	Second call for transplant - aborted
2008 Feb	Third call for transplant – successful
2008 Mar	Caught Clostrum difficile in Churchill
2008 Apr	Left hospital after nine weeks
	Worsening diabetic neuropathy

All this because I did not look after my diabetes.

My life has been changed forever; I do not work (yet), I cannot drive my car, I cannot play golf.

The following paragraphs trace the journey from diagnosis to today. I hope it will help you to avoid the mistakes I have made and avoid the pain and suffering I have endured.

MY STORY

We came to live in Wootton Bassett in December 1972 and we grew up there apart from moving to California for two years with my dad's work. I was always fit and active and weighed about 55 kilos. When I left school I worked in retail in a number of areas.

In May 1988, my parents noticed that I had lost weight and a visit to the doctor resulted in my being diagnosed as TYPE 1 diabetic. I was admitted to Princess Margaret hospital and trained in what to do and how to do it. I had to have **four** injections per day. In those days you were given phials of insulin and you had to draw down the correct dose to be injected.

THIS WAS TWENTY SEVEN YEARS AGO – IT IS DIFFERENT TODAY.

Over the next few years, I worked and played various sports, passed my driving test and moved out of my parent's house. I got married and lived in Rodbourne. Sadly the marriage did not work out and we were divorced after three years.

It was about that time that the "wheels started to fall off". I missed several injections, abused my diet and my diabetes. I missed clinic appointments so I was not being monitored properly.

After a blood test was done, I was called into the hospital and told by Dr Paul Price that I had kidney failure and would need dialysis and a transplant in the next few years. A few short months later I started dialysis.

DIALYSIS

It is now March 2006, and I was admitted to Churchill hospital in Oxford to be fitted with a device that would allow me to perform Peritoneal Dialysis, overnight and every night for eight to ten hours.

Each night I would set up my machine with bags of fluid and connect myself to the machine. When I disconnected in the morning I was free for the rest of the day. This method was more suitable for me than haemodialysis which requires a visit to the hospital three times a week for four to six hours for a different process. It was safer for my eyes.

There were a number of side effects:

- My blood pressure was very high
- My blood sugar was very erratic
- I was prone to infection which resulted in a few hospital admissions
- I became anaemic

All these required medication of varying types, some of which worked and some did not.

Meanwhile, I was having trouble with my eyes. I had several procedures at Great Western Hospital to resolve the problems. I was no longer fit to drive so I returned my licence to the DVLA.

I could no longer keep working and I was now living with my parents, in North Swindon.

On the night of 15th November 2006, I connected up to my machine and went to sleep. When I woke up in the morning I rubbed my eyes to clear my vision. **I failed!**

I WAS TOTALLY BLIND WITH ZERO VISION

I have remained in that state and unless new advances in medical development occur, I will remain that way.

This immediately gave me a number of problems:

- I could no longer perform my dialysis alone; my parents had to help me.
- My mobility was seriously restricted; I could no longer go out unaided.
- Life became very stressful which only made my conditions worse.

From November 2006 to February 2008, I continued with my dialysis and blindness at home with my parents. They became experienced in the whole setup, dealing with machine faults and recording all conditions that arose.

My diabetic neuropathy had become a real problem and I spent a week at the National Neurological Hospital undergoing series of tests. My parents came and stayed in a nearby hotel to supervise the dialysis as the hospital nurses were not trained in dialysis.

To make life easier for me, my parents had an extension built which gave me a ground floor living/sleeping room with a wet room. This has its own front door with wheelchair access. This made life a lot easier for me.

THE TRANSPLANT

My general health was erratic and worsening.

It was Christmas morning 2007 about 8am when the telephone rang.

“This is the transplant coordinator; we have a kidney and pancreas and we would like you to come to Churchill as you are number 1 on the list”

At first I thought somebody was fooling around but quickly realised this was the real thing. We packed up what we needed to take and travelled to Oxford.

We arrived at the renal ward about 10:30am. I was made comfortable and the preparation tests were carried out to ensure my suitability. They take forty eight blood samples. I passed all the tests and I was about to be transferred to John Radcliffe for the transplant.

All of a sudden everything stopped.

There had been a major traffic incident on the M1 and all the intensive care facilities had been allocated to it.

MY TRANSPLANT WAS CANCELLED.

We returned home to enjoy the rest of Christmas, pretty deflated.

About the middle of January 2008 we received another call from the transplant coordinator. I was second on the list but was asked to come to Oxford.

We set off again, arrived and started to do tests. However we were told that patient one was suitable and we could go home.

On the 7th February we had another call and I was told that I was third on the list and did I want to come in. If there was a chance of a transplant I had to go so off we went.

When we arrived I was told that one patient was unwell and was excluded. The other failed the matching process so the kidney was mine. I said goodbye to my parents and went by taxi to John Radcliffe accompanied by a young nurse on her first day.

I was very nervous about what was going to happen to me but there was no way back. The transplant of the simultaneous kidney and pancreas was completed in about eight hours and I was moved to intensive care. A “bleed” was detected and I was rushed back into theatre for it to be stopped.

After about 24 hours or so, I was transported back to the Renal Ward at Churchill. My new kidney and pancreas were both working and I no longer need insulin.

The expectation was that I could leave hospital in less than 10 days. Sadly, that was not the case. The hospital bug Clostrum Difficile entered the ward and infected several patients, myself included.

I received a very bad effect with being unable to retain any food and drink in my body and eventually my weight was reduced to 40 kilos (6 ½ Stone). I acquired other conditions

as a result and spent over 9 weeks at Churchill. When I was allowed home I could hardly stand and had to be nursed back to minimal health over a long period.

I still could not see but there was no dialysis and no insulin to inject.

As my parents were retired, they were able to devote as much time and effort that I needed to try to improve my condition. It was very difficult at times but we kept going.

MOVING ON

During the rest of 2008, I slowly adjusted to my new situation. The kidney and pancreas were working well but I was prone to infections. The medical staff at Churchill hospital were always there for me; they always helped me.

One day my parents met a blind lady with a guide dog at the local supermarket and they spoke about me. This proved to be a huge turning point in my life. The lady gave lessons to classes of visually impaired people in using a computer.

I joined her class and started to use a computer. It was more acceptable to me to be taught by a blind person like myself than by someone who could see. They also had a tenpin bowling group who met every Wednesday at the local alley. This opened up a new social scene for me as they played in a national league and had their own bowling balls and tee shirts.

As time went by I started thinking about my future. My parents were elderly and would not be able to support me in the future so I needed to become more independent. I would start by moving out into my own place to see how I would cope.

In May 2011, I rented a ground floor flat in North Swindon for six months from a private landlord. I bought equipment to help me live and surprised my dubious parents with my success. Living on the ground floor on a main road with the window open was neither secure nor quiet. In November, I moved to small bungalow in West Swindon which had an

enclosed garden. This was much better but it was also a private rental.

I now lived near my sister and her family and it was very comfortable and great to have a garden. My initial six month contract was renewed in June 2012 and I was happy with my improved independence.

In August, my luck ran out again. I was tenpin bowling on a Wednesday as usual and I slipped and turned on my right ankle. I thought that I had sprained it but carried on bowling.

When I returned home, my dad looked at it and saw it was out of shape. We went to A&E at GWH and it was x-rayed. The doctor could not understand why I was not screaming in agony as my foot had broken away from the ankle and turned around. It was reset without painkillers. I subsequently had a plate put into my foot.

This only happened because of my diabetic neuropathy masked the pain. The problem is that it can disguise serious injuries as well as all the other problems it creates.

I had to leave my bungalow in West Swindon and move back with my parents.

Despite all this I had proved to myself that I could look after myself.

We went away for Christmas 2012 and had a great time. I started to recover the foot problems and was anxious to get back to living on my own again.

SWINDON BOROUGH COUNCIL

Since I did not have the money to buy a house I applied to Swindon Borough Council to rent a place. Initially a low priority applicant, I eventually had a flat in Haydon Wick and moved in during September 2013. This is a sheltered flat with a resident warden.

As I could not use a lift alone, I could only leave the flat accompanied by somebody. A year later, a ground floor flat became available and I asked to be considered. The housing management at the council recognised the benefit it would give me and I was successful. I can now travel outside my flat to the common areas alone to meet with other residents. I also have access to a small communal courtyard garden which is protected.

This has increased my independence, improved my security and increased my social network.

I am especially grateful to Swindon Borough Council for the service and support I have received from them.

Through their adult care services, I have someone who takes me out twice a week to attend appointments and do my shopping. This reduces the dependence upon my parents.

TECHNOLOGY

I have invested heavily in technology. Without my audio devices I would not be able to live as independently as I do. Because a lot of these are "newer" technology they attract a higher price. In total, the investment is over £10,000 but it is worth it.

I have a good quality PC and printer with special software called JAWS. I do not use a mouse, just a keyboard and I cannot see the screen. JAWS tells me which keys I press and reads out what is displayed.

With my BT broadband connection I can send and receive emails, access the internet. Using a word processor I create and print documents e.g. shopping lists.

I have an MP3 player called Victor Reader Stream that I use to read talking books and play music using SD cards. I have read over 400 books since I went blind.

I can read printed mail with my photo reader SARA.

I have two "Pen Friends" which create and read back audio labels in my own voice. I manage my medication and my music collection with these.

I have a talking microwave which allows me to cook for myself.

There are others and they all contribute to my independence and help me enjoy a wider range of activities.

ASPIRATIONS FOR THE FUTURE

I will continue to live as normal a life as possible. I have no idea what challenges lie ahead.

I hope my transplanted kidney and pancreas will continue to function.

I hope that advances in medicine would, one day, allow me to see a little.

I would like to acquire the skills and opportunity to be able to work again.

I hope my parents are still around to support me, for many years.

I hope to expand my social life with new and different activities.

Finally, I hope these reflections inspire you to ensure that you manage your diabetes well and enjoy your life to the full.
