Ken’s story

Klinefelter’s syndrome or XXY is caused by having an extra X chromosome from conception. I have Klinefelter’s syndrome, I was not diagnosed until I was 36.

3 days after I was diagnosed, I went on a camping weekend. We were members of a ski club who went camping in the summer to help keep the club going. While there we indulged in some alcohol, possibly a bit too much! The trouble with alcohol is how depressed you can become after drinking it.

I decided that, since the main function of a human being is to ensure the continuing generations of life, it was quite pointless me being alive, given that I would never be able to have children. I staggered towards the riverside, taking more alcohol with me, with the thought of throwing myself in the river. Thankfully, I didn’t get as far as the river.

Diagnosis and Treatment

Despite having regular chest examination for asthma, it had taken a locum doctor to decide that, at aged 36, there was something not right with me. I had and still have female breast formation. The doctor referred me to an endocrinologist who spoke with my mother about the condition, and it was a done deal that I would start testosterone treatment at once, I do not think I was involved in the discussion, my mother was a dentist and dental anaesthesiologist. Through embarrassment I never told anyone other than my cousin, who used to give me my hormone injections, he was a GP.

Being told that you are infertile is extremely hard to come to terms with. I had always believed that it was my choice that I had not had children, but to have that choice taken away from you is devastating to deal with. Society assumes that you should have children so, for a lot of people with Klinefelter’s syndrome, to be constantly reminded that they cannot have children is often hard to deal with. Today, my biggest difficulty is organising myself.

Education

If I had been diagnosed as a child, my education experience could have been more productive. I didn’t get the support people that know they are XXY typically get. I was very shy and gullible and also tend to take the spoken word too literally.

I went to 5 schools to be educated. The first school only took boys up to the end of primary 3. That year I had my first major academic failure. I failed the entrance exam for the school that my brothers attended, which should have taken me from primaries 4-7, then onto secondary school for 1st year through to 6th year. With my parents at a loss with what to do with me, I then went to my 2nd school - the local one for primaries 4-6. I fitted in quite well there.

My third school was a boarding school, for primary7 and 1st year of secondary school. I did enjoy my time there, once I got over being homesick (which was hard). It had been my choice to go to this school, as my mother’s uncles had studied there and it sounded fascinating. I used to get a piano lesson once a week from an external piano teacher. After a few weeks the teacher told me “you are the worst pupil that I have ever taught, it’s as though you never practise from one week to the next” (which I didn’t!). I only ever had access to the piano room when she was there, and no one thought to tell me I could get the key to practice out with my lessons. With me being incredibly shy, I was never going to speak to an adult to query this as “adults knew best”. A lot of people with Klinefelter’s syndrome are never in relationships and so spend their lives very alone and depressed.

I was eventually allowed to go to the same secondary school as my brothers, but I had to sit an entrance exam and had to repeat first year at my new secondary school. I had really bad eczema whilst at that school and spent 3 weeks in hospital because of it when I was in 3rd year (aged 15). The doctor told me “don’t worry about the eczema, by time you are 17 and been through puberty, it will be a distant memory”. He was wrong about the age; I was 36 before it began to clear up. I had 40-50% of my body covered with eczema, especially at my joints. It only started to clear up when I went onto replacement testosterone after having just been diagnosed with Klinefelter's syndrome.

Looking back, I was bullied quite a lot as I did not fit in. I suppose as someone who has Klinefelter's syndrome and therefore doesn’t fit into the normal male role, I was an easy target. My next academic failure was in 4th year when I sat 9 Ordinary Grades exams and failed all 9. That was quite an achievement! I then went to my 5th and final school for 5and 6th years, where I learned shinty and played for the school team.

Driving

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I had a very keen interest in driving from an incredibly early age, about 10 years old and long before I was legally allowed to drive. I used to spend every opportunity driving my dad's car around our garden to such an extent I used a full tank of petrol over a weekend using only 1st and reverse gears. For over 30 years I worked as a van driver. I was just surprised that someone would pay me to drive and give me a van and free fuel, but being a van driver had its drawbacks, although I really enjoyed the freedom of driving. The pain and severe embarrassment of having to speak to someone to get a signature for the deliveries was also compounded by my deformed body shape, tall and skinny with no upper body strength coupled with having gynaecomastia as well. My work was mostly delivering paper and art supplies to schools, nurseries, and colleges. My employer, who I worked for over 15 years, once remarked that I was the one driver he could rely on to bring back an empty van, "but God knows what time zone you are in, it is certainly not ours!!"   I have always had a problem with timekeeping, despite what people are prone to think it is not because I am deliberately being late, it is because I am so disorganised which makes it extremely hard to decide what to take and what quantity.   No matter the length of the journey and season of the year, I always take a flask of hot water and coffee. At one-point last year I was fully covered by 2 different breakdown companies for my own van, as well as having a full tool kit. The trouble with having a van is you can carry a lot more than you really need to.

University

I always thought that I was not as academically thick as my school records suggested.

In 2006 I enrolled at college for a night class for mature students. Once completed I had to do a summer chemistry course prior to starting a diploma course in Environmental Science. The university decided there was not enough interest to run the environmental course, so with the help of a biro and a prospectus, I closed my eyes and chose which course I would do. Applied Bioscience won! I could do the lab work as it was practical, but I could not do the exams as it was based on memory. People with Klinefelter's syndrome have poor short- term memory.

One of my lecturers suggested that I approach student services for help. Initially they were extremely unhelpful, to such an extent that I thought they did not believe that I had Klinefelter's syndrome. I was due to see my endocrinologist, so I got him to confirm in writing that I did really have Klinefelter's syndrome. When I showed the letter to student disability adviser, he looked visibly shaken I said to him you did not believe I had Klinefelter's Syndrome did you? He replied no he did not and had assumed that as I was doing a science course, I had just looked up the most obscure condition there was so that I could access extra funding. By the time I had been assessed and help put in place, it was too late for that year.   I had to repeat 1st year and the exams I had already taken. I was told if I changed to Health Sciences there would be less exams, but more emphasis on written work. This was not true, but I was given the help of a notetaker, who could help me keep my coursework on track and on time (sometimes).

I now have a BSc in Health Studies and a Post Grad Cert in Alcohol and Drug Addiction.

Klinefelter’s Syndrome Association (KSA)

I joined the KSA when I was at university. I was asked by the chairperson at the time, Alison Bridges, if I would like to come to a 2-day medical conference that she was attending. It was only 12 miles from where I lived. It took a lot of persuading, but she eventually hooked me on the 2nd day by saying that food was included. As a student you can never turn down a free meal, so I went. The doctors I spoke to were interested in hearing about Klinefelter's syndrome from a patient’s point of view. I have now been to about 20 conferences trying to educate the medical profession that Klinefelter's syndrome is not rare, but that it is rarely diagnosed.

I am now a trustee of the KSA, and I volunteer on the Helpline. The KSA has been a registered charity since 1990. It is run entirely by volunteers and has a worldwide membership. It works to support its members and to raise awareness of KS/XXY. The KSA offers free membership to professionals with an interest in Klinefelter’s syndrome.

For more information, please see www.ksa-uk.net