

Siren Film and Video

Answer Project

Interview with Tony McCabe (Klinefelter's syndrome - 36years)

Interviewer: Who do you live with and what do you do for a living?

Tony: Okay, I live with my wife, Teresa. We've been married for three years but have been together for 12 years. I work for a fitness company. I give advice on health and fitness, but I'm also the Purchasing Manager for the company, so it's quite a responsible job and I enjoy it. I've worked for the company for six years.

Interviewer: So when did you find out you had Klinefelter's?

Tony: I found out I had Klinefelter's in 1992 when I was twenty-four / twenty-five. It was through an infertility test, that was the spark that caused the diagnosis if you like. In my previous marriage my wife already had two children so when we were trying for children and not getting anywhere I was the one that was tested and it was at that point I was told that I wasn't producing sperm. It then took a further eighteen months of investigation to find out what the actual reason for that was. It was then I was told I had the mosaic variation of Klinefelter's Syndrome.

Interviewer: Going back to when you were a child then, was there any indication? What were you like physically?

Tony: Physically I was always very small, poor bone structure, very weak, I didn't have any muscles, I didn't take part in sport ... particularly team sports, I wasn't good at that and I avoided those situations because I knew I just wasn't physically strong enough to compete. Really up until puberty that was the only way it manifested itself. It was knowing that I couldn't take part in the rough and tumble stuff that boys tend to do.

Interviewer: Were you often at the doctor's?

Tony: Not for physical complaints as such. I suppose I was to some extent a sickly child, but how much of it was psychosomatic and school sickness I can't answer that. But I don't remember being taken to the doctor on a regular basis.

Interviewer: So looking back were there any other problems you could say that you associated with it?

Tony: Not physically, no.

Interviewer: What about reading and shyness?

Tony: Yes. I was very, very shy. I wouldn't go anywhere on my own. I found it very difficult to make friends. I didn't have any real friends. I didn't hang around with large groups of lads, so I would just make one close friend and stay near him. As for reading, I was about eight or nine before I could read and write. It should have been, in my opinion, picked up as a child, but I slipped through the net.

Interviewer: Did you ever get bullied when you were a youngster?

Tony: Yes ... just because I wasn't physically strong enough, I didn't like to play football and I knew that I wasn't capable ... I knew that I didn't have the strength to tackle somebody, and when I did, because of my poor hand-eye communication, or foot-eye communication, on the odd occasion that the ball came to me and I had to kick it in the direction of the goal, it would go sideways, or, no where near the goal, and it just made me a very easy target for the bullies... it was an excuse for them to pick on me, so this made things a little bit more difficult. Again not being able to read and write didn't help because I couldn't read what was on the blackboard and sitting at the back of the classroom and all the other little things that at the time are quite small but put together mount up to a difficult school life.

Interviewer: And then what about as a teenager, which is difficult anyway?

Tony: Puberty didn't really happen, I got a few hairs here and there, but the testosterone didn't kick in because I didn't have any. So that became a very, very hard period of my life because all your peers were developing and I wasn't and you start putting it off so at fourteen or fifteen when they started to get bigger and stronger, I wasn't, so I became more of a loner. I started withdrawing into myself. And then as you get to, seventeen / eighteen you start thinking your friends are shaving and you're not, and you start asking others because you're generally mixing with people who are eighteen or nineteen, so you're asking them, 'how old were you when you started shaving?' – 'oh, I was seventeen', and you say, 'oh, okay I've got a couple more years yet', and then by the time you leave school you're mixing with work colleagues and, 'how old were you when you started shaving', 'oh, I was twenty', so you've got a couple more years yet, and you know, that was something that really deeply affected me and was one of the reasons that I needed to find out what was specifically wrong with me after I was told that I was infertile. At the time of that happening I didn't do anything about it and that's why it took eighteen months. But being twenty-four and not shaving I knew at this point that I

was more than a late-starter. So through my teenage years there was a lot of battling going on emotionally with myself, and why wasn't I the same as the other lads in the school or the other lads in the area.

Interviewer: And were you bullied as a teenager?

Tony: Yes, to a certain extent, but not as much as my earlier years. I was easy to be picked on you see. I didn't have any muscles so I was an easy fight. They knew that I couldn't hurt them. It's always good to make somebody in the playground cry, so, yes, but it wasn't that often, it was only ... I don't know, maybe I can think of half a dozen occasions throughout my teenage years when that happened, but it was half a dozen occasions I'd rather didn't happen.

Interviewer: When you found out, what were other people's reactions? What did your parents think for instance?

Tony: At the time my dad was very, very good and he dealt with the situation excellently. Unfortunately my mother really struggles to deal with it ... and even now she'll change the subject if I bring it up. So I think she's obviously devastated. Occasionally she decides to talk to me, but I think she feels guilt ridden, you know, 'is it something I could have done to have changed this', and I try and put her mind at rest that there is nothing she could have done. As for other people I didn't tell anybody.

Interviewer: What about your wife?

Tony: My wife has been with me through all of it. I knew her as a friend at the time I was told I was infertile and by the time I was diagnosed as KS we were seeing each other. I suppose I need to explain ... when I was told that I was infertile my marriage ended within six weeks. So that was one of the reasons that I sort of confided in Teresa my wife now. So she's been there all along and she's been very, very supportive.

Interviewer: So she knew before you entered into a long relationship with her?

Tony: Yes.

Interviewer: What about friends? Did people think maybe you were gay?

Tony: No. I've never been thought of as being gay. I've always had girlfriends. The only real incident I had was after I phoned the organisation that I now run - the Klinefelter Organisation, I

received a letter back from one of the committee saying that it was OK to be gay and it doesn't make me any less of a man. This really upset me at the time because I hadn't mentioned being gay or that I felt gay, and he had just introduced it into this letter and I couldn't understand why. I know a lot of KSers are gay, the percentage is very high, and I know other men who feel feminine because of the way their bodies look. Such as the breast development and the pear shaped appearance that some guys can have.

When I was at the meeting in Glasgow up until that point the doctors had never told me any of the conditions associated with Klinefelter's they just told me I could never have children. It's only since then and meeting the other guys that they filled in all the gaps and told me all the other symptoms that are associated with the condition. We're at high risk of osteoporosis, ... we are at high risk of testicular cancer,... of getting a condition called gynecomastia which is breast development in males,...and we're generally of poor health. We tend to get a lot of cold's, so if there is one going round more likely than not we will get it. It can be as simple as that. Another condition is called torodontism which is brittle teeth, your teeth tend to shatter very easily. Now not all KSers have this condition, in fact they can have none of them and go through life perfectly fine, apart from being infertile, or they can have all of them and life can be very uncomfortable. Personally I have had the gynecomastia and had to have a double mastectomy to have them removed.

Interviewer: What was the mastectomy experience like?

Tony: Gynecomastia (*breast development*) manifests itself in swelling around the breasts and around the pectoral region, so when I went to see my consultant, I said 'I think I have this' and she said to me 'yes you have, we've known all along that you had it but you never raised it as an issue so we didn't tell you. But since you have raised it as an issue, yes you can have them removed.' There are two operations that you can have ... depending on the severity of the gynecomastia. In my case I wasn't that severe. My right breast was graded at five out of ten. Ten being the most severe and my left was graded at about three, so it wasn't that bad, but as far as I was concerned it was bad. So what they do is they make a small incision around the nipple, just go in and suck it all out. If however, it is more severe and I have met guys who are very, very badly affected – they could almost wear a bra they're that bad, then the operation is a lot more drastic, basically they lift up the breast and do a full incision along the pectoral line and remove the breast tissue and fat from there, but then they're

left with scarring. However if it's seriously affecting them then it's easier to hide the scars than it is to hide the breasts. I found the whole experience quite depressing. Here I was having a female operation, with the doctors and nurses saying to me 'so you have just had a double mastectomy?'. I thought of the operation in terms of removing the gynecomastia not having a double mastectomy. It took me a long time before I could except the operation in those terms.

Interviewer: And what about hormone treatment?

Tony: Yes I'm on hormone treatment. I started on that when I was diagnosed at twenty-four or twenty-five and I'll be on that for the rest of my life. I've had every form of treatment available now. Primarily they start off with tablets, but in adults they are not really strong enough to give you the levels of testosterone that you need. For a teenager they would be fine to kick start puberty for them but as an adult they were ineffective on me. So after about six months on that I then went on to implants. A lot of men that I know say they are very good you just have it done every four months. It's just a small incision either in the abdomen or the buttock and they place four pellets in, one for each month, and it gives a sustained release of testosterone over the four months. In my case the first time I had it done it was successful and when I went back four months later I had it done again, four more pellets were put in, in my buttock this time, and it was a nightmare, they just kept coming out, they wouldn't stay in. I had puss oozing out of a hole in my cheek of my bum, and I thought it was an infection, but it was actually the pellets which were breaking down and starting to leak out, of the incision and this prevented the wound from healing. So they tried on three occasions to put these four pellets in and each time my body just wasn't accepting them. Now I have these round scars on my bum. So after that they decided to put me on the injections and that is pretty much what I've been on since. I've been on the injections. On average you have one injection every three weeks and that provides a slow, medium and fast release of testosterone over the three weeks. It gives the best form of testosterone in to the body. It's the most practical. It's the easiest to do. And it's really the treatment of choice. However, since July they have managed to get testosterone into a transdermal gel. Basically you just rub it on your body and it gets absorbed into your system, so if you don't like injections then this is a good way of taking it in. I have been using it, but I don't find it as good as the injections. It doesn't give me the levels of testosterone that I need to be able to function effectively. I also tried for a while the patches. Now there are two forms of patches. The first is a scrotal patch, but that's not really very effective with us, because having small testicles this patch is huge and it's just far too big

for KS men. The second patch is a patch that you just put on around your abdomen or round your thighs or your upper body, put it on anywhere really, and this provides a daily release of testosterone, but a lot of people suffer with the stickiness of it which can cause blisters and you can be allergic to it on the skin, which is the problem I had with it.

Interviewer: So do you have normal sexual relations.

Tony: Yes our sexual relationship is fine. Normal desires, normal libido. But only since treatment started. And only really since I started on the injections. But since I have been on the injections that's more than adequate. It's fine, no problems, if not a bit too much as far as my wife's concerned. Prior to that my libido was very, very low. How I managed to keep so many girlfriends in the past is beyond me but in hindsight, more often than not I didn't have sexual relationships with them. Two reasons – (1) I didn't have the desire and (2) I tended to be embarrassed about my testicle size.

Interviewer: Do you think KS has affected your marital relationship ?

Tony: We've had to work at it, just as in any marriage or any relationship. I tend to get an idea and become quite pedantic about that idea and not want to let it go. In general we aren't very good at communicating how we really feel and particularly when our testosterone levels are quite low we become quite hormonal, so we'll be crying all the time and be argumentative and all the things that some women go through on a monthly basis. You know, that is what it is like for us, pretty much all the time, pre-diagnosis or before testosterone treatment. So we can be very difficult to live with, flying off the handle for no reason and then not being able to calm down from that. Although we've been together twelve years, I'm completely happy now, but it has been a struggle at times and we have thought, 'are we in the right relationship', but I've got a strong wife and a good woman and I believe whole-heartedly that KSers need that – you know to just say, 'Tony you're being silly, stop what you're doing, listen to me. This is how you should react in this situation', and once I have been told that and I know that I can be told that, I'm quite prepared for Teresa to tell me that. I sort of back off, listen to what she has to say, and view the situation through her eyes and deal with it from there.

Interviewer: Do you have any other problems?

Tony: Concentration is one of the biggest problems that we have. If there are two things going on at the same time we struggle to do both of them. If you take that further along the line to a

classroom situation then it becomes quite problematic. You've got to read what's up there on the blackboard and listen to what the teacher's saying, and that's where things start going wrong, because we really, really struggle with that, and again, put yourself as an adult into a job situation. You've just started, a new job, how to work the computer or how to do this job, but have to listen to the instruction at the same time. It can cause enormous problems, and you have to be able to say, 'you're going to have to show me this again.' We are better a learning if we can be shown how to do a job. I think that type of learning works better for us. I also think that we need to understand why the job has to be done in such a way. Being told 'because it has always been done that way' is not good enough. We have to understand why this is the process.

Interviewer: Did you go into the health and fitness profession because of your condition?

Tony: My health and fitness life style started around the time that I was diagnosed in 1992. It was a big year for me that. I knew that I wasn't right, I knew that there was more to me than being told I was thick and to my small stature and I wanted to change that, so along with going back to college and getting an education I also started going to the gym. Now I'm only 5'5 and back then I weighed seven and a half stone, but I'm now twelve stone. My drive, my motivation to get into the gym to try and put some muscle on and look more masculine was because I felt girly or boyish and not like a "real" man. When I first started training, not a lot happened, because I didn't have any testosterone. Once the injections started a couple of years later, then that started to encourage the muscle development and I started putting on weight. It's only in recent years, the last two or three though that I found out that my weight training has actually prevented me from getting osteoporosis because it's good for that – it strengthens the bones as well as the muscles. I had a bone density test done in 1999 and they showed me the graph and they said the only reason I'm in the average section was because of my weight training, because I was going down to the gym three times a week, so for me, now, not only does it help me feel and look more masculine but it's also preventing a medical condition.

Interviewer: And then you took that up as a career?

Tony: Yes, I saw the job in the paper advertised for just a sales assistant at the muscle and fitness shop where I used to go to buy my proteins and stuff and I applied for the job and I got it and that was in 1997 and now I'm the Purchasing Manager for the company. It's not a huge company by any means, but it's turning over a million and a half per year and I have to make

sure, to try and increase that through reducing costs and getting better prices so there's a lot of researching of new supplements that are coming out onto the market and what we need to have to make us more effective at selling what the consumer wants.

Interviewer: So how do you think it's affected your life overall?

Tony: In hindsight it has made my upbringing more difficult than the rest of my siblings with the learning difficulties etc. which we didn't know about at the time, we just put it down to me being lazy or slow or just not bothering, but now we know that Klinefelter's did have an effect on my education. My education, now however, I have an honours degree and it's something that I worked very hard to achieve. I received a 3rd class honours which I used to be ashamed of, but now that I realise what I have done to get that, I am very proud, considering that I was eight or nine before I could read and I had left school with no qualifications at all.

I am struggling to deal with the infertility aspect. As I'm getting on now, I'm in my mid-thirties, this is an issue for me and it's something that I'm having counselling for.

As for the rest of my life with KS I try and get by as best I can. I try not to let it rule my life. I fight it. I have a degree when most KSers haven't. I have muscle when we are told we shouldn't have. I have been with the same woman since 1991 when we are told we can't keep relationships.

Interviewer: What would you say to prospective parents who knew they had been diagnosed as going to have a boy with Klinefelter's syndrome?

Tony: I got this telephone call a few months ago. A couple were told they had a week to decide whether to abort or not and they wanted to speak to me, and my initial reaction was to say, hey, look at me, you know, I've a good job, I've been married for three years, been with the same woman for twelve and don't do it! But then I couldn't do that, because some KSers are more severely affected than others. I'm not as affected as some other cases that I know and I had to point that out, you know your son could have, not will have, but could have problems, both mentally and physically and you have to be aware of that, but knowing what could happen gives you the power to do something about it, unlike my mother who didn't know why I was struggling, you will know and you can get extra tuition and tell the school, and say what learning difficulties he will have. Your child is not thick or stupid, he's just a little bit slower than some other boys of his age. The

couple I spoke to a few months ago decided to keep their baby, after speaking to me and another KSer I put them in touch with, and also the positive response from the consultant.