

## Answer Project

**Transcript of edited interview with Imogen (Turners Syndrome – age 47) (*not real name*)**

**Interviewer:** Can you describe who you live with and what you do for a job?

**Imogen:** That's my husband of getting on for 24 years. I'm a Project Administrator for a childcare charity.

**Interviewer:** Is that a full time job?

**Imogen:** It is, yes. Full time, a little bit of everything. Reception, general secretarial stuff. You name it, it is part of the job description.

**Interviewer:** When did you first find out that you had Turners Syndrome?

**Imogen:** It would be when I was 14, maybe even 15, because my parents waited until I started asking questions. I was diagnosed when I was roughly 2 years old, at the famous children's hospital in London, but in lots of ways I am very grateful for the fact that nothing was said until I started asking questions. I think I had known for probably at least 2 years before that that something was up. But that was it.

**Interviewer:** Why were you grateful that you didn't know before?

**Imogen:** I think there would be pros and cons about either approach, obviously. I think basically because it let me have a childhood. I think it's quite difficult to know what the impact of knowing from an early age might have been. We'd seen a lot of doctors and things when I was younger, but it was never properly explained, fully explained, so I suppose the general sense of knowing 'something was up' stemmed partly from that and obviously partly because puberty wasn't happening; - it was sort of, why not?

**Interviewer:** So what was your childhood like?

**Imogen:** Very happy. We lived abroad. I was born abroad, and we lived abroad when I was the ages 5 to 11. My Dad travelled a lot. I've got one sister, older sister, and I would say on the whole it was very stable despite all Dad's travelling and very happy.

**Interviewer:** Did you have any particular problems when you were a child?

**Imogen:** School was a bit different, - secondary school. I failed the 11+, so at that point I was sent to a private all- girls' school for the best of reasons – smaller classes; it was thought it would help, particularly as we knew I was hopeless at maths! But I had a pretty horrible three years of being bullied there until the girls who were doing it actually left for some reason. Then in the sixth form I went to a different school which was mixed gender and terrific;- fantastic two years. Marvellous teachers. Brilliant headteacher.

Total acceptance from my peers. I think it was a great launching pad for university.

**Interviewer:** In that previous school, were you bullied because of your Turners syndrome?

**Imogen:** I think just because I was little. They threw me about because they could basically. And it only stopped when I slapped one of the girls who was doing it very hard across the face one day, which actually made me feel dreadful because I should have been able to stop them some other way. I think, looking back, I possibly made it worse because I showed absolute contempt for the people who were doing it, and I don't think they liked that very much. But we weren't supervised properly at all, so play times, break, lunchtimes weren't much fun. I think I used to look like I'd been dragged through a hedge backwards sometimes.

**Interviewer:** So when you were a little girl, I mean from 2 to 11 - was that quite a normal childhood?

**Imogen:** Yes, because we were living abroad. My primary education was in one small private school, then a forces (Navy) school for 3 years. I would say the two years in sixth form were the best.

**Interviewer:** You say your parents found out when you were 2: how did they come to terms with and cope with it?

**Imogen:** I think I haven't really talked this out with them. I think they have both had a lot of anxieties for me, but more my mum, because mums do worry. I think they did their best to keep it as hidden as they could, and I got a terrific sense from my family background really that I could do anything I wanted, if I put my mind to it. I think Dad was particularly good at that without actually saying it. It's just knowing that the family had a belief in me; it's been a real strength. They must have kept a lot of worries to themselves I think - for the best of reasons.

**Interviewer:** And what was your reaction when you were eventually told what was the matter?

**Imogen:** I suppose that's the drawback of not knowing from an early age: even if you have a sense that something's up, it's obviously quite a shock. I don't think people necessarily realise actually; there's probably a period, maybe even a few years, of almost post-traumatic stress or trauma, but that might be overstated. It's quite hard to know how much was just growing up, and how much was finding this out about yourself. I think because of my background I was able to see a lot of my reactions as 'normal'. I don't think I ever had any problems thinking perhaps I shouldn't be thinking or reacting this way because I've got Turner's and perhaps it's not usual. I just totally accepted that the way I reacted was - it was perfectly normal, and during my teens there was quite a strong sense of wanting to hold on to that. So okay the body may not be doing certain things, but my instincts or my emotions are

just like any other teenagers', thank you very much. And I suppose that there's also a sense of fighting against what you know is probably most people's perception of what growing up is all about. When puberty comes the secondary sexual characteristics are called as such because that's what they are; they're not what make you male or female. I think for most people who don't have any problems though, that's what they see, and that's the obvious thing. So that was a very big part of my reactions.

**Interviewer:** Did you take growth hormone?

**Imogen:** Right, well nobody ever suggested growth hormone. Not so far as I am aware anyway. Certainly not to me directly, and that might be because I'm probably on the taller side for Turner's. So that wasn't an issue, which I'm quite glad about.

**Interviewer:** How tall are you?

**Imogen:** I'm about 4'9". But I have actually shrunk a little because I'm 47 now. So I was slightly taller. With the HRT, I was led to understand that if I went on it too early it might mean that I didn't reach my full natural height, so I actually delayed it and didn't start taking it till I was 22. I had already met my husband. I don't know how many girls nowadays are probably following that pattern, but the HRT was new then anyway. The only thing on offer, which is really ironic, was the pill. Basically, that's what we got put on. But it was - we'll wait until they think I've stopped growing.

**Interviewer:** So you didn't develop secondary sexual characteristics before that? Did that bother you much?

**Imogen:** Very little. I suppose the body shape was probably what they would call pre-pubescent really. Once I started the HRT, things happened rather quickly. That's a funny sort of adjustment as well. I don't know whether to call it a difficult period - I think it was in some ways, and nobody else can do it for you or cope with it for you. You've got to do it yourself. I think holding on to your own identity, which you have obviously developed because you have reached that age before you go through those changes, is not particularly easy. I keep coming back to that in a way. I think I have come to terms with it now. It sounds weird probably but the person that I was then, the girl I was before the HRT, was me, and I think in a way she felt a bit 'left behind'. It's in relatively recent years that I have worked that through. She's still there; she's a part of what's going on now. She didn't get 'left behind', but I think it's hard because you've developed your own personality before these things happen. In some ways they are easier to cope with because you are relatively mature, but in others it's like, "what is it"? You know, "me" getting left behind, - but 'we' got there. I don't know whether that makes sense or not.

**Interviewer:** So you left school and you went to college. Did you have the same opportunities as everyone else, did you feel?

**Imogen:** After school I went to University, to Durham, and did a General Studies degree, so that was one year of Indian civilisation and three years of theology, which was split into biblical studies and church history, and modern European history. It was terrific. Really good. I made some really good friends.

**Interviewer:** So having Turner's didn't hold you back from further education at all?

**Imogen:** Not in itself; I mean, my hearing loss was to some extent an issue, and I needed glasses from the age of about 11. Which is interesting actually, because we did what was called an intelligence test and being a girl with TS I supposed I wasn't getting the shapes right. The teacher, after we had done this test, came up to me and told me that in a certain section of the test which involved shapes and things, I'd got all the on the left wrong. She asked did I need specs? We went for an eye test and I did need them. But one wonders whether it was just me not being very good at spatial things again. But never mind. I don't honestly quite know, apart from the fact that I used to sit at the front, how I got through it all, because I didn't have the hearing aid in those days – they wouldn't actually give me one until about maybe seven / eight years ago because the ears get so wet. Then I came across a really nice female ENT specialist and started saying "things are a bit difficult at work", and she said brightly and breezily, "Well I don't see why you shouldn't have one" and that was that.

**Interviewer:** And they never gave you one till that time?

**Imogen:** No.

**Interviewer:** Do you have any other physical problems?

**Imogen:** No, for me I think my hearing loss has been the main problem associated with Turner's. I happen to have a long standing chronic fatigue problem as well.

**Interviewer:** Was that separate?

**Imogen:** Totally separate. I think in some ways that is more difficult at work and has far more impact. The lack of inches are just an irritation really. I don't see it as a real impairment. It's just irritating when you're shopping and you have to have somebody there who doesn't mind reaching something off the top shelf at the supermarket for you, or something like that. Being married to a six-footer helps as well!

**Interviewer:** Do you have problems with people staring at you or anything like that?

**Imogen:** No, not particularly no. I had one experience that sticks out because it was rare. It wasn't particularly offensive, just annoying. One elderly lady at the bus stop one day said "It must be difficult being so tiny, dear". I felt

like kicking her on the shin and saying “If you only knew, lack of inches is the least of my problems; you know nothing; be quiet’. But of course I didn’t, just tried to ignore her really. There’ve been things like that, where people felt they had a right to pass comment or intrude, but it’s been rare.

**Interviewer:** Do you think it’s stopped you getting jobs?

**Imogen:** I don’t think so, no. An ex-colleague, who is a friend, saw the advertisement for where I am now and she said, “This is absolutely you - you have got to apply for this”. So I went for it. It was back in the days when they were allowed to ask women about whether they were likely to leave and have children, so that is interesting. I was asked directly, “Well, are you likely to leave and have children within the next two or three years or so?” I looked the interviewer in the eye and said “That is not possible”, and he didn’t know what to do with himself, he was covered in confusion. Fortunately another man who became my line manager had the good sense to move things on quite rapidly, and just accepted what I had said. But I thought they deserved it for asking the question. Now they are not allowed to, of course.

**Interviewer:** What do you feel about the infertility?

**Imogen:** Well, it’s been sad, for me, but my husband wouldn’t have wanted children anyway, so I think that has been part of what has made ‘us’ right. I think it was one of the most difficult things I had to do, telling him, but from his reaction I knew straight away there wasn’t a problem there. And then I suppose I settled down, sort of coming to terms –no, “learning to live with” is probably better, and then all this assisted conception stuff came on stream. I knew that I was just going to go totally up the wall unless I sat down and spent some time thinking through how I felt about it, really. And my husband was brilliant, because that meant I had to totally disregard how he felt really and just say, “Right, how do I see it? how do I feel about it?”. And I came to the conclusion that it’s just not a road that I would have wanted to go down anyway. I find the whole thing quite repellent, quite honestly, personally. If you’re honest with yourself there’s no equivalent to things happening naturally. And if you do go down the assisted conception route, for me I would have had to see it as something totally different to be able to cope with it; and I faced myself with the fact that it’s so often unsuccessful. How does one come to terms with that? Now I can quite happily say that it has created no obstacles in our relationship, because I can honestly say to my husband: “Well, I wouldn’t have wanted to do this anyway”.

**Interviewer:** It created no obstacles?

**Imogen:** It didn’t; yes I can quite honestly say it didn’t create any obstacles, because I have been able to say to my husband it’s not a road I would have wanted to go down anyway, and for me adoption is the same. Adoption has to be about the child. It’s different, and if you go down that road I think you have to acknowledge that it’s going to be different. Not worse, not less, just different. So, yes, it has been a sadness, but I think that I have managed to think my way through it like that. It’s getting a bit late now, anyway, at 47.

**Interviewer:** Do you have normal sexual relations?

**Imogen:** Oh yes, no problems there.

**Interviewer:** So how would you describe your quality of life overall?

**Imogen:** Very good. I have a lot to be grateful for. I think I can honestly say that the chronic fatigue has probably impacted more, far more, on my quality of life than Turner's has.

I think the importance of finding the 'right' partner is obviously crucial to the quality of life and there was a wise old Quaker who centuries ago said "love well but love wisely"-Choose the right one.'- I think that says it all really.

I know my mum has said that when I was very young, somebody, I presume some medical person, said it was half way to being a boy, which just makes me curl up inside and want to scream and be very, very angry; on mum's behalf as well as my own. My mum said "You were a very girly little girl". There was another occasion when I was still very young, a lady doctor said, "Oh yes, we've got a little cretin here". I can vaguely remember mum being distressed, but me not understanding the word at the time. In more recent years my mum says "I wish she could see you now." That's great. I suppose in a way there's been a sense of, not exactly feeling I had to 'prove' myself, but wanting to do that for my parents. In a way, saying "We'll show them"!