



Now 38, Phoebe has made a film about her story to help others

I'M PROUD TO BE A HERMAPHRODITE

Phoebe Hart shares her courageous journey with Liz Graham

"I have a condition called androgen insensitivity syndrome (AIS). I look like a woman but I have male chromosomes. Basically, I started off in my mum's uterus as a boy, but my body didn't respond to testosterone. The code was there to be a boy but it didn't hold, so I developed along female lines. I have female genitalia but no uterus and I was born with internal testes.

"AIS is one of many intersex conditions. It's called that because there's a crossover between male and female chromosomes or sexual organs. AIS is genetic and one of the more common ones, but it still only affects one in every 25,000 people.

"I also use the term hermaphrodite to describe myself – it's a provocative word and can be offensive, but I think it can be reclaimed in an empowering way.

"I had a carefree, happy childhood. I ran around with no shoes on, climbed trees and just sailed through things as a kid.

"My parents found out I had AIS when I was five but I didn't find out until much later. I remember going to hospital for tests, but didn't know why and didn't think about it.

"It was when I was 11 or 12 that I was first told I was different. I was having a sleepover at my house, and all the other girls there had started their periods except me and were talking about it.

I got up, found my mum and asked her when I would get mine.

"She told me I'd never menstruate and I didn't have a uterus. I was completely dumbfounded, but at the same time glad there was an explanation for why I hadn't got my period.

"However, Mum said this was a secret and I shouldn't tell anyone, so I got an inkling that what I had was something weird or shameful. I wanted to ask more questions, but Mum seemed so embarrassed I didn't.

"After that I became a bit closed. I fell out with friends, I didn't want to talk to them, I spent lunchtimes in the library by myself. For a few years, I felt like an alien and a freak.

For more information Visit the Androgen Insensitivity Syndrome Support Group at www.aissg.org

As a child, Phoebe was not told about her condition



The truth revealed

"By my last year of school I had pulled through and felt better. However, later that year, when I was 17, my mother told me about my condition. She told me then because the doctors had advised I should have surgery to remove my internal testes and the surgery had been booked for a month's time. She also thought I had only then become old enough to understand the biology of my condition.

"The revelation was overwhelming. My mum also told me my sister Bonnie, who was 12, also had AIS, but didn't know.

"My parents were following the advice of doctors at the time. The thinking was you couldn't tell a girl as young as 11 or 12 that they were a boy, as they wouldn't be able to understand or cope. But kids are more resilient than that – it's worse not knowing. I told Mum I could have understood much earlier and made her tell Bonnie immediately. Bonnie and I became so close after we found out; it was like having our own mini support group.

"A month later I had surgery to remove my internal testes. I was pretty angry at how the medical fraternity treated me. In hospital I had medical student after student examining me – I wanted to escape. My pleas for being put in touch with others with AIS were fobbed off – it wasn't until a decade later, with the arrival of the internet, that I met someone else outside my family with AIS.

"I was also not informed about what my surgery would mean for me – that I would have to take hormone replacement therapy for the rest of my life, because my testes were supplying me with all of my hormones. If I had the choice again, I wouldn't do it. If you keep your testes there's a risk of them becoming cancerous, but the risk is minimal and can be monitored.

"After the surgery, falling in love was a huge focus for me. I hadn't been intimate with anyone yet and had been terrified of it. I knew that mechanically, things were 'different' down there for me. I had tried to insert a tampon when I was younger

and couldn't. Rather than having reconstruction surgery to lengthen my vagina, I did it manually over a period of time, with a special dilating device. When I finally plucked up the courage to give sex a go, I was surprised how easy and enjoyable it was.

"I had a natural sense of my sexuality when I was younger, but that got lost for a while after my medical intervention. But in time, I established what I liked and what I was like. Meeting and falling in love with my husband

James when I was 28 made a big difference to my sense of self and my acceptance of my body.

Reaching out to others

"There are positives to having AIS. I never had acne – not being able to process testosterone gives you great skin! And it's great not getting your period every month. I'm also naturally curvaceous. But I do feel like I have missed out on feminine rights, like my period and bearing children. There are reminders every day of my condition and what I can't do, but you have to choose to take less notice of them, to get on with your life. We have adopted a daughter and that's been an amazing gift.

"I made a documentary about my life because I wanted to help other people and I think it's doing that. And it's not just helping the intersex community – I've been approached by people who have seen my film and said they felt the same way as me growing up but they were bullied or they were fat – a lot of us have felt rejected because of our bodies.

"Making the film has made a big difference within my own family – my condition is still a delicate issue, but it's discussed. I think my mum and dad felt a lot of guilt about how I was told and how my medical intervention occurred. It's also helped me to tell more of my friends. I used to be afraid if they knew they wouldn't like me anymore, but they've all said they love me and it doesn't matter. I've learnt you can tell people anything; just do it honestly and they'll be accepting.

"My advice to parents of intersex kids is to get as much information as you can and join a support group. If children are born with ambiguous genitalia, there's pressure to have surgery earlier on. That can be risky, because there's no informed consent. Sometimes it's worth waiting.

"I feel proud of who I am and of the intersex community – each one I meet is my new hero."

+ Watch Phoebe's story, *Orchids: My Intersex Adventure*, tonight on ABC1 at 10pm.