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True Life Stories

The birth of a eunuch child is a traumatic event, not only for the child but also for the parents. They have to deal with issues of social scorn, taunts and derision, while trying to come to terms with the fact that there are crucial and irreversible decisions that have to be made in respect of their child, sometimes at a stage when the child is too young to comprehend the ramifications and provide any meaningful informed inputs. Their happiness at being blessed with a child is often mixed with the sorrow of having to put the child through the misery of remedial measures and putting on a brave face.

The following narrations are factual events, as described by the people who have had the misfortune of having faced these issues, along with their explanation of how they dealt with such adversity.

A stepson is still a son but I was ...

Before saying something about myself, I would like to share a childhood memory with you. If you are a Bollywood fan, you must have seen in various movies step sons and step daughters being beaten by step mothers or being forced to go and seek alms. It was the year 1991 or 1992, cable TV had just arrived in India and I was watching a '*Ghar ho to aisa*' type movie

on TV along with my two siblings. The movie was a social family melodrama. During the show, I cried on many occasions when an innocent kid used to be beaten up by her stepmother, reminding me of my personal experience. After watching this movie, my innocent mind got this strong perception that if a kid is beaten up by his/her mother, then she must be the step mother, not the biological one.

After few days, my mother started beating me with a stick as usual. For the first time, I got angry of her and told her, "My mother must have died when I was born. You must be my stepmother, my father's second wife that's why you are beating me."

Today I realise that I was worse than a step son to my mother. A step son is still a son but I was neither a son nor a daughter. I was a born eunuch and a matter of eternal shame for her.

I was the younger of two brothers. My God fearing Brahmin parents wanted a daughter, Laxmi, in their family and what they got was a eunuch instead. I was an unwanted child for them. It was not possible for them to get rid of me, nor could they ever accept me. I was not allowed to attend school like my other siblings, given discarded clothes to wear and stale food to eat. There was not a single day when I was not beaten, either by my father or mother. This was routine for the first eight years. Then, I began to understand the difference of my sexuality as the neighbouring kids started mimicking me and calling me a '*hijra*'. Unable to bear the torture and humiliation, I left home one morning without saying

anything to my parents, never to return. For a week I survived by begging, till Sultana *Bua* came to my rescue.

It has been almost two decades since I left my home. Though I am happy with my fellow eunuchs, sometimes I feel sad thinking that my parents never tried to find me. If they had wanted to, they could have found me. Ever since I left my home, I have wanted to meet them, just to ask them if being born a eunuch was my fault.

- **Sarla**, 32 years
(Lahurabir, Varanasi 221001)

She must be a *chudail* ...

I am the mother of a 4 year old child with CAIS. Prior to the birth of my child, I had never heard of this condition. My first born was normal but the second was a girl with ambiguous female genitalia. Communicating with members of my family about this condition is almost like a taboo. My mother for instance is a very nice person but ignorance still claims the best part of her. I can remember once we were watching television and there was a program about a woman without a uterus, her exact words were 'she must be a *chudail*, of devilish origin'. Currently, she looks after my AIS girl and she loves her very much. On occasions she has asked, what's this 'bump' on her vagina and my reply was "Don't worry, she's just the way she is." Should I tell her that her grandchild is not of devilish origin? I am worried that if she comes to know of my daughter's condition, she may do her harm.

- **Sumitra**, 26 years
(Behind Mahesh Nagar, 80 Feet Road,
Jaipur 302004)

The struggle has exhausted me ...

Throughout most of my childhood my parents, especially my mother, laboured to instil in me a female identity. These efforts have had some effect. I present myself as a woman, have many womanly attributes and am treated by and large as a female. Unfortunately, this struggle has almost exhausted me. All this time I have laboured to prove something which is in some sense not true and at best a terrible simplification of a rather complex state of body and mind.

I'm not exaggerating when I say this process had for a while almost spent me. For much of my young adult life, for at least the years between the ages of 15 and 35, I remember having the experience of being in the midst of some positive experience almost daily. However, in the midst of the compliments paid to me, the exciting encounters and feelings of physical pleasure, the thought that something was not quite right would intrude into my mind, nevertheless.

I remember that almost daily experience as one of a lack of genuineness, an illegitimacy, a fear that I would be found out and ridiculed. From a very early age I felt my personal history was out of the norm, that I looked a bit different, felt a bit different and was treated differently than most females. This was never acknowledged. My doctors said only trivial things to me, my parents avoided any mention (and probably any thought) of my difference. My Indian culture dealt with the only gender ambiguity that seemed speakable – transsexualism – with a snicker. I internalised the apparent taboo and lived with a great fear of myself.

I fear that parents in their (desperately anxious) attempts to give their children normal lives, will rob them of the chance to come to terms with their own difference.

I don't wish to appear unkind or unfeeling to parents. I have so much empathy for these families, just as I have loved my family through our experience. What is important to emphasise, I believe, is that healing and a kind of wholeness and equanimity are possible. All children in this situation may not grow up to identify as intersexuals but there is a very good chance they will perceive of themselves as different to a greater or lesser degree. Not to prepare such children for this self-confrontation is to do them a terrible disservice. These children will run the risk of never being comfortable in their own bodies and never at ease with the world around them.

I realise that the prospect of a lengthy course of psychotherapy may seem daunting to parents who have already suffered considerable trauma but I can't imagine a substitute process. It would be hoped that these children can benefit from expert, informed counselling and be availed of the opportunity to join a group of others like themselves to facilitate self-exploration and gain support. I imagine the participation of loving, accepting parents in the early stages of this therapeutic process would be integral to success. Their child will become very special, someone who knows herself very well and someone who will very probably be capable of great courage and sensitivity to adversity.

- **Chitra**, 46 years
(Brij Vihar, Pitampura, Delhi 110034)

How can my daughter have testes?

In April 1994, when my daughter Maya hadn't started her periods, I took her to see my General Practitioner (GP), the month after her 15th birthday. I told him that I thought it could be an imperforate hymen. He started to examine her externally. I could see Maya was embarrassed and when he started to put on the rubber gloves I said that I wanted her to be examined by a female gynaecologist. He asked me to examine her myself.

I examined Maya and then my younger daughter, Usha, who was nearly 12 at the time. I could see a difference. It was the first time I had seen Maya 'down below' since she was about 4 year old. I could see more of Maya's 'insides'; in fact I thought that she might have damaged herself in some way on her bicycle.

We saw a lady gynaecologist at the hospital and asked for her opinion. She examined her and said it was not an imperforate hymen since she had been able to insert a cotton bud but she would arrange a scan. Later, the gynaecologist told us that Maya had been born with no womb and that her ovaries were in a strange place, in her groin. I was shocked to hear this and was unable to sleep that night. How could this happen to my daughter? How would she be able to get married? There were so many questions but no answers.

I phoned the gynaecologist next morning and asked for an early appointment. My husband and I went to see her the following week along with Maya. She told us that Maya could never have a child, that her vagina

might need to be stretched and that her ovaries would have to be taken out.

A couple of weeks later, I told my GP the news. When I told the GP that Maya's ovaries had to be removed, he told me they were not ovaries but testes. How I got home I'll never know. I couldn't say anything to Maya when she came back from school. My husband told me not to be so stupid, "How could she possibly have testes when she is a girl?"

I phoned the gynaecologist the next morning and told her what the GP had said. She asked my husband and me to visit her the following day. She told us they were 'gonads', not testes. I asked if these 'gonads' would make her look any different than she looked already and she answered no. That was all I wanted, gonads, testes, ovaries or whatever – as long as she looked the same. Then, in January '95, Maya had her ovaries/testes/gonads removed. She started her HRT (Hormone Replacement Therapy) in February. A year later, I consulted a surgeon in Mumbai about the possibility of Maya having a vaginoplasty. His reply was, "Why are you doing all this? It might never be used. After all she is neither woman nor man. She is an 'in-between' sex." I couldn't believe what he was saying and he even repeated it later on in the conversation.

I and my husband have not shared this truth with anybody, as we don't wish that others should make life miserable for my daughter.

– **Radhika**, 53 years
(M G Road, Bengaluru)

Why was I not told the truth?

I was told of my condition at age 15, when I was on a trip to New Delhi with my parents and was admitted to a hospital for a severe infection.

It's not that I was told the truth that caused problems but the fact that it was delayed so long.

I had been convinced that all the adults in my life - parents, doctors, even teachers - knew exactly what was wrong with me but were doubly punishing me for some unknown reason. By not telling me the facts and that they were aware that I had found out, they were thus imprisoning me with my own unutterable discoveries.

The usual course of management for the condition is to remove the testes and to put the AIS patient on lifelong hormone replacement therapy. Without full disclosure, it is at least a matter of debate as to whether agreement to such treatment constitutes informed consent. The same might also be said of the other medical procedures that AIS women have experienced - displayed as freaks in front of doctors, subjected to medical photography and having blood and tissue (often labial tissue) samples taken for research.

– **Lata**, 47 years
(Udhampur, Jammu 182302)

I was paraded naked before strangers ...

My decision to drop all medical care was the direct result of the humiliation and obfuscation I had been subjected to over the years. Junior hospital doctors were paraded past my vagina when I was 11 or 12.

Not once was I asked how I felt about any of what had transpired. I was a patient with a terrible secret that even the doctors and my own mother couldn't or wouldn't discuss and here, I was paraded naked before strangers. Is this treatment ethical?

– **Sukanya**, 32 years
(Bada Bazar, Shillong 793001)

My child will always be special to me ...

My own personal involvement is as the father of a 12 year old AIS girl, Poonam. Just before her first Diwali she was operated on for an inguinal hernia caused by internal testes. Against orthodox society, we as parents decided not to have the testes removed and to bring Poonam up in full knowledge of her condition from as early an age as possible.

My first reaction on being told of her condition was that of a proud parent: "Wow, I always knew she was special." But is she a girl or is she a boy or is she a? Is she neither or is she both? These are things that are both, perplexing and unnerving for me.

"What a lovely child! Is it a boy?" This is a common question. But why do they ask me this and why is it necessary to know the gender? I think it is a mix of curiosity, politeness and social conditioning.

Poonam has many qualities that I admire and respect and is growing into a healthy and bright, although talkative, child. Any negative attributes she may develop due to her AIS will come from society, not this family.

To be honest, doctors and parents shouldn't look for some panacea for telling children who they are. Each person must find the way best suited for them. It's not easy but it will be a damn sight harder and destructive if they're not told. The moments always present themselves, so be ready for it. Put it simply and appropriately for the child. The parents' feelings are unimportant. If you do your best, whatever the outcome, that is the correct way. There is no right or wrong way, no guilt or blame, no matter what happens in the future, only do your best for the child.

– **Ramesh**, 38 years
(Anegundi, Hampi, Karnataka)

We want our daughter to learn from us ...

My 9 month old daughter has mixed Gonadal Dysgenesis. The external genitalia is female, with what the Doctors have termed a 'moderately' enlarged clitoris. She has no uterus, a short vagina and one undescended gonad which they want to remove before her first birthday. The doctor/surgeon is also recommending a clitoral recession, to tuck it back but not reduce the size by removing anything. My husband and I are really torn about whether or not this is really necessary. We are also having a hard time deciding whether or not we should share any of this information with our families. The reasons being: 1) they may not be able to support us and 2) we want our daughter to learn from us, not a relative.

As first time parents, we were naturally excited when our 'daughter' was born. At that time her clitoris was slightly enlarged but no one thought anything of it

because she was premature and the doctors said that such swelling was normal.

The surgeons recommended cosmetic surgery, including a clitoral recession to 'normalise' the size of her 'moderately enlarged' clitoris. They suggested this be done at one year of age, while at the same time, removing her one undescended gonad. They also recommended a vaginoplasty and hormones at puberty.

After much reading, discussion, consultation and prayer, we have decided not to have the clitoral recession done. We did decide to have the gonad removed. It is evident now, that our child will develop a sexual identity within the next few years. What she decides remains unknown to us for now but that is okay, because we love her and will accept whatever decision she makes.

– **Maria**, 25 years
(2nd Main Road, Kurinji Nagar,
Lawspet, Puducherry 605008)

As a mother, I want to protect my daughter ...

I am the mother of an 8 year old daughter who has PAIS. My daughter was born by C-Section. The gynaecologist told us that we had a beautiful baby girl. Then she was taken by the pediatrician and was checked out. At that time I knew that something was wrong. I had been worried during my pregnancy because I needed to take medication for my asthma and one of the side effects of one of the medications, was that babies could be born with a cleft palate. So I thought that our baby had a cleft palate.

The pediatrician then came over and told us that he wasn't sure if we had a boy or girl. I find it incredible that I didn't say anything to him about his insensitive comment. I can only think that we were both still in shock.

Our baby was back in the hospital when she was 3 months old, having her testes removed because according to the doctors they could become cancerous. She needed to have surgery done on her genitals.

We have told only a few people about her genetic make-up. Our biggest fear was that people would look at her and treat her differently. Would they look at her as a boy pretending to be a girl? Some people can be so cruel and as a mother I want to protect my daughter. I love my daughter with all my heart and I am trying to do what is best for her.

All I want for her right now is a happy childhood. Yes, I think that she is happy. She is a very sensitive, kind hearted little girl. True, she prefers to play with her soft toys and horses rather than Barbies or dolls but so did I as a child. I know she prefers jeans to dresses but so do I. She is my wonderful daughter. Yes, I worry about her future but I worry about all of my childrens' future.

– **Gayle**, 30 years
(NH 17, Panji, Goa 403001)