

Patients and Parents in Decision Making and Management

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So now, where should they begin? How should they co-ordinate their slow crawl back from the desert? What should they say? What could they tell people? Who was entitled to the whole story and who could be kept at a distance with a half-truth?

Anna's parents knew the facts – knew the possibilities, that is – but then settled for not talking about them. They pretended that they were sparing their daughter's feelings, but really they were sparing their own. Nothing in their lives had prepared them for catastrophe.

From 'A Change of Climate' by Hilary Mantel, Penguin Books, 1995, ISBN 0 14 01.2775.5.

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Preface

Patients and parents whose lives are affected by intersex conditions such as androgen insensitivity have chances to influence decision-making and management both in the clinical setting and in the family. The prime qualifications for this are a knowledge-base and confidence to articulate concerns and information to doctors, family, partners and friends. This chapter explores some of the psychology of being a patient or a parent under these circumstances, so that clinicians can better understand their needs and idiosyncrasies in relation to some medical conditions that have been subject to a great deal of ignorance, secrecy, shame and taboo.

We shall examine chronologically, from birth to adulthood, the issues that affect decision making, bringing in parental issues in the course of this. The basic assumptions are a) that the doctors have truthfully disclosed the full diagnosis, at least to the parents, b) that we are considering decisions made not only in the clinical setting but also in the outside life of the parents/adults concerned, c) that the observations relate mainly to AIS and similar conditions, and d) that we are considering patients at the female end of the male-female continuum since that is the AIS Support Group's main area of experience/expertise and since this is a gynaecology textbook.

Introduction

For most of the 50 years since Morris first reported the phenomenon of 'testicular feminization' in the medical literature (Morris, 1953), the main tenet of the doctor-patient relationship has been to actively discourage open and informed discussion about such topics, both within and outside of the clinical setting, and in the outside world. In the last 8 years or so this has started to change, helped by societal and technological changes. The advent of AIDS gave the general public a vocabulary for talking about sex. The rise of internet communications/publishing has provided an ideal medium for isolated 'sufferers' to make contact with each other and discuss their situation (with a high degree of privacy or even anonymity) and for the patient support/ advocacy groups that emerged in the early-mid 1990s to establish a worldwide presence.

For the 50% of AIS patients diagnosed in infancy/childhood, possibly as a result of inguinal herniae, it is probably the attitude of their parents that will be the most pervasive in their adjustment to their situation as they grow up. But the parents themselves will be hugely influenced by the behaviour of the clinicians who care for their child, as will the older child to some extent as a result of the way she is treated during early clinic visits. For those patients diagnosed in adolescence as a result of primary amenorrhoea, their introduction to the subject is likely to be by direct interface with a diagnosing clinician but with parents and family influencing the degree of openness and acceptance thereafter. Most patients in this category say that their interaction with the clinician who diagnosed them is hard-etched into their memory and has an enormous impact on the way they see their condition, and themselves in the years that follow. In either situation, it is the way in which the clinician handles the clinic interaction that is of supreme importance in setting the scene, with the parents playing a vital secondary role.

Of course it is the *patient* who *has* the condition and will have to deal with it on a practical level throughout her life and yet so much of clinical practice over the years seems to have

been aimed, not necessarily intentionally, at making the parents and even the doctors feel better about the situation, at the expense of the patient's long-term well-being.

Dr. David Sandberg, a health care professional (psychologist) and adult intersexual from Buffalo Children's Hospital's Psychoendocrinology Department writes (Sandberg, 1995/6):

The program for treating intersexed children is actually geared towards the parents, not the child. When the child grows to adulthood, and is no longer the parents' child and charge, s/he is invariably 'lost to follow-up'. The problem disappears – for family and medical professionals – but *we* are left alone in our agony, isolated from peers and any emotional support, left to contemplate, alone, “what is wrong with me”.

Doctors may say “One might wish the world to be different [that parents should accept, and not feel compelled to ‘normalize’, their intersexed child] but that's the way it is”. I was born intersexed, and my parents were horrified and ashamed. I was ‘treated’, and lied to, and I was made to feel like a freak and a monster *anyway*. And *that's* the way it is.

Surgery is not at the top of my personal list of grievances; that place is reserved for the cruelty of silence and the restriction of choice. I want to see parents and clinicians have as much information as possible – especially the stories and feelings of intersexed adults – as they make decisions about the care of intersexed infants and children.

With or without surgery, if the parents see their child as a ‘freak’, the prognosis is poor. Families need to receive counselling at all stages in the child's development. The child also needs age-appropriate information, with the goal of full [truth] disclosure. I cannot imagine anything worse than such an individual learning from a total stranger at some point in adulthood that all they had been told were lies or half-truths.

Neonatal/Childhood Treatment

Feminizing Genitoplasty

There are essentially two related, but somewhat separated situations here. Firstly, there is the baby who has genitals that are 'ambiguous' (i.e. not typical of either of the two currently recognized sexes) such that questions arise about the appropriate sex of rearing and about whether surgery should be employed to reinforce the chosen gender, and secondly there is the child who is clearly at the female end of the male/female continuum of genital appearance but has a larger than average clitoris so that surgery perhaps has a higher ‘cosmetic’ component to it.

In a pioneering article social psychologist Suzanne Kessler analyses interviews with six specialists in paediatric intersexuality concerning the medical decision-making process and describes how *cultural* assumptions about sexuality in effect supersede objective criteria for gender assignment (Kessler, 1990). In doing so she makes three key statements:

There are no published studies on how these [intersexed] adolescents experience their condition and their treatment by doctors.

There is no reported data on how much emphasis the intersexed person himself, or herself, places upon genital appearance and functioning.

Most doctors claimed that the parents were equal partners in the whole process but they gave no instances of parental participation prior to the gender assignment.

Paediatric urologist Justine Schober says (Schober, 1998):

Success in psychosocial adjustment is the true goal of sexual assignment and genitoplasty. The psychosocial long-term outcomes represent the most necessary information to determine if we are successful in treating intersexual patients. However, in conditions other than CAH, outcomes are generally unavailable... ..Surgery makes parents and doctors more comfortable but counseling makes people comfortable too, and is not irreversible. Patients wonder if thinking that surgery will improve the psychological outcome for the intersexual child is a mistake. They question if surgery could mean impairment of sexual function in adulthood. It may be illusory, but patients believe that the ability to choose for oneself may favourably affect the results of surgery. Surgery must be based on truthful disclosure and support, and permit decision-making by parents and patient.

The intelligent and articulate mother of a 15 month-old PAIS infant with ambiguous genitalia wrote a long letter to the UK AIS Support Group in mid 1999 (Anon1, 2001). The infant had been whisked away following a Caesarean birth and undergone feminizing genitoplasty on the recommendation of an endocrinologist, a surgeon and two paediatricians. The parents had been afforded very little say in the matter having been given no information to enable them to contribute to the decision. The mother said that she had later obtained a few copies of the AIS Support Group's newsletter, A^LT^AS, and that "It was a huge relief to finally get some in-depth and honest information which as a concerned parent I was totally desperate for." She said that her endocrinologist had "told her to be wary of support group information and seemed to think the education he provided would be sufficient". "How very wrong he was!" she said.

She described the tumultuous emotions she went through after the birth and how she would sneak out of the bedroom at night to cry uncontrollably. She and her husband decided they needed more information but said that "pestering our endocrinologist and surgeon was of very little help as they had only scant answers where we needed in-depth discussions" and that "attempts to encourage our endocrinologist to help us make contact with other families affected by AIS [...] were met with rather weak excuses, e.g. [that] after the first year or so of diagnosis most families have come to terms with AIS and don't want to network but prefer to get on with life."

Their endocrinologist eventually sent them a copy of Dr. Garry Warne's patient/parent booklet on CAIS (Warne, 1997). Through him, and the support group, the mother made contact with other parents and affected adults. She said she "spent many hours on the phone [to these people] and began to have a sense of empowerment that knowledge brings..." She expressed much gratitude for the support group's newsletter. But she also said that reading in A^LT^AS about the growing debate concerning childhood genital surgery *after* her child had undergone this procedure had filled her with doubts and remorse that she had 'allowed' this to happen. She wondered whether the support group was unhealthily biased against such surgery. Her anger and emotional turmoil were partly based on a fear that the wrong decision could have been made and her child's future compromised, but also on a feeling that her desire for information and her right to be involved in the decision-making had been ignored, overridden or obstructed.

In 1995, at a time when adult intersexuals were just starting to question the wisdom of childhood genital surgery, and intersex support/advocacy groups were becoming established, we included the following in our newsletter (Anon3, 1995):

In a recent TV documentary, made by a Jewish father, and bravely questioning the ethical basis of religious circumcision, a psychotherapist said: “At one time the prospect of not sacrificing live animals to the Gods would have seemed unimaginable in our society. But once people start to question the accepted view and say “I’m going to do things differently”, that gradually becomes ‘the way things are’.”

But we couldn’t quite imagine the bravery of those first few parents who would go against the established practice with respect to genital surgery. And yet by 2000 not only had several intersex taskforces/working parties been set up to evaluate the issues (e.g. In N. America, the North American Task Force on Intersex (NATFI); In the U.K., the British Association of Paediatric Surgeons’ “Working Party on the Problems of Children Born with Ambiguous Genitalia”; In Australia, the Murdoch Children’s Research Institute [MCRI] Sex Study Group) with some of them involving support group representatives as well as clinicians, but some parents were doing their own research and rejecting surgery on their children.

The mother of a 3½ year-old with 5 alpha-reductase deficiency emailed us from the US in late 2000 (Anon2, 2001). She related how, about a year earlier, on the basis of tests that suggested 5-alpha-reductase deficiency (and not the PAIS that was originally diagnosed), she and her husband had reassigned their child from girl to boy and did not plan any surgery unless the child requests it when older. She said:

Of course, if the doctors had had their way, his penis and testes would have been taken out *way* before results of the tests were available. As it was, the doctor waited 4 *months* to tell us that the initial diagnosis was incorrect. I was *so* angry. Research has shown that there is brain masculinization in utero for these [5-alpha reductase deficiency] children and that these children will continue to masculinize normally at puberty (although his penis and genital differences will never change). And these children do form a strong male gender identity.

The mother of an infant diagnosed with 46XY mixed gonadal dysgenesis emailed us from the US in January 2000 about whether or not to allow clitoral reduction surgery (Anon2, 2000). She emailed again in November 2000 when the child was aged 1½ years (“New Paradigm?”, *A^LT^AS* No. 18, Spring 2001) explaining how she and her husband had arrived at their decision not to allow the surgery:

A mix of emotions surfaced for us [when problem was discovered at birth]; sadness, frustration and confusion. The surgeons attempted to console us by recommending cosmetic surgery, including a clitoral recession to “normalize” the size of her “moderately enlarged” clitoris.... The endocrinologist was not much help either, saying only to do “whatever the surgeons recommend”.

Without any tangible education or support, we set out on our own.... We found helpful information on various websites including AISSG, ISNA and ISGI. We met with Cheryl Chase of ISNA who provided numerous articles and put us in touch with several parents. We spoke to Deborah Brown of ISGI at length on the telephone.... We met with Bruce Wilson, M.D., an Endocrinologist at Devos Children's Hospital in Grand Rapids, MI and spoke to his colleague, William G. Reiner, M.D. a Psychiatrist at Johns Hopkins University. Some of the articles we read included ‘*Management of Intersex: A Shifting Paradigm*’ by Bruce E. Wilson and William G. Reiner; ‘*Rethinking Treatment for Ambiguous Genitalia*’ by Cheryl Chase; and ‘*Care and Counseling of the Patient with Vaginal Agenesis*’ by Sallie Foley, ACSW and George W. Morley, M.D.

Some parents are also taking things into their own hands in areas such as diagnostic tests. A 38 year-old CAIS group member emailed from Continental Europe (April 2001):

My sister is pregnant 5½ months now and they do not know if she is a carrier. But they do know she will have a XY child, from an amniocentesis earlier in the pregnancy (the carrier tests did not have result yet, and the pregnancy came 'suddenly'). Last Friday they had an ultrasound to look at the baby's sex. The doctors whispered a lot, looked for almost an hour, but did not want to tell the results. The doctors wanted a team discussion – about the ultrasound video they made of it – after the weekend and told her they would let her obstetrician know. They left the parents in despair. This weekend they could not wait anymore, and they went to a commercial ultrasound office whom they did not tell the reason, but the lady there confirmed it was a baby girl, so an AIS child!

Gonadectomy/Childhood HRT

Clinicians do not seem to have a consensus view on whether puberty in AIS is 'better' or 'more natural' via oestrogens from intact testes versus oestrogen from HRT following early gonadectomy. On the cancer front, the risk in AIS seems so low before adulthood that early gonadectomy is not justified on these grounds alone (Anon4, 1996).

There is also the ethical issue of removing organs from a child without their informed consent and the question of whether early gonadectomy paves the way for the adults to gloss over the child's condition, and indulge in secrecy and subterfuge, in the teenage years. We've heard it suggested at a medical conference on AIS that childhood gonadectomy is more often practised for the convenience of the doctors/parents than because of any proven/documentated benefit to the patient.

The mother of a CAIS infant complained to us in 2001 that a paediatric endocrinologist's first words to her were "OK, so when's she coming in to have those gonads taken out?" and that she felt very pressurized to agree to the surgery without any real discussion about it. The rapid advances in reproductive technology may mean that when today's infants reach adulthood, the primitive spermatic material from intact AIS testes might be used to fertilize an egg donated perhaps by an XX relative? This is a good enough reason for not having them removed prematurely unless absolutely necessary.

At a UK AISSG meeting one well-informed family said that they were not going to make the decision regarding gonadectomy on behalf of their 9 year-old AIS daughter; and the child's CAIS aunt still had her testes at age 32. Some parents are becoming aware of the high incidence of osteopenia and osteoporosis in adult AIS women (Anon6, 1996) and are questioning whether early gonadectomy could contribute to this.

It seems also that XX girls start producing oestrogen earlier than previously thought, some years before any outward signs of puberty (Anon3, 1997), and produce more oestrogen from their ovaries than XY girls do from their testes. One of our UK medical advisors (Dr. Richard Stanhope, Paediatric Endocrinologist, Institute of Child Health and Gt. Ormond St. Children's Hospital, London) is thus recommending that girls with AIS should be started on low dose oestrogen HRT whilst still in childhood in order to help them lay down healthy bone tissue, even if they still have their testes (Anon6, 1996). Some parents are starting to ask about this.

Tissue Samples and Informed Consent

At a UK AISSG meeting some parents of young AIS children had many questions about diagnostic and carrier status testing. Concern was expressed about the time taken to gain the results of the latter. The practice of taking genital skin samples from the clitoris or labia of

young children seemed to be a source of particular anxiety. Several parents expressed confusion as to the purpose of such samples; they questioned whether informed consent by parents was being observed; and they related how long-term physical discomfort and psychological trauma in their child had resulted from this practice.

They asked whether such procedures were needed in order to make a diagnosis. The combined wisdom of those at the meeting with medical knowledge suggested that a diagnosis of AIS could be reached by doing relatively simple tests on a blood sample (genetic karyotyping, examination of the response to injected hormones etc.) – tests which could be carried out by their own regional hospital. Any tests requiring a genital skin sample would be to research the exact mechanism of the inability of the body cells to respond to androgens, genital skin being chosen because of its high concentration of androgen receptors.

In some cases parents were being told in vague terms that such tests “would help doctors understand more about AIS” but they were not receiving any feedback on what the tests had revealed and said they felt that the information flow was often one-way only – from the family to the doctors. One mother angrily told how, the day before a gonadectomy on her 8 year-old (diagnosed as an infant) she received a phone call from a researcher at another, distant hospital asking her permission for a genital skin sample to be taken during the surgery, indicating that details of her child’s condition had been passed on to a clinician who was not responsible for her care.

The mother of a 23 year-old with AIS described how she had recently arranged to have carrier-status tests done on various family members by a specialist AIS research department in a hospital outside her health area and with whom her family had had no previous contact. Whilst chasing the results by phone she was shocked to be told that the department had known about her and her family in relation to AIS for many years.

Parental Attitudes

Opportunities and Problems

At a UK AISSG meeting the AIS adults were asked by the parents how traumatic they thought the revelation of XY chromosomes and testes would be to a teenager (assuming a female gender ID). The adults thought it depended largely on how solidly the youngster had been able to build a positive sense of self and gender up to that point and, very importantly, how good her future prospects of fulfilling a role in relationships seemed to her.

The adults offered an analysis based on their observations of young women who had attended all the support group meetings to-date. The worst outcome appeared to be where there had been a long-term awareness in the family of ‘a problem’ (and possibly a diagnosis) but with secrecy and/or a lack of openness and discussion about it, or where there had been childhood hernias with mysterious unexplained operations, and/or a discovery of vaginal hypoplasia. The best scenario appeared to be a) where the first hint of a problem was the failure to menstruate in teenage years and b) where there was no severe vaginal hypoplasia. Paradoxically the first situation gives the parents the most time to come to terms with things and plan how to help their daughter in an open and progressive way, and yet this so often *doesn't* happen. The second scenario is 'a-bolt-out-of-the-blue,' but since parents and teenager are learning the facts together there is less chance of an atmosphere of secrecy and shame

developing; and of course the parents have already seen that their daughter has not grown up to be a freak, even if that's how *she* sees herself.

It is vital that parents of young children should meet affected adults and observe reality rather than living with their imaginations and fears. Parents need to 'open the box', take everything out, have a really good look at it, and maybe repack it in a different configuration; so that they are neither swept along by clinicians' exhortations about how "normal" and "female" their daughter is, or will be, nor by their own irrational fears of unusual sexual development and 'how terribly it could all work out'. They need to steer a middle path, via *information*, *discussion* and *analysis*, not rhetoric and imaginings.

The parents of an infant/child newly diagnosed with an intersex condition have a very steep learning curve ahead of them. They need to grasp some complex genetic and embryological concepts, possibly with no prior education in biological subjects. There is a huge tendency for them to be overwhelmed, and to shut off and retreat into the safe territory of a) an overemphasis on the 'normality' of their child (including the so-called "heterosexual imperative"), and b) the comforting notion of "my/our little girl". The 'mirage of normality' and the resulting denial and secrecy become more important than acknowledging their child's need for emotional support and full medical care.

Parents may find it hard to consider one's child as a future adult who will need to function emotionally and sexually: so they continue to try and protect them from the pain of knowing about the condition. But this denial only hinders their youngster's healthy development. (Anon7, 1997).

Willingness to Learn

There are enormous benefits to be gained by parents and patients, in dealing with any unusual condition, from meeting other affected people, expanding their horizons and appreciating the wide variety of (often positive) responses to what one might have seen as a death sentence. At a UK AISSG meeting one family attending with their 9 year-old AIS daughter described how their reaction, when told of their daughter's XY chromosomes, was "Wow – how interesting! She's really special! Let's see what we can find out about this" and a 30 year-old with AIS said that she felt like some kind of angel when she found out the truth of her condition (quite a common reaction). Parents attending the meeting might also have heard the words of an AIS 33 year-old, who'd been fed the usual half-truths as a teenager about "underdeveloped ovaries" and had overheard nurses discussing her and saying "but she seems so female!":

When I was 21, I was travelling in India and came across a newspaper article in the Indian issue of 'The Times' [Aug or Sept 1981?] about Joan of Arc and which speculated that the historical figure might have had a condition called AIS (TFS). There seemed to be similarities between my own symptoms and those described in the article. I rushed back to England and asked my consultant if I had this syndrome. I experienced a feeling of joy and relief on receiving confirmation of this, because there was a definite reassurance in knowing that my unusual condition was after all a 'known quantity', that it had a name, was documented in the literature, that there were other sufferers and that I was not just a one-off 'freak of nature' after all.

A PAIS woman in her late 30s wrote:

Once they had finished all their tests, I was informed that a bikini cut from hip to hip would have to be done to carry out an internal examination. They didn't say what they were

looking for and I didn't dare ask. I had just turned 14. The operation took place in the radiology theatre – I saw the sign on the door as they wheeled me in. The secret murmurings of my flustered parents and doctors convinced me of the fact that I had cancer and no-one was telling me. I thought they were going to give me radiotherapy during the operation. When I came round, the doctor told me that they had had to remove my ovaries and that I wouldn't be able to have children. That was a terrible shock....

...Having reached the youthful age of 35, I decided that the time had come for me to look things in the face.... My consultant had died, my medical notes had supposedly been destroyed. However, the endocrinologist was still alive and he put me in touch with Professor Ieuan Hughes in Cambridge. ...he spent a great deal of time examining me and patiently answering all the questions I had always wanted to ask. He explained that because my cells had been hardly able to absorb the male hormones in my body, the Y chromosome could not take effect and make me into a boy. Thus I had been born a girl. Afterwards I hopped on to my bike and drove back into town, filled with a deep sense of relief. I remember thinking, "I can live with THIS!"

Although we don't want to over-emphasise negative experiences, we feel it is vital that today's parents and doctors should also hear about the bad experiences of adults who have grown up with conditions like AIS and know what the adults are discussing, so that they learn about the issues that will be occupying their daughter's mind as she reaches maturity, and so that history doesn't repeat itself.

In the early-mid 1990s, when our contacts list consisted merely of a few parents, we were rather wary of the feminist-inspired discourses from some quarters, rallying opposition against patriarchal attitudes in intersex treatment such as the feminizing of male infants whose genitals don't make the grade (Anon2, 1996). But this changed when we read more of the writings on psychosocial aspects of intersex (such as those mentioned under "AIS in Books and Articles" on the AISSG web site) coming from Suzanne Kessler (Kessler, 1990), Anne Fausto Sterling (Fausto-Sterling, 1993), Morgan Holmes (Holmes, 1994), Cheryl Chase (Chase, 1995) and later from Alice Dreger (Dreger, 1998, 1999) and others. And further interest in these ideas came when increasing numbers of *adults* with AIS contacted us, told us their stories, and started to discuss these aspects of AIS amongst themselves. We began to feel that these issues were in fact very important in explaining the attitudes of medicine to intersex (including the neglect of vaginal hypoplasia by paediatric specialists in their published material on AIS). And this was even though questions of genital ambiguity were not of direct personal relevance to many of our members (who predominantly have CAIS or high grade PAIS). So we started covering these issues in our newsletter, A^LT^AS.

Many parents may find such sociological concepts/discussions difficult to handle, but we believe our role is not to 'cotton-wool' parents but to provide information and encourage openness and enquiry. We want to try and provide a balanced offering of support, information and rocket fuel, but we do feel parents should be prepared to consider some tough social, ethical and philosophical questions, even if the impact on their own situation is indirect. If parents read, and think, and talk (within the family, and with counsellors and other parents/patients) about these matters as much as possible – almost until they are saturated to the point of tedium – they will then get a sense of what all the angles and the outermost reaches of current discussion/ knowledge are. Then, the less threatening the demons will become, the fewer murky, menacing corners there will be, and the better they will be equipped a) to put their own situation in perspective and b) to actually *manage* the situation in their child's best interests.

There *are* parents who are willing to get to grips with things but who, like the mother of the PAIS baby mentioned earlier, are thwarted in their endeavours by the clinicians in their path. A mother related (in 1996) how she learnt about her 16 year-old daughter's CAIS (Anon1, 1997):

The gynaecologist told us that Sally had been born with no womb and that her ovaries were in a strange place, in her groin.... I phoned the gynaecologist a few weeks later and asked to see her (she had made the next appointment for Christmas time and I thought "You can't just tell someone they have no womb and to come back in four months").... The following week I took Sally to see her. She told Sally she could never have a child, that her vagina might need to be stretched and that her ovaries would have to be taken out. In my ignorance, I asked if they could leave the ovaries in place so that perhaps in the future her younger sister might act as a surrogate mother. But she was adamant that the ovaries had to go.

A couple of days later I told my GP the news. Meanwhile the gynaecologist had written to him to tell him everything. When I told the GP that the ovaries "had to go", it was then that he told me they were not ovaries, but testes. How I got home I'll never know. I couldn't say anything to Sally when she came in 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 I to go in 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, on 17 November, Sally and I went for the final consultation with the gynaecologist. She asked to see Sally first; I sat outside. After an hour or so I was getting nervous. She then called me into her office, and with Sally sitting there she told me Sally had XY chromosomes. This meant nothing to me. I looked at Sally and she was pure white; she knew what it meant. The gynaecologist gave me the address and phone number of a lady at the 'AIS Support Group' in case I wanted to talk to anyone about it. The term 'AIS' meant nothing to me either.

The next day I called in to tell my GP the news. When he asked me how much I knew, I replied "Everything". He then said "Well you know you have a boy then. XY equals boy". I said that she couldn't be a boy as they weren't testes, they were gonads. He thought I was in denial, when I kept on saying that she couldn't be a boy. He was saying over and over again, "Mother, you have a boy. XY equals boy". I walked out of his surgery vowing never to enter it again. He should not have told me anything anyway since Sally was over 16 years of age.

I got straight onto a bus to town and looked up 'AIS' in the medical department of a large book shop near the university. It was then that I found out the truth. There I was, reading about my beautiful daughter, on my own, finding out exactly what 'AIS' meant. I was shaking all over. I was nearly fainting, at the clinical photographs etc., with the eyes blacked out, thinking this could have been Sally. I felt sick. Somehow I managed to get home, and I phoned the support group. The lady calmed me down and explained everything and the following day the group's factsheet was in the post.

On 4 January 95 Sally had her ovaries/testes/gonads removed. She started her HRT in the February, and in the March my husband and I went to the very first [UK] AIS Support Group meeting in Mansfield. It all happened so quickly. If the lady I first phoned and the rest of you hadn't been there for us I can't think what might have happened.

I wanted to make a complaint about the GP at the time but there was Sally to consider, I would have had to mention her name etc. I changed to another GP in a different practice. I told him everything about AIS, and about the other GP, and he agreed to take on the whole family. I gave copies of every issue of ALIAS to both the new GP and the gynaecologist.

Yet when I recently visited the new GP and told him I had written to a London gynaecologist about the possibility of Sally 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. This was only a couple of days before the 4th support group meeting in Sept 96.

Whilst I feel so mad, and I want to complain, I do not want Sally to be involved. I have not told her what the new GP said about her. I've written to the gynaecologist and told her, and await her reply.

Support group members often encounter doctors like this who are not all singing to the same hymn sheet, as well as a great deal of ignorance amongst GPs. We have also been surprised to find that even paediatric specialists do not seem to be aware of the recent discourses on the psychosocial aspects of intersex. We feel that specialists who are making irreversible decisions (sometimes involving surgery) affecting how youngsters will function as social and sexual beings really owe it to their patients to be conversant with these issues. And how can they encourage parents to read around the subject if they haven't done so themselves?

Guilt, Denial and Taboo

There are many excellent parents who cope well with their intersexed child, but there are significant problems in some cases. There is often a problem with maternal guilt/denial, with some parents projecting AIS as only a fertility problem; a notion often inherited from the clinician/s. There is commonly a fear of genetic and intersex aspects of the condition. It seems that mothers are particularly fearful of these matters and it is perhaps an unnecessary but understandable guilt that plays a large part in this, once they learn of the X-linked recessive nature of inheritance in AIS. We have observed that many fathers seem to cope better and appear to handle things more objectively, at least as judged by some very supportive yet rational fathers who've attended our meetings with their AIS daughters. Maybe there is less guilt at having brought what is seen as a defective baby into the world.

At a UK AISSG meeting two adults with CAIS related how a childhood hernia and hints of a 'reproductive problem' had led to fear and secrecy within their families and a delayed diagnosis; how in their teens they had resorted to medical libraries in order to find out their diagnoses (accurately in both cases) and how they had lived absolutely alone with the knowledge, and with no therapeutic intervention, for many years thereafter. The 47 year-old was the first person with AIS that the 36 year-old had become aware of (and only the previous week) and the 47 year-old had made her first contact (with a 17 year-old with AIS) only 2 years before. Neither of them had ever had a chance to articulate their anxieties about their condition to *anyone* until that point. They both expressed anger towards their otherwise very caring mothers for their complete lack of backbone and initiative when it came to facing reality, trying to overcome their taboos, and seeking information/treatment for their child, and for not talking with them about their problem, albeit in a society much less open than that of today.

The two AIS adults said that the idea of *blaming* their parents for their condition never had, and never would, enter their heads, since they had always accepted it as their own problem and a fact of nature, albeit a very stigmatizing one because of the censorial attitudes of doctors, parents and society. But they did feel angry that their parents had defaulted in their duty to *manage* the situation. They felt that instead, the child had been forced to 'become the adult' and manage it by seeking information in secret. Both the adult AIS women were

adamant that the effects of the secrecy were far more damaging than the truth itself and that the enormous amount of energy invested by both parents and child in keeping their respective secrets would be much better spent in being open and seeking early medical and psychological guidance. Both women thought that parents were protecting themselves rather than their child by being secretive and withholding information.

Strange Notions and ‘Fixing’ Things

Some parents develop very strange notions about their youngster’s condition/treatment and doctors should not underestimate the level of medical misunderstanding in parents. One mother in the support group believed that her CAIS daughter might develop a hairy chest at puberty and understood vaginoplasty surgery to be the insertion of a plastic tube to serve as a vagina.

The mother of a 3 year-old PAIS girl received our factsheet in response to a phone enquiry in late 1996 but she didn’t subscribe to the group. She’d not responded to any of our subsequent communications encouraging her to get more involved in the group. In 1999 we heard through a third party that the mother felt antagonistic towards us because “the woman on the helpline would not accept that her (the mother’s) brother had the *complete* form of AIS. OK, it’s very rare; he might be the only recorded case, but.....”, the mother had explained. We told the go-between that if the mother had joined the group back in 1996, had obtained our newsletter, had come to meetings and heard guest clinicians speak, had talked with other group members etc., she wouldn’t still, three years on, be failing to grasp the very basic medical facts (e.g. that it is almost impossible for her brother to have CAIS because he would almost certainly be her sister) and denying herself other vital support/information as a consequence.

A mother who has received A^LT^AS over a number of years was adamant that she preferred the term ‘testicular feminization syndrome’ to the newer ‘androgen insensitivity syndrome’ because Morris had coined the former term (and others later used the term “classical testicular feminization syndrome”) to refer to patients with the *complete* form of the condition (before it was discovered that there was also an incomplete form, later known as Partial AIS). She felt the term AIS was “too general” and “covered other situations”. The implication was that she couldn’t face the fact that AIS is a spectrum that includes PAIS women with a larger than average clitoris, and even (heaven forbid) men with mild PAIS. Most adult AIS women hate the older term, regarding it as very stigmatizing and inappropriate to their social status as females. We are not party to her AIS daughter’s view since it appears she has still not been told anything about her condition by parents or doctors even though she is now in her early 20s.

There is a natural desire amongst many parents to want to ‘fix’ things for the future. There is general and pressing anxiety in parents of young children, even infants, over “what will happen at puberty”. We usually recommend that having asked a few relevant questions of their medical specialists they don’t overconcern themselves with this and devote more energy to reading about and understanding the psychosocial aspects. The mother of a PAIS infant assigned as a girl had a piece of her own ovary frozen for possible future use by her child. Members of an AIS adults’ email discussion circle couldn’t agree on whether this was a caring self-sacrifice or an overanxious and unnecessary attempt to further ‘normalize’ the infant’s life experience (the child had already had extensive genital reconstruction surgery). Interestingly, the mother declined our offer to send her a newly published intersex issue of the

J Clin Ethics (Dreger, ed., 1999) which would have brought her right up to date on the very latest insights, from both affected adults and psychologists/doctors, on the psychosocial aspects of intersex treatment.

Parental Control/Censorship

There is a significant problem with some mothers making it into *their* problem. Some mothers seem focussed on a relentless quest to turn themselves into AIS experts, seemingly without intention of ever sharing the information with AIS daughters in their late teens who still don't know the truth. They keep requesting information on AIS, and on truth disclosure, and yet seem embarked on a long-term academic exercise to try and justify *not* talking about things, appearing to have no plan to ever give their daughter her autonomy and allow her to deal with it herself like an adult.

Sometimes an extremely anxious mother of a teenage AIS daughter in, say, her mid/late teens will have attended group meetings for a number years without her daughter's knowledge. We don't know if these young women will ever be told the truth about their condition or will ever be told about the support group so that they can meet others and escape from their mother's well-meaning but unhelpful over-protection. How can they not know that "something is going on".

Some mothers are very controlling in the domestic setting, seeking to influence who *knows* what, and who *says* what about AIS within the family. A number of support group members have described how they had plans to hold a family meeting, to fully educate their parents and close relatives about their AIS and to give them literature, but this had been expressly forbidden by their mothers (Anon1, 2000).

Keeping it in the Family

Some parents, like many clinicians, are inclined to believe they can handle everything without outside help (from counsellors, from the support group) and that they hold all the answers. Virtually all the glowing 'fan letters' sent to the support group, saying how useful our literature/ meetings have been, how it has changed their lives, etc., are from adults with the condition – not from parents of young children. Nearly all the personal stories submitted to our web site are from affected adults rather than parents, and parents do not seem willing to take part in reputable media initiatives, in order to raise awareness, in the way that the adults are.

The long letter mentioned earlier from the parent whose baby had undergone genital surgery was really the first time the parent of an infant/child had written to us at any length about their experience. We do very occasionally hear from parents of older children. The mother of a PAIS 13 year-old wrote (Anon1, 1998):

I am one of those guilty parents who have not given you any feedback, but you summed up the reasons why in your article "Parent Problems" [Anon7, 1997]. I could not have expressed it more articulately and it shows what a brilliant listener you have been. My daughter ____ is now 13 (PAIS) and I'm still kind of shell-shocked, although now much more in control, thanks to the education through ALIAS and the one group meeting I attended in March '97. I was firmly of the opinion my daughter would not be told the full facts (i.e. that she was XY) until that meeting where I met ____ and her three daughters. Her youngest girl, of 17, had the biggest impact when she said she would have liked full disclosure at an earlier age. There stood a bright, pretty girl and, although emotional during the meeting, she was in control.

We mothers wish to protect our children from every hurt, as we inflicted these XY chromosomes on our daughters through something beyond our control [Not strictly true. The X comes from the mother, the Y from the father. But the genetic fault which causes AIS is carried on the X]. I personally have been so afraid that my daughter could be so emotionally damaged by being told the full facts that she would no longer be able to cope with life. It has only been through ALIAS, and meeting with other mothers and affected adults, that I have changed my opinion. This parent/ child emotional support, which has so far been missing, is the key to getting things right in the future.

But this sort of letter..... any communication..... from a parent is very rare.

Although a significant proportion of the UK group's subscribers are parents (44% in 1999/2000), most of our meeting attendees are adult women with AIS and similar conditions. There are notable exceptions. An overseas family have brought their PAIS daughter with them to several UK meetings since she was 9 years old. There, the youngster herself, who speaks English, hears adult women talking freely about all the things that many parents might consider taboo. So she, like the adults at the meeting, sees how these can become just topics of normal dialogue. She may see some of the women cry but she also hears them laughing uncontrollably over dinner and late into the evening.

Parents, on the whole, seem to prefer to deal with AIS within the family. We perceive that while most parents are happy to receive newsletters, many may be too ashamed to attend meetings and confront the fact... and admit to others... that they have an intersexed child? It is our impression that more parents of young children used to attend in the early days when the meetings were smaller and more informal. Now that the adults have become stronger and more confident, maybe this has deterred the parents from attending because they feel intimidated (even though we provide a private parents' discussion group on the second day of our weekend meetings). Maybe this is a failing of our group, but no parents of young children have answered our calls for them to get involved and to help plan and run our services.

Only three out of 35 parents with known email addresses even *acknowledged* an invitation in 2000 to join a parents' private email discussion circle we were offering to set up for them. Meanwhile the affected adults are all networking like crazy. Has the internet revolution passed parents by? It is very important that clinicians should make parents (and patients) aware of the fact that increasing number of affected adults are every day discussing every angle and nuance of being intersexed (in meetings, in A^LI^AS, by private email.... and in online discussion groups and chatrooms tailored to every possible 'flavour' of intersex, i.e. male, female, intergendered/ androgynous etc.) and that sections of society are becoming much more open and interactive on this subject. The UK AIS Support Group recently helped a social anthropology student with her MA thesis on how intersexed people, and groups, talk about themselves on the Internet (Nahman, 2000).

Maybe parents don't have the concept of a *community* of peers in the way that the adults do. Parents sometimes want the impossible (one-to-one contact with a family with the *same* condition, with *same* aged child, in *same* geographical area) but that is usually difficult to arrange (these conditions are rare!) and is not always the best option. We feel that they'd benefit more by coming to meetings and hearing a variety of experiences/viewpoints.

The affected adults gain enormous benefit from their association with the support group, and by bonding and networking with others, but we have a problem on the whole in getting parents of young children actively involved, and this is where we need the help of the medical

profession, specifically clinical psychologists, in trying to help parents *at the point of diagnosis* to realise the benefits of expanding their field of view beyond the family.

Counselling/Psychotherapy

For Parents

Parents of AIS youngsters need a lot of help themselves before they can really understand and help their children. It is important that parents are encouraged to deal first with their own feelings/fears so that they will be better equipped to help their children through the learning/adapting process.

Doctors should *not* emphasise to parents that “It’s very rare” or say “It’s not something you’d really want to discuss with anyone” but they need to encourage them to talk openly with a trained counsellor and to seek information on the options (what and when to tell their child, sources of ongoing psychological support, information about treating vaginal hypoplasia when the time comes, the timing of gonadectomy and HRT, etc.). Otherwise they can become imprisoned by their own negative feelings, leading to isolation and inaction. It will be regarded as a lost cause, or something too terrible to even mention in the family, let alone to outside people who otherwise might have helped the child to realise her potential.

During a discussion on truth disclosure (Anon4, 1998) a CAIS 49 year old said:

I agree [that parents often can’t be trusted to do the job on their own] and I think that AIS is so complicated biologically and psychologically that it is too risky to leave it to parents to explain things on their own. My parents just never grasped the biological facts or sought to inform themselves, never mind thought about them, or reached any sort of understanding or digest (beyond the concept of ‘a normal girl with a fertility problem’) that would have enabled them to help me (and I was far too stigmatized by my own independent discoveries and, above all, by their silence on the matter, and the obvious discomfort of the medics, to ask *any* questions *at all*).

I feel that at the time of diagnosis, the health care professionals must fully educate parents (and daughter, unless an infant/young child at the time), and provide professional psychological counselling, so that if the parents can’t or won’t get to grips with it – scientifically/medically *and* emotionally – then at least the girl can be rescued from this nightmare situation, and be given a space in which to explore things with a professional, because if her doctors/parents don’t explain it all to her in detail (and they all talk about it until they’re blue in the face), she is going to find out all the biological facts anyway (or worse still, bits and pieces, and strange, stigmatizing terms) from sources like medical libraries, and will be completely on her own with it. In my view, parents should, with the help of counsellors, be forced (as it were) to overcome their hangups about discussing things openly, for the sake of their child’s mental health.

For Children

The following is the major part of a letter, which first appeared in ISNA’s newsletter, by a certified marriage, family and child counsellor (Slocum, 1995) who herself has the partial form of AIS:

Most of my life (I am 46 at present) I have endeavored to feel female. Most of my childhood my parents, especially my mother, labored to instill 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 labored 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 almost daily of being in the midst of some positive experience (for example, a compliment being paid me, an exciting encounter, feelings of physical pleasure) when into my mind would intrude the thought that something was not quite right. 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 culture dealt with the only gender ambiguity that seemed speakable – transsexualism – with a snicker. I internalized the apparent taboo and lived with a great fear of myself. Another person I know with AIS has had to live in the same way and describes the anguish as her having, in her own words, “to every day slay the dragon”.

I fear that parents in their attempts to give their children normal lives, will rob them of the chance to come to terms with their own difference. I suppose there is a great need to feel that the right thing has been done in choosing early surgical intervention. There might be a need to feel that everything has been fixed, or nearly fixed and that their child's acceptance of their difference will be as decisive as their surgery. Whether or not this type of surgery can ever be viewed as decisive is another critically serious topic. It would be nice if a young person didn't have to wrestle with puzzling terms like 'intersexed' and did not have to contemplate what existed before surgery. But that is not the fate of those of us born like this [just as it is not the fate of someone rendered paraplegic in an automobile accident to walk away from the scene.] (Author's words paraphrased for publication in ALIAS)

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 emphasize, I believe, is that healing and a kind of wholeness and equanimity are possible. All children 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. To not 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 realize that the prospect of a lengthy course of [psycho]therapy 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 themselves very well and someone who will very probably be capable of great courage and sensitivity to adversity.

But counselling has to be *appropriate* counselling. A father at a UK AISSG meeting told how he and his wife had been recommended to take their 9 year-old CAIS child to the Tavistock Centre in London (a family psychiatry centre with a unit specializing in gender dysphoria problems in children) for 'gender counselling.' But he was concerned that “it [AIS] might be seen as being a gender dysphoria (transsexual) issue, which it is not, and that this might just create more problems in the mind of a child of that age.” This is a valid concern and underlies the need for more psychological counselling tailored to biologically-determined sexual anomalies.

John Money may be the *bête noir* of the moment because of his influence on the practice of genital surgery but he had some sound things to say concerning psychosocial matters, even before these issues became more prominently debated in the early-mid 1990s. In several of his papers/books Money identifies a need for counsellors who identify themselves as pediatric sexologists, specializing in the sexual problems of children (Money, 1987), an important qualification being an in-depth medical knowledge of intersex conditions. He refers to this “talking doctor” as a psychologist or psychiatrist with training in sexual medicine and psycho-neuroendocrinology whose services should be available throughout childhood and early adulthood. Unfortunately such professionals are very rare.

A discussion amongst some AIS women (Anon4, 1997; Anon5, 1997 and Anon6, 1997) covered the terminology and advice given in medical textbooks and its relevance to counselling and psychosocial well-being. One text book had recommended “counselling and support for the parents, the individual and partners in later life.” One of the women commented:

It must be really nice to have a physician who is so helpful and deeply involved in one's life that he'll take care of explaining things to your boyfriend! My impression is that, in real life, they don't even have the time to explain anything properly to parents, or to patients themselves. Anyway, by the time someone is old enough to have romantic partners she should long since have been provided with the words she can use to handle these situations herself. Instead, most of these books advise keeping the patient in at least partial ignorance, which makes her dependent on the ‘counseling and support’ they recommend, but which few doctors are actually ready to supply.

From the patient's point of view, the best option is not to have a life so messed up that one needs support in order to face one's ‘special situation’. I feel that such ‘supportive’ counseling is a waste of time, and that counseling should be businesslike and oriented towards providing information, not ‘hand-holding’. What I believe in is for a counselor to promote the patient's self-reliance and ability to cope with whatever situations he or she will encounter. They can do this best by providing accurate and complete *information* about his or her condition and treatment options, and about *sex* in general. Unfortunately, most counseling professionals are not geared to do this. Child clinical psychologists with specialized knowledge of AIS and related conditions, and of sex problems and their treatment, are very rare.

Also, there is a taboo on talking about sex with children, and people rationalize keeping them in ignorance as being necessary for their emotional well-being, when, in fact, it is more likely to be harmful. Counselors are unlikely to get into talking about erotic arousal, and sensation or orgasm with a child. They might fear getting into trouble with the parents or hospital authorities, or even being prosecuted under laws intended to protect children from pedophiles. Even when I saw counselors as a young adult (aged 21-22), I perceived an attitude of prudish avoidance of these topics on the counselors' part. It seemed this way to me even though I was shy and puritanical myself.

The current approach seems to be to avoid dealing with sexual problems until the person becomes an adult, even if the problem has by then become more complicated. One could call this protecting children from what they are not yet ready for, but one could also call it shrugging off a responsibility so that someone else can deal with it later. I think I've mentioned before that some of the overemphasis on gender identity in such conditions possibly stems from prudish avoidance of the real issue – *sexuality* – in dealing with a child...

...what I'm saying here is that by making gender identity the justification for whatever management/treatment is applied to a child, doctors can talk in terms of the existence of, or the achievement of cosmetic normality – whether the child looks, or can be made to “look

normal, like other boys (or girls)” – rather than having to talk in terms of ability to have sexual intercourse.

Teamwork

In order for parents (and patients) to play a greater role in decision-making there needs to be a shift in responsibility in the doctor/parent relationship, with parents and patients doing more thinking for themselves and not taking on board “hook, line and sinker” everything the doctor tells them. And doctors in turn need to relinquish some of their control over the situation and (funding of services permitting) delegate some responsibility to their clinical psychology colleagues.

There are well established, objective facts concerning the biological situation in AIS. On the other hand any considerations of gender identity and orientation have an inherent degree of subjectivity, haziness, and unpredictability. But it seems that clinicians sometimes offer fuzzy information, half-truths or straightforward untruths concerning the biological facts then issue dogmatic pronouncements and reassurances, as if from on high, concerning the more nebulous issues of sexual identity. It's time doctors stopped feeling they have to issue edicts on such personal and mutable matters as gender identity and sexual orientation, and arranged for counsellors or psychotherapists to help people explore these and the many other psychological issues for themselves.

The parents are unlikely to seek counselling or contacts for their child if they have only one ‘script’ running continuously in their heads. This script says “Well the consultant kept on assuring us, over and over again, that she is a normal female, in spite of her XY chromosomes and testes, so that’s all we need to keep telling ourselves for everything to be absolutely fine”. They become fearful and intolerant of any discussion or intervention, or any contact with other people that might remotely question the truth of this Delphic proclamation. The script becomes a kind of life-raft that parents desperately cling to, trying to convince themselves that it was all a dream and the shipwreck never happened. I think this approach will be seen by the *patient* for what it is – a damage-limitation exercise.

Why do doctors think they have to hold all the answers? They are not trained in psycho-social or psycho-sexual aspects; and intersex conditions are not usually medical emergencies. It could even be argued that experienced counsellors, and not doctors, should actually disclose the basic diagnostic information in such cases or that the case management around the time of diagnosis/ treatment should be overseen by a psychology professional, to ensure that the management plan will facilitate normal psycho-sexual development and enable the patient to anticipate personal relationships.

In 1996 a paediatrician commented to ISNA concerning some of their literature, saying that although it had been “remarkably illuminating” he felt the medical profession came in for quite a hammering. He thought it rather unfair to describe a urologist as merely a plumber whose role is to repair and lengthen pipes in infants to make them male. He said that he had always worked very closely with paediatric urologists in the management of infants with ambiguous genitalia and that their input went far beyond the pragmatic surgical management.

Cheryl Chase of ISNA replied to him (our italics):

It is very gratifying to hear that some of the information we are providing has been thought-provoking. In that light, I would like to open a dialog on several points from your letter with you. First, you say that the input of paediatric urologists goes far beyond the pragmatic surgical management. Indeed, as we see it, that *is a large part of the problem*. Paediatric urologists are not specialists in emotional issues. They do not generally have extensive training or experience in psychotherapy nor in sex therapy and sexological theory. We believe that the team which guides the treatment of these infants and children should be headed by such a mental health specialist.

The above recommendation has been strongly endorsed by the AIS Support Group (Anon1, 1995; Anon2, 1995 and Anon1, 1996).

At a symposium on intersex management held in London on 28 Jan 2002 (jointly organised by clinicians and AISSG) there was a general air of anxiety amongst paediatric clinicians. Several were getting quite agitated and saying things like: "Well, I have the parents in front of me..." or "I'm in the hot seat..." "...and they are asking me what I advise, so I *have* to tell them *something*.... so what *do* I tell them (e.g. about early/late gonadectomy)?"

Support group participants in the audience answered "Well.... you tell them that the risk of gonadal cancer, in AIS at least, is *very* low before puberty/early adulthood... you put them in touch with a clinical psychologist if possible, and you put them in touch with other parents via the support group... so they can discuss things at length, and in their own time, and can explore *all* the angles. There is no hurry to do surgery unless it's a life-threatening situation." Intersex is largely a psycho-social phenomenon and not a medical emergency, and doctors should not feel they have to be the only people to advise parents.

Late Childhood/Adolescence

What/When to Tell

At a UK AISSG meeting there was discussion about the best time for truth disclosure and it emerged that there were probably no hard and fast rules because of differing family backgrounds, medical histories, character strengths/weaknesses in the youngster etc. But the AIS adults advised that the sooner one is able to deal with the full psychological impact of the condition (by knowing that all the cards are on the table) the sooner one can get the immediate trauma over, and the sooner one can get on with one's life. The meeting heard of the experience of two young AIS women – a 19 year-old present at the meeting and a 23 year-old (mother present without daughter). Both had experienced emotional difficulties until such time as they had been given the final pieces of the jigsaw after which they were able, quite suddenly and dramatically, to get on with their lives in a positive way. After many years of anger, depression, low self-esteem, the 19 year-old now had a steady boyfriend and the 23 year-old had been recently married.

To suddenly drop a bombshell on a teenager might well cause a degree of acute distress and might well mean that their school work suffers for a year, but life is not a bed of roses, and it is unlikely that a CAIS teenager will not have been wondering exactly *why* she has not menstruated or developed pubic or underarm hair, or possibly *why* her vagina is very short. It is far better to be able to face reality and have a chance to talk about your fears early on, than to spend your whole life under a stone because you are so stigmatized by an awareness that even those who brought you into the world cannot accept what you are.

All this seemed to give hope to some of the parents of young children; that there could be light at the end of the tunnel, in the face of their dread of having to talk truthfully to their daughter at some point. And one set of parents announced that they were going to go home and start talking to their 8 year-old. When it came to revealing information to a child diagnosed in infancy/childhood, it was thought that a phased truthful approach was best, with the aim of full disclosure perhaps by the mid teens. This means a strategy in which each *piece* of information given is *in itself* truthful, so that there is no need for backtracking at a later date. For example, to introduce a notion such as ‘malformed ovaries’ and then to have to modify this to ‘gonads’ or ‘testicular tissue’ if a teenager happens to find out later about her XY chromosomes, was felt to be a recipe for disaster, and is likely to generate a great deal of mistrust and anger. And to hint vaguely to a 14 year-old, who has already been told that she is infertile and has had her ‘ovaries’ removed, that she “may need another (unspecified, but in fact a vaginoplasty) operation at some stage” just sets up more questions than it answers. It is also very important that there should not be long gaps where no information is given and in which doubts/questions and insecurities will arise.

Parents should not have to cope with all this on their own! The meeting urged parents to push for professional psychological counselling, so that the medical system is encouraged to put more emphasis on this element of the equation.

Adult Issues

Meeting Others

The best therapy (together with psychological counselling) is to be in touch with others who are similarly affected, and yet this has been the action that, in the past, many doctors have been least willing to facilitate. This vital step is unlikely to happen if the truth about the condition remains an ‘unspeakable monster’ in the clinic and/or within the family.

Most support groups seem to be set up and run by women. We have failed to get the significant number of PAIS men who’ve contacted us to get together and form any sort of concrete mutual support facility for men in the way that AISSG was set up by women. A man who co-founded (with a woman) an intersex advocacy organisation told us that in his experience most support groups set up/run by men are not successful. A high percentage of doctors are men and have traditionally been reluctant to put patients/families in touch with others affected and/or have been scathing about the role of support groups. Is there something in the male psyche that doesn’t appreciate the benefits of peer support?

Normalization and Empowerment

By far the most frequent comments we receive from affected adults, on contacting the support group, are that they are “absolutely amazed that there are others with the same story” and (usually after attending their first group meeting) that they “no longer feel like a one-off freak”. A 37 year-old, who had suffered secrecy and denial in her family, described at a group meeting in 1996 how finding the support group in late 1994, and at last being able to meet others with AIS who were ‘making a go of their lives,’ had enabled her, for the first time in her life, to feel like she was part of the real world – a member of the human race instead of an outcast.

Patients become highly suspicious when doctors go 'over the top' in emphasising their normality, or their femaleness, and yet seem determined to prevent them from discussing things with other patients. However, meeting others will definitely normalize things for the isolated patient.

There is a perception amongst some people that support groups are full of people who are miserable losers, who only meet together to complain and depress each other. This is not the case, with our group at least. You could say that those who make the effort to seek us out and come to meetings are in fact the most brave and resourceful of the lot, because after all, most of them have already had to ferret out the basic diagnostic information about themselves from sources like the Internet. Yes, we get people who are in a desperate state and who cry throughout their first meeting, yet after one or two meetings find they are coming along mainly for the social activities.

A CAIS 39 year-old in the US wrote:

Meeting other women with AIS, finding them to be normal, makes it easier to view yourself this way, I think this is what caused me to make great strides in coming to terms with AIS. When I started going to meetings in the UK, I would literally look around the room and think to myself "This is a group of great women about whom I don't feel the least discomfort that they have XY chromosomes or once had testes." By being able to find this so utterly acceptable in them, I came to be much more accepting of myself. It's like the other group members are a mirror of ourselves and when we like what we see in the mirror it becomes easier to appreciate ourselves and to understand how others could find AIS acceptable in us.

A PAIS 44 year-old wrote:

Prior to meeting AIS women, I had this impression that there were aspects of my physical looks, or a vibe I might put out that would make people think I was not a woman. Baggage. I'm overly sensitive to it, and it remains an issue.... And I remember regularly probing my face in the mirror from age 14 to 20-something, to see what was different. Was there something in my face that gave me away, that was subtle to me, but more obvious to those who looked at me – especially women, since they'd be the first to know, I thought. Today I don't think so. It has been a big change since the day I first asked ____ [CAIS 39 year-old], at the [AISSG USA] group meeting in NYC in Sept 96, "Can you tell by looking at me?" I had wanted to ask someone that question for three decades. I've been in solitary confinement for all that time. Yep, I got parolled last year. My only visitor was my mother. Kidding aside, in some ways I view my current life as 'restarting' [last year] in Sept 96. I was 14 when I was given 'the story' by the doctor. Maybe there is a part of me that is only 15 years old inside today.

Patients talk about gaining a sense of empowerment via the support group, about gaining a label for their condition, about understanding the medical jargon at last (one of the aims of A^LT^AS, to bridge divide between lay and professional). It's partly a case, as already mentioned in connection with parents, of knowing what the outer limits are and of gaining the reassuring knowledge that all the cards are on the table and that no gremlins are lurking in corners.

Exorcising the Past

Hearing how others have exorcised what happened to them in childhood or adolescence often inspires people to seek out historical information. This is often a vital pre-requisite to moving forward. At a group meeting, a father who works in a caring profession explained the steps involved in grieving and in coming to terms with a personal loss or problem. He pointed out

that unless the problem and the accompanying pain are first faced in their entirety, and acknowledged, there is no chance of moving on to the next stage, which is one of dealing with them and ultimately accepting them.

Intersexed woman increasingly seek access to their medical records. They may also need to come to terms with non-essential surgery, carried out earlier in life without their informed consent. They may follow the example of the group member who, as an aid to coming to terms with her condition, compiled what she calls her "workshop manual" containing all her support group literature, copies of letters between her clinicians, and her own thoughts on her experience of AIS. Seeing what was discussed about you, and possibly seeing clinical photographs of yourself, can be very painful indeed but it can also be cathartic and empowering in piecing the jigsaw together and moving on.

Words, terminology etc. are tools for *communication* – of ideas, concepts etc. – and this can break down if those involved are not talking on the same wavelength. Some doctors take scientific/biological terms (e.g. "gonads") and stretch their established meaning (the meaning they would use when talking to their clinician colleagues) to mean something a bit different when talking to patients. This is in a well-intentioned but misguided attempt to either a) conceal diagnostic information and/or b) soften the blow for their patients. But this can have adverse practical consequences apart from any considerations of emotional pain, in for example raising false hopes.

Some affected adults contact the medical specialists who treated them as youngsters in order to "level the playing field" at last. This can be beneficial for both parties, patient and doctor.

A CAIS 25 year-old emailed (Anon3, 1999):

...this week I got a phone call from the surgeon who did my gonadectomy 8 years ago. I had been trying to contact him for the past year, wanting to get copies of my charts.... but he always avoided me and never returned my calls. I was going home for Easter and really wanted to confront him, his avoiding me has made me all the more annoyed at everything.

What I *was* most upset about was the fact that he had told me that he was removing my ovaries. For the following 6 and a half years, I was puzzled and then extremely angry that he hadn't preserved any of my eggs so that one day I might have my own surrogate child with my own genetic input. So it was with some relief in that respect when I found out about AIS and the fact that I never *had* ovaries, there *were* no eggs to harvest.

So I arranged to have a conflag with him, educate him somewhat on disclosure and throw some support group literature at him and tell him to educate himself, and I was looking forward to it, to being in control over that which he took so much control of before!! I planned to walk in there looking brilliant, tall, proud and every bit like I'm coping with this "terrible news" that he felt like he had to keep from me all those years ago.

OK, the consultation.....No nerves at all; I walked in, shook his hand firmly and was pleasantly surprised to see that I was actually taller than him. One down to me! ...I told him that I had been angry that he never thought to harvest any eggs from my 'ovaries', for future surrogacy. His reply? "I never told you that you had ovaries, I said gonads". So I was supposed to presume they weren't ovaries based on the non-information I was given?

To give him his dues, he was apologetic, never denied that I should have been told the truth.... he rubbed his eyes a lot and told me he admired me. So I guess that's that, and that's another thing out of the way. I'm sending him the AISSG factsheet and the most recent ALIAS. He said that he's never encountered this before except as a med student in Canada

years and years ago and I'm the only AIS patient he had. Everyone, you are all stars and I am so happy to be "one of you".

It seems that all this talking in euphemisms ("ovaries", "hysterectomy", "broken X chromosome" etc.) and the stretching/reinterpreting of an established meaning of words results in communication breakdown, dialogue-failure and even elective mutism in medical consultations, and deprives people of an honest and truthful baseline from which to sort out their options and make life decisions.

Informed Consent

A 22 year-old AIS woman emailed the support group (Anon4, 1999) saying:

The doctors I have spoken to are so vague, that it seems that they don't fully understand this disease or its effects on the patient. They have always been hiding something from me.

She explained how she'd been told that during a vaginoplasty the surgeon would also be repairing her clitoromegaly. When she woke up she learned that the surgeon had decided she didn't need the latter procedure. She said:

Now after reading more of this [AISSG] literature and speaking with him at the follow up appointment; [I see that] he was in some way trying to hold off the final surgery because he wasn't sure if there would be a loss of sensation to the clitoris. He actually tried to trick me, a 20 year-old woman at the time, instead of discussing all of my possible options. The more I read on this [AISSG web] site the more I know about my condition

A 43 year-old with the complete form of AIS wrote to the support group in mid 2000 (Anon2, 2000):

During the late 1970s when I was first investigated (aged 21) I was lied to and my testes were removed without my permission. I was simply told that they were going to remove some 'lumps'. If I had been a complete man the doctor would never have dared do such a thing. I do not understand why having a genetic defect somehow gives doctors the right to ignore my basic rights as a human being. When I found out what had been done to me (a few years later) I felt like I had been betrayed and mutilated.... If I sound angry it is just that they were difficult experiences... I have always lived in so much fear (it is a taboo subject even in my family) that I felt like I had committed some great crime.

After my testes were removed I experienced a range of psychological symptoms including: hot sweats, depression, mood swings and a distinct feeling of being generally unwell; even though I was taking oestrogens. My depression was not due to my discovery of having AIS because the doctors had lied to me and I did not know.... I would go to the medics and beg them to give me my testosterone back and they refused again and again. I was convinced that it was the cause of my depression because I remembered how different I felt before and after the gonadectomy. Eventually I met Prof Jacobs and Dr Conway at the Middlesex [Hospital] and have not looked back. After 10 long years of depression I got the hormones, and straight away began to feel as happy and well as I had felt before the op.

I am still angry that it took me that long – angry that a doctor can tell me lies, remove all the testosterone that my body had naturally produced for 21 years, replace it with synthetic oestrogens and then refuse to give me my testosterone back! It doesn't take a genius to work out that this sudden and complete change in my hormones would have some effect, and no-one even bothered to check up on how I was coping.... Although I realise that the testosterone has no effect upon my tissues, there has been no research to see if it is active with regard to the brain and general mood. The team at the Middlesex [Hospital, London] have been great, they are the only medics I have met who genuinely want to help and ask me what it is I feel I need....

I could have understood if I had been a child, but I was 21 when I was operated on and what they did to me was not only unethical, but illegal. There is not much in this world that belongs to me but I feel strongly that once I become an adult my body is definitely mine... I am just so glad now that I never gave up fighting.

Confidence and Communication

An AIS adult at an early group meeting likened her family situation to ‘a trick done with mirrors’ where “the parents project their unease and the child reflects it back (compounded by the probable unease of the treating physician) so that the whole issue gets passed around like a hot potato.” It was also described as “a huge pink elephant in the middle of the sitting room but whose presence no one would ever acknowledge.”

She later wrote to another AIS woman:

To save your parents from mental anguish and having to deal with things, you shouldered more of the burden yourself – inverse to the way ‘family’ is supposed to work. I remember repeatedly thinking as a teenager “How am I going to get myself out of this?” What I meant was not how would I make it all go away (I knew that was an impossibility). Rather I thought “How am I going to summon up the courage to get the help I need, how am I going to find the strength to talk about it?” (even though I didn’t yet know the truth and know what ‘it’ was), “and how the hell am I ever going to build a normal relationship?” I couldn’t even imagine telling anyone I was unable to have children and didn’t have pubic hair – the two things I actually knew and understood at that age.

The image of being painted into a corner was vivid in my mind since the age of 12 or 13. It haunted me until age 36. I never saw any way out of the corner except by taking my life, until I came across the letter [from another AIS woman, in a medical journal, giving the support group contact details]. The letter wasn’t just a release from a corner, it was a release from the prison that was my mind, a place where everything was locked shut inside and could find no freedom of expression. And when I read the description, in ALIAS No. 1, of “...the process of hearing oneself actually saying out loud those words that you thought would forever remain as circling thoughts in your head”, I convulsed with sobbing (the word convulsing is not an exaggeration; I had never cried from so deep a place, or as intensely as when I read that quote). Nothing I ever read so brilliantly depicted how I felt about my life experience and the ordeal of keeping it all locked inside my mind.

The quote referred to in ALIAS No. 1 was actually as follows:

I have found, late in life, that there is in fact considerable power and healing ability in the actual process of articulating or verbalising one’s fears about such things, almost irrespective of any response from the listener – it’s the process of hearing oneself actually saying out loud those words that you thought would forever remain as circling thoughts in your head.

If the patient has never articulated the words describing her condition to ‘safe’ people like parents, counsellors and other affected people, then she will not be able to play an active role in managing her treatment when face-to-face with a doctor in a threatening environment. This is especially true when she has just had her bodily deficiencies highlighted by a nurse, technician or receptionist asking about her last period (known within the support group as “the mother of all questions”) or a cervical smear test, or has had to wait in an infertility clinic area plastered with baby photographs from grateful parents, or has had to undergo scrutiny from doctors in training. She is more likely to behave as a defensive, monosyllabic child who

wants to get out of the room as quickly as possible, rather than the intelligent communicative adult that she most likely is in other areas of her life.

A CAIS woman wrote (Anon6, 1997):

I recently came to the realisation that because I'd never actually had the wherewithal to say the words "I have AIS" out loud in front of another human being, or to admit to having had testes, I'd never been able to claim 'ownership' of my condition. Well, I might perhaps have mumbled my diagnosis incoherently, fighting back the tears, when occasionally in adulthood a new doctor, surrounded by an army of students, would ask "Well what do we have here then, perhaps you'd like to tell us about your problem?" but I had never actually articulated the words spontaneously and clearly, and felt reasonably OK about it – until the third support group meeting in March 1996. This was a very momentous event in my life. I was in my late 40s.

Personal empowerment means that patients are more likely to communicate effectively with the doctor in the clinic; more likely to meet the clinician half-way and develop an equal partnership. This should make the doctor's job easier.

If the pink elephant is acknowledged in the clinic situation also, then at least there's a chance of an adult-to-adult exchange with the doctor. Talking with others enables it to be integrated into one's persona, so that it's no longer a huge externalized burden or monster, always held at arm's length and waiting to crush you at any moment. It lessens the fear of breaking down in front of the doctor at the mere mention of your condition because that's the only time the words are ever spoken out loud.

Some patients know a lot about their condition – from their private research, not necessarily from doctors – but are just not used to *articulating* any of this to other people, so that while they may be intellectually in control, they may be a disaster in the emotional arena. The patient may have spent many months steeling herself for an informed discussion during, say, an annual clinic visit but may retreat back into her shell if she finds that her efforts are not reciprocated or taken seriously.

A CAIS 37 year-old wrote:

I hate going to the doctor and getting blank stares when I tell them I have AIS, even when I spell it out – 'androgen insens....' And even when I revert to 'testicular feminization' they don't have the correct details for the correct syndrome. A senior resident I saw today (Stanford is a teaching hospital) thought I'd had a uterus and a dual set of gonads – ovaries *and* testes. When the head of the department (one of the top urogynecology experts) came in he didn't recognise 'androgen insensitivity' either but knew much more about the medical details when I said 'testicular feminization'. "Good lord, how long has the name been changed?" he said. I hate the feeling that a bunch of doctors are going home tonight to drag out the textbooks, and with young doctors I hate the slightly shocked look when they finally do understand that it's an intersex condition.

Sometimes I am proud of how much I have learned about AIS in the year since I discovered the truth and I am glad to show off my knowledge and my ability to talk about such an upsetting subject, but there are times when I really don't want to know more about this than my doctors. It didn't bother me to have to educate my family doctor, but *these* guys are supposed to be on top of things. They were nice guys, kind, respectful, considerate, but I was still quite upset.

The senior guy asked me why this information is kept from patients and I explained that the medical community has believed that we are incapable of handling the testes/karyotype information. The room was full of male doctors and he said “Well, we all have Y chromosomes and they work quite well for *us*.” Well, I had a *large* laugh at *that*. I told them that Y chromosomes don’t work so well when you have AIS, have been raised as a female, and quite want to stay that way.

I now find it useful to make sure that a new specialist knows ahead of time that I have AIS, before I come in. When I have to see a new one, I call ahead and ask to speak to the nurse when I make the appointment. I tell her I have AIS and say it used to be called testicular feminization but patients find that term very offensive. I make the nurse or receptionist take a very detailed message about my having AIS and ask if the doctor can call me back to confirm if he or she has ever had an AIS patient before. It prepares them (the nurse has no clue what I’m talking about but the message seems to get passed on clearly) and also warns the doctor in advance of my preference in terminology. I usually get a call back and it gets the awkward moment of recognition out of the way on the phone – where I can’t see the slack-jawed, bug-eyed, dumb-ass look that comes over most of them, until they finally connect ‘AIS’ with the old term, and with testes, XY chromosomes, etc. Residents are especially good at this facial expression :-)

AIS women often come across doctors who cling to the out-dated terminology. The mother of a CAIS infant visited her GP in 2001 and was annoyed to see the words “Testicular Feminization” in sky-high letters on the computer screen displaying her daughter’s medical records. When she asked for it to be changed to ‘Androgen Insensitivity’ the GP said “Oh, we don’t use that term here in the UK, I’m afraid. It’s a trendy Americanism”. We told the mother to inform him that it was an *American* gynaecologist (Morris) who assigned the *old term* to the condition before its true aetiology (target cell insensitivity) was discovered.

Autonomy/Responsibility

Secrecy and poor communication deny patients their right to know about health risks associated with their condition and to seek monitoring/treatment. Another very common cry from new group members is “ I didn’t even know about the increased incidence of osteoporosis in AIS.... [or] about carrier status.... until I joined the support group”. Some were not prescribed HRT following early orchidectomy, and now, osteoporotic in early middle-age, are considering legal action.

People gain information via the group that helps them take responsibility for their own health care. They are encouraged to persuade clinicians that they are at risk of osteoporosis, and need bone density scans, even though they might be much younger than the usual, post-menopausal group considered most at risk. They learn how to obtain a certificate exempting them from UK prescription charges on the basis of having a condition requiring long-term (HRT) therapy. They hear of the amazing benefits of vaginal oestrogen cream in alleviating, even curing cystitis, and in facilitating the use of vaginal dilators, even though many specialists will tell them that systemic oestrogen should suffice.

Contact with others can also influence more dramatic treatment choices. Finding that your problems/issues are by no means unique, reading intersex discourses and realising some individuals actually take pride in identifying as intersexed, intergendered etc., can make you feel a lot better about your body. This means that some patients may then decide they do not want the genital surgery that seemed at one point (when the doctor was the only one doing the talking about her AIS) to be the only answer.

A 27 year-old PAIS woman emailed to a group of AIS women:

I never had the clitoral recession surgery myself, although I certainly would be a candidate for one.... I don't know if I just had enlightened doctors who saw no need to 'normalize' me or what, but it was an un-subject and never discussed at all.

I was/am a pretty traumatized kid over the whole AIS thing, especially the enlarged clitoris, which I never spoke of to anyone. The last mention to another human being about it, before finding the [AIS email] circle and especially _____ [another group member in similar situation], was my Mom telling me as a young kid not to worry about it, that I would grow into it. (Wrong, Mom, but it was a nice try). The idea of someone seeing me naked, someone seeing that 'thing' mortified me to a degree I still haven't conquered. I shut off the entire idea of relationships and sex for this lifetime because I didn't think I would ever find someone who could understand or accept it, not that I would have thought about giving anyone half a chance to come to any understanding or acceptance.

Now, as I climb toward that mystical age 30 mark, I feel like I'm finally getting my life into some kind of order and coming to believe in the fact that I can have a normal, happy life. Since finding the support group and the [AIS email discussion] circle, I'm a lot happier with my lot in life and realize that I'm glad I didn't risk the loss of sensitivity through the surgery. I realize now that it is not impossible to find someone who would understand and love me for me, and who would not worry, to the extent that I do, about the size of my clitoris. It bothers me a lot that I can't be totally sure whether B.C. (Before Contact) [with the group] I would have gotten the surgery, but with the realizations I've come to since then, I'm glad that I didn't do it. More than anything, I want to make sure that someone who does it has had the chance for those realizations that came to me relatively late in life.

Finding their Voice

Finding their voice at last, via support/advocacy groups, has enabled XY women to inform clinicians of their real concerns. For a long time doctors have been talking *about* them without actually talking *with*, or listening *to* them. So what are the burning issues for AIS adults?

Overall, the main concerns of XY women seem to be a) the major problem of secrecy, leading to isolation with lack of information and support, b) the devastating effects of being displayed as a freak in front of medical students and being subjected to medical photography c) the immensely stigmatizing medical terminology used, (supposedly behind their backs but which can be seen in the medical section of any academic bookshop, e.g. "genetic males" or "XY males" [with 'males' used as a noun], "male pseudo-hermaphrodite", "under-masculinized males", "under-virilized males", "hairless pseudo-female", "sexually infantile" [referring to nipples] etc., etc.), and d) lack of certain female bodily attributes. Generally these are the things that doctors and parents dismiss, gloss over, or fail to acknowledge as being traumatizing. The issues that, in the longer term and with appropriate support, seem lesser concerns are the XY chromosomes and the testes (neither are discussed much at our meetings), infertility in many cases, and inherent gender identity (in CAIS at least). That is, all those things on which doctors and parents concentrate their thoughts/anxieties.

It seems that the medical profession has been worrying for years about what might be called a "deficient maleness" in conditions like AIS (and even talk about it in these terms in their research papers, even when describing girls/women with the complete form of AIS), whereas patients have been mainly concerned with their "lack of female attributes" and this is what they talk about at meetings. Things like a) lack of menstruation as a rite of passage, absence of pubic hair (in CAIS), and presence of pale under-developed nipples (all much more overt

and everyday reminders of their 'difference' than chromosomes or gonads – and a source of great anxiety for most AIS women), b) vaginal length, and size of clitoris and labia, c) sexual response and experience, testosterone and libido, d) HRT preparations, e) comparison of body features (height, length of limbs, size of hands, feet, teeth), f) body odour (general lack of in CAIS?), etc., etc.

One thing that everyone notices at our meetings is how one can dispense with all niceties and get down to the nitty gritty straight away, in stark contrast to how most affected women operate in their normal lives, even with women friends. I think most feel they missed out completely on adolescence, and on 'girly' comparisons like this, because of feeling so stigmatized, marginalized and unusual. By meeting others you gain a sense of belonging to a peer group at last and can share commonalities but, importantly, it also shows you that there is as much variety between XY women as between women in general and that not everything about yourself that you 're unhappy about is due to AIS or Swyers..... or whatever (the "AIS bucket" phenomenon).

Youngsters with CAIS may well be very confused and anxious about their physical/functional differences, compared with other girls, but underlying gender identity is not as fragile as many doctors/parents seem to think. The way to resolve the former is to allow discussion, counselling and meetings with others. Over-emphasis by doctors/parents on essential 'femaleness' in CAIS is unnecessary and is, in itself, likely to convey an sense of acute unease to the affected person.

There seems to have been a 'mythologizing' of CAIS promoted via an overemphasis of these patients' femininity, both in the literature and in dialogues between doctors and parents/patients. There seems to have been an idea going around that AIS women are somehow more attractive, and behave in a more feminine way than other women merely because of their complete insensitivity to male hormones (the old "air stewardesses, models and movie stars with AIS" notion). Whether true or not, these ideas are probably popular because a) they make the syndrome seem more remarkable and b) they reassure those people who are uncomfortable with the idea of an XY woman. But such notions are of little help to the affected women themselves and many members ask that we remove them from our literature.

We suggest infertility to be no more of an issue than in women who are infertile for other reasons, except that those with AIS have to shoulder this burden from an early age (maybe this makes it easier in adult life?). Most support group contacts in long-term partnerships seem to have dealt with, or plan to deal with this via adoption, surrogacy etc. The burdens are probably 'stacked', with unresolved vaginal hypoplasia possibly taking precedence over infertility in those who have this additional deficiency?

Sex Talk

A common complaint by adult women to the group is that the doctors will *certainly* talk about infertility, will *probably* pluck unsubstantiated reassurances out of the air about gender identity, *may* talk about gonads and chromosomes; but the one thing they *never* discuss fully (beyond glib exhortations of 'normality') is the patient's fitness for sex and relationships, topics that are at the forefront of her mind. The group can provide help in the emotional, you're-not-the-only-one type of support but we can't offer the much needed specialised

psychosexual counselling, although we do have psychosexual therapists who occasionally attend our meetings.

A CAIS 39 year-old submitted her story for our web site:

I've learned what little I know about AIS through dribs and drabs over the years, even though I was diagnosed with what I now know as CAIS at 16 or 17....

I did not have intercourse until I was 34 and I believe the social retardation I suffered as a result of how my diagnosis was handled severely affected my personality, my ability to form intimate relationships and my self perception as a woman. I was given what everyone euphemistically referred to as a "hysterectomy." But I heard the words, "short vagina" said in passing, with no explanation and no elaboration. And it dramatically affected how I saw myself. I was so embarrassed by the very thought of it – how can you bring yourself to discuss *that* with a middle-aged white guy? Your mother? Anyone? I pretended it didn't matter and though my mother explained all the scientific stuff to me, I was only interested in the practical effect of it all: I couldn't have sex.

Well – I knew I could try but that it would be humiliating. So I didn't. For worse (or for better) I didn't *dare* "go all the way" with anyone – through college, through law school, and for years as a lawyer. And the longer I went a virgin, the more difficult it was to subject myself to the humiliation of someone rejecting my sex. All types of scenarios were played out in my head: "What??? No hair? What's wrong with you? I can't get it in!!! Oh my God! What's that scar? Testes?????", etc...

As I write this, I know it sounds so ridiculous. But I always felt I had so much more explaining to do than any other girl and I couldn't imagine how I could finesse the way I looked and how my body was made without diverting the romantic mood. My fears continued to escalate. By 34, I felt I was a freak, or would be perceived as one. But I took a huge risk and planned to have sex just to get it over with... So inhibited was I that it took him over three hours of massaging me to achieve penetration.... As it was, it turned out to be a positive experience. One of the happiest memories I think I'll ever have is driving home on a sunny day, age 34, knowing that I had had sex. How pathetic it would seem to most people, but it was the first time I felt that I was normal. If only I had known it was possible decades earlier, my self concept might have evolved....

....there seems to be an effect on my psyche that remains from all those years of not being able to connect in that way. Am I imagining this? I try, but I think that now I'll always be too independent to form the kind of romantic, emotional, sexual attachment that most other people take for granted.

If anyone has been through this, please let me know. I'm sure there are psychological implications that haven't been explored. One of the first steps is having someone to identify with. That's what is so great about this [AISSG] website.[I] hope that one day I can get over it. But it's hard and the rejection – if it ever happened – would reach such fearful magnitudes that I might never trust anyone ever again. Which explains my dilemma, but doesn't solve it.

Even younger women, born in more liberal times, have the same problems. A 23 year-old woman wrote from overseas:

I have the very same experiences as Elizabeth [on the website]. I am quite good-looking, smart girl, successful and attractive. My only problem is that I have never had sex or a real relationship with men. All my merry friends would be shocked by this fact. I try to avoid lying to them, I just don't talk about sex with my friends....

For much of this dilemma, (knowing myself this is a bit stupid) I blame the doctors who made my diagnosis. I was thirteen, and there had been infertility – probably exactly AIS – in my mother's side of the family, so there were some doubts there might be something wrong in me too.... I was diagnosed to have "testicular feminization". The young male doctor displayed a figure of my chromosomes, told I had a genotype of a male but appearance of a female. "The patient has a short, blind vagina and there's some risk of a tumor if it's not operated", I heard during the process.... It came clear I cannot have children, but simply not a single word of sex. Nobody offered me any counselling, nobody explained to me what this peculiar condition might be.

It's been ten years now since the first diagnosis. I haven't been at gynecologist's even once. I haven't had sex or relationships or talked to anyone about it... It's only now I have found out that there actually *is* reasonable information about this and there are other names to it than this "testicular feminization", which I feel somehow inappropriate. And what's most important, I have found out there is a lot of other people with AIS too.

I know the doctors are not the big bad devil in this trauma, nor is my AIS. It is a complicated mix of many things... Still, I think that it would have been easier to grow up if the doctors would have treated me as a real living and feeling person, not as a medical freak, and if somebody would have talked to me seriously about me, genders and sex. Now they really made me feel like sexual outcast. They made me think that, for example, school lessons of sex issues were not meant to me: teachers spoke about sex of another species, the species of the normal. Anyway, the problem was not that I was told about my AIS. It is good to know that. I had always known there was something special in my body or my gender, and the diagnosis makes many things clear which was a true relief. The problem was the way it was told.... I just was hinted I was a monster to other people, and that's what I think is unforgivable cruel.

Vaginal Hypoplasia

Decisions concerning vaginal hypoplasia involve questions of the timing of intervention and the method used. We have the impression that treatment in childhood is more often advocated in the US than in the UK. But at a UK AISSG meeting two paediatric endocrine nurses outlined an ethical problem involving a child (late childhood) in their care whose parents wanted to schedule a gonadectomy and a vaginoplasty at the same time. The parents were being secretive with their child and were not allowing the medical staff to give her any information which might allow her to give informed consent. The AIS adults felt that these parents were feeding their own anxieties about the whole issue, and that this would be patently obvious to the child, whose long-term interests would not be served by the proposed action. It seems more sensible to delay treatment until the patient is wanting to be prepared for sexual activity and can play a part in the choice of treatment.

There seems to have been an overemphasis on surgical vaginoplasty methods at the expense of less invasive methods in which the patient has some control of, and involvement in the process; methods like the Frank manual pressure dilation technique (first described in 1938) or surgically assisted pressure dilation methods like the Vecchietti procedure, a method that the AIS Support Group has been encouraging doctors and patients to look into for some years now (Anon3, 1996; Anon 5, 1996; Anon7, 1996; Anon3, 1998; Anon5, 1998; Anon6, 1998; Anon1, 1999 and Anon2, 1999).

The founder of the US AIS Support Group told us in 1998:

The McIndoe operation and Baldwin intestinal transposition are still very much the favored surgical alternatives to this day. Last week a mother of a teenager in S. California contacted

me to tell me these were the two suggested methods presented by surgeons in a major metropolitan teaching hospital near L.A. I quickly sent the mom information about the “modified Vecchietti” method and suggested she inquire why this alternative had not been suggested. I’m really curious about what the surgeon’s response will be when the mother presents this alternative.

I suspect that the Vecchietti isn’t ‘high tech’ enough to appeal to most surgeons’ interests – viz. they would not feel they had really accomplished anything by performing the procedure because they assess ‘accomplishment’ more in terms of the technical marvels of their operations and less in terms of the end results achieved by their patients. It strikes me that as both the MRKH support groups and our group promote the Vecchietti it will result in the failure to suggest this as an option being malpractice – even if the surgeon has legitimate reasons (can’t imagine what they’d be) for favoring the Baldwin or McIndoe.

It could be argued that the use of surgical vaginoplasty is another example of doctors seeking to control everything themselves, to wave a magic (surgical) wand? Pressure dilation can produce results that are as good, if not superior, to the most successful surgical outcome. The neo-vagina is created from stretching existing vaginal tissue without any cutting, so it retains its innervation, it lubricates naturally and involves no scarring. But it does require a lot of psychological back-up and support, because motivation to perform the rather tedious procedure twice a day is all important and is difficult to sustain. Very few gynaecology departments have this back-up in place. As with general psychological support, the emotional needs of women coping with vaginal hypoplasia have been sadly neglected by the medical profession and this is where a multi-disciplinary approach is so important.

A lot of genital surgery in children has been fuelled by anxiety over the performance aspects of males with a small penis. But because medicine has not shown the same degree of concern about the capacity of female sexual ‘equipment’ (and thus no corresponding imperative to *masculinize* those in whom vaginal length falls short of the norm) there are some who, showing no outward signs of the panic-inducing deficient maleness, didn’t have their non-standard genital morphology even properly recognized until relatively late and who have lived their life believing it precluded them from sexual relationships. A middle-aged CAIS woman wrote (Anon2, 1998):

I discovered by self-examination in my early teens that my vagina was almost non-existent and told myself I could never have relationships. Every gynaecologist I saw following my eventual CAIS diagnosis, and clinical recognition of my anatomical problem, in my late teens, advised me against treatment unless I was about to get married or had a regular boyfriend (and I only saw one or two such clinicians; I felt far too much of a freak to go near them any more than necessary). But they didn’t offer me any counselling to help me form such a relationship (and I felt far too traumatized and freakish to speak out in consultations, beyond answering ‘yes’ and ‘no’). Everyone was so busy going on about how I was a normal female, in spite of my AIS, that I just didn’t *dare* challenge this by asking how on earth I was going to have sex with a 1 cm vagina. And no one mentioned the non-surgical pressure-dilation method until I had eventually undergone two plastic surgery operations (McIndoe skin graft and William’s vulvo-vaginoplasty), which I now regret since they left me with scarring, and some disfigurement, without really helping matters. Being able to *talk* about the vaginal problem, and my whole AIS situation, would have been a lot more use to me.

She described her anguish at the reaction of a partner to her disclosure about her situation (Anon2, 1997). She also said:

At first (before the discussion turned angry) he did try to comfort me, and to be helpful, and said that in his experience, and in discussions with friends, he’d come to the conclusion

that it wasn't what you *had* that mattered but what you *did* with what you had; and that maybe I should be adopting a different paradigm and thinking 'sensation' rather than thinking 'morphology'. At the time, I thought "what a stupid and unhelpful idea", but on reflection some months later I decided it was possibly one of the more sensible things he'd ever said (!) and I began to wish that I'd had a chance earlier in my life to discuss this possible mindset with a psycho-sexual counsellor – since our high-tech medical system hadn't seemed able to provide me with a vagina at the time when one might have been of use to me in developing some view of myself as a sexual person, in the sense recognized by this society.

It is important that any young woman considering treatment for her vaginal hypoplasia should be given the opportunity to discuss the options not only with her specialist/ but also with *other women* who have undergone various types of treatment.

An AIS woman in her mid 30s, emailed:

I went through the McIndoe [skin-graft vaginoplasty] surgery at 18.... The doctor didn't give me appropriate forms (dilators) for home use [after the surgery], so I had one thumb-sized form and one large wide one which I could never insert fully. Why he couldn't obtain appropriately-sized dilators prior to or shortly after the surgery, I don't know, but this was the major obstacle I never overcame. The pain of trying to use these forms at home, with no real help from the doctor, and a difficult examination in his office with the speculum, made me rule out sex entirely. I feel saddened that the surgery was carried out without adequate discussion and preparation beforehand. No mention was made of using pressure dilation before surgery, or the possibility, or necessity, of using sexual intercourse as a means of dilation/maintenance.

The negative experience with this surgery, and with the particular physician, resulted in me not seeking medical attention for over 18 years [she has never been prescribed HRT] and the complete avoidance of friendships with men. If the vaginal issue hadn't been the major problem, I think I would have lived a more normal social (sexual) life.... but the fears of difficult or impossible vaginal intercourse, just made sexual contact out of the question for me. Besides this, I never understood how a girl with no pubic hair, and two very prominent abdominal scars, and now two large skin-graft scars, could explain the situation to a man and not lie, freak out the man, totally turn him off, suffer rejection, etc.

The support group meetings have given me hope toward leading a more normal life. Just hearing everyone expressing their sexuality, in their myriad ways, has made me feel better. I find myself accepting myself more, and am not as uncomfortable talking to men.... In a way, it's a shame I didn't feel this way in my 20's.... It is difficult to imagine starting an emotional or physical relationship for the very first time in one's late 30's, but it is perhaps more of a psychological barrier than a physical one. The emotional and physical isolation can only be harmful. Now that the information about dilators and Vecchiotti procedure is more widespread, the vaginal issues can perhaps be better addressed.

Hormone Replacement Therapy

It has been our observation that hormone replacement therapy is such an individual thing that this is the one area in which there is almost no point in women discussing pros and cons amongst themselves, other than perhaps issues relating to delivery method (e.g. tablets vs patches). A number of XY women are experimenting, under medical supervision, with testosterone-based HRT. There is also the (so far unanswered) question as to whether or not progesterone has benefits for patients without a uterus.

Rights of Carriers

In the case of AIS, denial and secrecy also cause problems for XX women in the family who might be carriers and who have a right to be made aware their potential carrier status so that they can make informed reproductive choices.

A 37 year-old PAIS woman was at a UK support group meeting with her carrier sister. The sister related how she only learnt about AIS when she became pregnant in her 30s (even though her AIS sister had been diagnosed in her teens). She would very much have liked the chance to rehearse her feelings about all the implications/choices (pre-natal tests, abortion etc.) *before* becoming pregnant.

A CAIS 49 year-old emailed to the support group (Anon3, 2001):

Today my niece – the daughter of my non-AIS sister (my other sister and I have AIS) – announced she is “with child”. She is 3.5 months pregnant. This should be great news to me yet my blood turned cold because my non-AIS sister *could* be a carrier.... I only found out about carriers last year when I got more info about AIS when I joined the group.

My non-AIS sister had a carrier test a year ago but still has had no result. We will chase tomorrow but lack of funding makes these delays happen. The big problem is.... if she *is* a carrier, my niece could also be a carrier and the baby could be AIS. Is this right do you know? I am so worried. My niece had said she did not ever intend to have a baby. We had agreed not to tell her [about AIS] until we got the results of the carrier test but now it's too late.

Both my sisters have the denial factor – won't discuss AIS. My non-AIS sister has said I must not tell my niece now. She says – and she has a good point – that the stress involved could upset my niece and so damage the baby. She says that she may *not* be a carrier. Also that the baby could be a boy, or OK [XX non-carrier female] anyway.

Sorry ...this is a tricky one to follow but I could really do with some advice here. It is an ethical dilemma. And a no-win situation. After the last group meeting I was all set to tell my niece about my condition too... What do you think I should do?

It sometimes works the other way round. At the same group meeting a CAIS 35 year-old who had learnt her diagnosis late in life – not from a doctor or from her parents but in a letter from a cousin – tearfully explained how other people in her family (e.g. carriers) had been told more about her condition than she had. Being ostracized had been far more painful to her than the diagnostic knowledge itself.

In 2000 the web site of the British Association of Paediatric Surgeons was displaying an article (MacKinnon, 1998) giving recommendations on truth disclosure in AIS, saying:

The diagnosis, if proved, may not lead to any immediate benefit to the patient or alteration in management. It could be argued for some families that investigations under such circumstances are not in the patient's interest.

When doctors advocate secrecy or half-truths like this, an obvious question is what about the rights of XX female relatives to know about their possible carrier status? Imagine the anger all round when a baby's AIS diagnosis is communicated to the parents and the mother's sister suddenly realises she herself must have AIS; and that no-one had the guts to tell either her, or her XX sister earlier in life, so that they could each deal with the actuality... and the possibility... respectively, in a useful way.

A father wrote to us in 2002:

First of all, thank you for the information that your organization has provided over the web, it has been invaluable. I am a father with an infant with CAIS. I found out by way of a hernia operation [on our baby]. My wife has a 25 year-old sister who also has CAIS but we have only just found out what it actually is. She was originally diagnosed with the older title, testicular feminisation, but was told at the time that it was a one off and a freakish event by her doctor. She was also very much misinformed on her condition and basically grew up thinking she was a freak, all because her doctor didn't look into it but merely assumed he knew all there was to know. So you could imagine the surprise we all had when we learnt what it actually was, through my little girl, _____ [baby's name].

How do doctors know what information may or may not be in the patient's interest? It's the sowing of these early seeds of secrecy and ignorance that may result, in 20, 30, 40... even 50 years time, in these 'babies' being severely traumatized by reading words like "male pseudo-hermaphrodite" upside down in their medical notes. They may be too petrified to bring up the subject until later in life when they finally contact a support group saying: *"Well, it seems the doctors never told my parents anything.... so they never discussed it with me.... so I've just lived in the belief I was an one-off freak, for all this time."*

If doctors put their energy into helping us to publicise to society that these conditions/states actually *exist*, in Nature, and that it's not so bad for people with access to a support group, then there wouldn't be this perceived need to keep certain parts of the truth from certain parents/ patients. It just seems like yet more paternalism and 'doctoring' of information, with medics once again setting themselves up as the gatekeepers of diagnostic information without, apparently, even considering involving clinical psychologists.

As AIS becomes less of a closet issue within families, there will be an increased demand for carrier testing services to enable XX female relatives to make reproductive choices. To-date this has only been available on an ad hoc basis, as a favour on the back of genetic research into the androgen receptor gene, for which funding is now drying up.

Telling/Educating Others

The question of what to tell friends, partners and other family members is a major issue for XY women. Through discussions with women at support group meetings and by email it has become clear that *preparation* is all important. By the time the affected person comes to tell others she should have reached some resolution of her feelings about her condition by having talked at length with other affected women, with counsellors, psychotherapists etc., and should have had a chance to rehearse, in these non-threatening situations, what she might say when facing those with whom she is emotionally involved.

The worst situation is for the woman to be using the process of revelation as a primary means of resolving her own conflicts. If the teller is not used to talking about her condition the exchange is likely to be fraught with additional complexities, with the listener having to cope with the woman's probable distress as well as having to deal with his or her own reaction, and with the teller then getting mixed signals reflected back from the confidant/e in a "hall of mirrors" scenario. If, on the other hand, the woman herself is comfortable with her situation and can "spill the beans" in a confident, almost light-hearted manner, then the listener is far more likely to have a positive reaction, which in turn helps the "bean-spiller".

A middle-aged CAIS woman wrote (Anon6, 1997):

It's almost unbelievable that in middle-age I should find myself agonizing over what, if anything, to tell my first ever real boyfriend about my condition. And that someone with whom I was emotionally involved had to be the very first human being to whom I'd ever articulated the words; and so late in life. In the emotional breakdown precipitated by my eventual disclosure of the truth to him – some two years after the early failure of the relationship [severe vaginal hypoplasia having made intercourse impossible] – I also found myself bringing up the subject of my medical condition with my parents for the first time, only to find that my father couldn't understand the medical basis of it at all and my mother wouldn't even try, still refusing to acknowledge my condition as being anything other than a fertility problem.

The same principle applies to parents who have the task of revealing the truth to their daughter. They really owe it to the listener to have sorted out their own feelings, conflicts etc. as much as possible, long before they embark on the telling.

The timing of telling others is very problematic for adult women. If it's a potential partner, do you tell them on the first date on the principle that if they can't cope with it up-front, then there's no future in the relationship? Do you tell when things get serious and sex is involved (particularly relevant in the case of vaginal hypoplasia or a larger than average clitoris)? Do you wait until the relationship seems likely to be long-term and issues of fertility come into play? Telling a partner *early* risks jeopardising the relationship. Telling a partner *late* risks accusations of lack of trust.

How *much* should one divulge, just the infertility, or the whole bag of tricks including the testes and XY chromosomes? How does the average androgen-sensitive man-in-the-street process the notion of an XY woman with testes? Whose needs are being served by a decision to tell? Does the other person have a right to know or is telling only advisable if it causes the affected woman herself pain to keep secrets from a loved one? It presents many dilemmas that women need to have explored beforehand.

Conclusions

Adult women with AIS and similar conditions have made enormous progress in the last eight years or so, in coming out of the closet, gaining confidence, influencing medical practice and changing social attitudes. Intersex is now something of a hot topic in popular magazines and TV programmes. It is gratifying to see the number of psychological studies that are now underway and that a shift away from the medicalisation of these conditions is taking place. The main problem area, in the eyes of the support group, is the continuing isolation amongst the parents of infants and young children, and a huge ignorance amongst many general

practitioners. Future decision-making could also encompass issues of assisted conception brought about by advances in genetics.

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