

Support Groups for CAH and AIS

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In the late 1970s, soon after I joined the staff of the Endocrine Clinic at my hospital in Melbourne, the mother of two children with CAH asked me if I would write something to explain CAH to lay people. Not having done this before, I felt the need of more information, so I sent out a questionnaire that I had prepared to the parents of all our CAH patients. In it, I asked them about their child's birth, who said what to them, and how they felt at the time. I was not prepared for some of the replies I received. One came back with the ink badly smudged by the mother's tears. She said she had not been able to face the questionnaire for 3 weeks because of the searing memories it revived in her, and answering the questions had been extremely difficult for her. Many of the other responses were laden with emotion too. It made me realize for the first time what pain these people had experienced and what a tremendous unrecognized need there was for some counseling and support.

I wrote a small booklet about CAH in which I tried to put myself in the parents' shoes. When it was published, I thought that I would invite all of the parents who had helped me to a meeting where the book would be launched and where we would have a discussion about some of the issues. About 40 or 50 parents attended this meeting. Again, I was unprepared for what followed. These parents had never before met other families with children like theirs. They had never had an opportunity like this where they felt free to tell other people exactly how they felt. One couple told the others that they had not been able to face having another child with CAH after the first experience, and they had had their next pregnancy terminated. Others admitted the same. People told their stories tearfully but with great eloquence. I was concerned that things might get out of hand during the meeting, but afterwards the parents said they felt better and they would very much like more meetings.

Over the next months and years, we held many meetings, organized by the Endocrine Department, and the attendance grew. I made sure that I had someone there who was

a mental health professional (a psychologist or psychiatrist) and a social worker. We tried many different formats. At one meeting, the parents entered through a row of quickly prepared poster displays, which stated facts about CAH and posed questions for them to consider. We left some boards blank so that the parents could record their questions. We would generally start off with a short talk about some aspect of CAH and would then disperse into small groups for discussion about an open-ended question such as, "What concerns do you have for your child's future?" or "What are your child's needs and what are your needs?" These small group sessions have always been the most popular part of any meeting. We would then reconvene the whole group for a plenary discussion. One parent from each group would be asked to summarize the discussion from his or her group and their points would be summarized on an overhead transparency by the chairperson.

A panel of health professionals would then answer questions arising, with general discussion from the floor. If any visiting experts were in town, we would invite them to the meeting. Mel Grumbach attended one in 1983, and Maria New met a number of parents in the mid-1980s. We involved parents in planning the meetings and took their advice on the topics to be discussed. They asked for discussions about how to tell other people about CAH, how to avoid adrenal crisis, how their daughters' sexuality would be affected by their past surgery, whether or not they would be able to have children, how to help the children avoid becoming overweight, and about research developments. Prenatal diagnosis and treatment were particularly hot topics. Attempts to involve young people with CAH were not particularly successful because they always had better things to do and were getting on with their lives.

In the mid-80s, we encouraged the parents to take more responsibility for their own meetings and they elected a steering committee, which developed a constitution, which led to the formation of the CAH Support Group.

The CAH Support Group has had many successes, and it has greatly assisted the parents of newly diagnosed children with CAH, as well as the Endocrine Department. It sees its role as "providing support and educational information in order to assist individuals and families affected by CAH to maximize their health and well-being, and to advocate on behalf of and promote the interests of those affected by CAH." The group produces a newsletter, has a website, and holds regular seminars. They are in touch with similar groups in other countries. One member of the group has single-handedly raised nearly \$A100,000 to support research into CAH and related conditions. The parents who had asked me to write the original educational material for other parents later won a lottery and generously donated \$A75,000 to support the department's CAH program.

Things have not always been rosy. In 1993, the CAH Support Group became very upset with me over an article that was published quoting me in a popular women's magazine. The title of the article, which featured an interview with one of my patients and her mother and which quoted me, was, "They couldn't tell my baby's sex." What the other parents objected to was that the article revealed to the world that girls with CAH not only had a condition requiring medications but also they were born with ambiguous genitalia. The problem was that some of the parents had not disclosed the latter aspect of the condition to other members of their own families (for example, the child's grandparents) or at school. I had disclosed what they thought at that time should have been kept secret. A rather savage campaign of letters was organized and complaints against me

were laid. I argued that the best interests of people with CAH were served by educating the community. This view prevailed, and eventually the controversy died down. Every parent who attacked me has since come along to apologize, even though that was unnecessary from my point of view. More importantly, they agreed that openness was the best policy. At the height of the storm, I began receiving letters from adults with CAH who, until that time, had been totally isolated with no knowledge of the support that was available. One said, "Today I had the exhilarating experience of reading the story of [the girl] with CAH ... I was so pleased to hear that she and her mother knew so much about it, as my parents knew very little."

A CAH CLUB FOR HANOI

Since 1995, I have been developing collaboration with an endocrine department in Hanoi, Vietnam, and a pediatrician from Hanoi, Dr. Vo Thi Kim Huê, had received 18 months' training in our department. On returning to Hanoi, she had carried out an extensive study of her CAH patients for her Ph.D. thesis. Having seen our support group in operation when she was in Melbourne, she asked us to help her establish a CAH Support Club in Hanoi. In 1999, the couple who had won the lottery offered to come to Hanoi with me, at their own expense, to meet the Vietnamese parents. They also provided money to have my parent information booklet translated into Vietnamese, and copies were photocopied for every CAH family in Hanoi.

The first meeting of the Hanoi CAH Club was held in September 1999 at the National Institute for Pediatrics and was attended by about 80 parents and grandparents. Some had traveled for days to get there. There was a buzz of excitement as the Director of Endocrinology, Prof. Nguyen Thu Nhan, began with an explanation about CAH, using the recently translated educational material we had brought. After lunch, we gathered and every person in the room stood and introduced himself or herself. Several people spoke passionately with tears streaming down their faces. They told how their children faced abuse and humiliation because of their general virilization and abnormal genitalia. They asked why could they not always obtain the drugs their children needed, and wanted to know what could be done to improve the general situation. Prof. Nhan invited the parents to elect a committee. This was accomplished within 10 minutes!

Subsequently the group has had two more meetings. Advances in treatment have been achieved. Prednisolone has been superseded by hydrocortisone; Florinef is now used instead of injectable DOCA. The children with CAH in Hanoi now look different: they are no longer cushingoid, they are growing, and fewer are suffering adrenal crises. The older children say that they feel much better. They are happier, and so are the parents.

AIS SUPPORT GROUP

In the early eighties, AIS used to seem a much more difficult condition to explain to parents and patients than CAH because of the need to explain the concept of an XY female. Like everyone else, I found other ways of getting around the problem, such as saying, "there is a chromosomal abnormality" (without saying what it was) and "because of this, the gonads have an increased potential to develop cancer and therefore they need to be removed." In 1983, we encountered a family who found that this explanation lacked credibility, and they became very agitated. I decided to tell them the truth about AIS, a topic being researched in my lab at the time. In doing so, I was very worried because I had not heard of anyone else doing this. The result, however, was very satisfactory all round. The parents thanked me for giving them information that at last made some sense. The mother went and had her niece's chromosomes tested and

they, too, proved to be XY. The second family was counseled. Both mothers then disclosed that they had a sister with the same condition. I counseled her too. Other patients were referred to the clinic and I counseled their parents about the facts of the matter. In 1985 the social worker and I decided to invite the group of parents who “knew” about AIS to come to a meeting, and six couples came. We gave them a handout containing the same facts that they had been given verbally. The meeting went well, and others followed. At one meeting, some of the young women with AIS were invited and a 78-year-old woman who had been to see me addressed them about her extraordinary life. At another meeting, one of the fathers said, “We have all been interested in hearing each other’s stories. Why don’t we write them down?” Subsequently they all did, and we have the dossier of stories in our files. They form an interesting archive of the views of parents in the era before the Internet and the development of the large patient advocacy groups that now exist.

In 1993 I began an e-mail correspondence with the AIS Support Group in the United Kingdom and found them a wonderful source of insight into what it is like to be a woman with AIS. The women in the U.K. taught me a great deal about how wrong some of my attitudes had been. My assertion that women with CAIS could be considered more feminine than XX women because they are only able to respond to estrogen and not male hormones was torn to shreds. “How can a woman with no uterus consider herself to be more feminine than a woman with a uterus?” they rightly asked. Together, we worked out ways of explaining AIS that were at the same time truthful and affirming. The book that was published in 1997 should carry the name of the newsletter editor for the AISSG as coauthor, but she declined.

In 1996 an AIS Support Group Committee was formed in Melbourne at the request of a woman who came down from Brisbane to Melbourne to meet some of our adult AIS patients. Several meetings were organized, but parents and some patients were reluctant to “come out” even in this discreet environment. In 1997, Sherri Groveman, then the President of the AIS Support Group in the United States, was a guest speaker at the annual scientific meeting of the Australasian Paediatric Endocrine Group, and in the same year, a leading activist from a New Zealand intersex patient advocacy organization was invited to visit our department for consultations with health professionals and parents. In 1999, the issues surrounding genital surgery for infants born with ambiguous genitalia started to surface more forcefully in Australia and were aired at AISSG meetings, with health professionals present. Things were going fairly well until June 2000, when a representative of the group decided to tell her story as a follow-up to programs about the “John/Joan” scandal, on national television. The program degenerated into a savage attack on doctors. This created a lot of anger among doctors, parents, and patients. Many of those with moderate views then distanced themselves from the support group, and thus the fragile “community” of families affected by AIS was polarized. Disputes have recently arisen between the Australian group and groups in other countries, and for a time, the Australian group aligned itself with more radical groups. More recently, harmony has been restored and once again the group is engaged in a very constructive dialogue with health professionals.

OVERALL REFLECTIONS

A support group is an organic entity with a life cycle that is perhaps only now becoming better understood. The first phase may be thought of as the “pastoral” phase. In this phase, the group seeks ways of providing educational information and support for other

people affected by the same medical diagnosis. The overall needs of all parents and patients are considered paramount and the policy is to be as inclusive as possible. There is close cooperation with the medical team. The group acts to provide support to the medical team by helping to organize meetings, suggesting topics for research, and fund-raising. They act as advocates for the needs of affected people. The relationship between them and the medical team develops into a valuable extension of the one-on-one clinical relationship between individual doctors and patients. The doctors consent to coming down from their pedestals. They ask to be addressed on first-name terms and are present when the group debates contentious issues, as well as at social occasions. Both sides get to know each other's needs better.

In the next phase, the organization becomes more clearly defined and the responsibilities of office bearers grow accordingly. This attracts people with more professional skills, who apply their minds to the issues at hand. They need to identify some important challenges and projects that will give the group a more significant role to play, because they want to "make a difference." These issues need to be different from what has been traditionally offered to be worth addressing. This sows the seed of confrontation. Members of the group begin to take sides about ideology. The debate intensifies, and some members leave. The pastoral role of the group suffers because unity of purpose has been sacrificed and some people feel excluded. The group dwindles in size. The power brokers lose interest as their power base diminishes. The group starts to meet less frequently. The medical team is consulted about ways of reviving interest in the group. A new team of members is recruited, and the cycle starts again.

For many groups, the Internet has been a powerful tool for attracting more people of like mind to join the organization. Those who disagree with the philosophy of the group, which is usually clearly stated on the website, do not associate with it but join another group that is more to their liking. Communication between members of the group is easy because of e-mail, and there is no need to involve members of the medical team at all. The distinction between what members of the group think and what doctors think is drawn more and more sharply. The group can make pronouncements on any subject, but the number of people represented, and who they are, remains concealed. At present, the challenge is to make sense of what is provided at random. The Internet can, unfortunately, be a vehicle for hate mail. Counseling and support can be made available to affected people, by affected people, in complete privacy. This clearly appeals to those who are socially isolated by their condition and is empowering for them. Nevertheless, the information available on many websites is highly biased and in some cases frankly misleading.

WHERE TO FROM HERE?

From the point of view of patients, support groups are good because they complement what the medical system has to offer. They have the power to alter a person's perception of his or her condition. Patients and parents feel empowered and supported. If a rare disease affects them, it does not seem so rare when there is a group. In the past, they have not been given as much information as they would have liked; through the support group, they can readily access information and comments from other affected people about that information. Doctors and other health professionals also benefit by learning more about patients' needs and views, through being able to work with the group in recruiting people for research projects, and from funds that may be raised.

Support groups are an innovation of the 1980s and 1990s that should be nurtured. It would be very worthwhile for someone to study more carefully the dynamics of support groups and the reasons why some people choose to join them and others do not. My own belief is that groups function best when they retain close links with the hospital or clinic and when a member of the medical team (who may be from any one of a number of disciplines) is willing to give a lot of time and effort to the activity. From this point of view, hospital departments should give staff members time for this activity and not just expect them to do everything after hours. Someone needs to advocate for this to make it happen. Appropriately qualified staff should be appointed to ensure good liaison with support groups. Support groups may need to revise their mission to reinforce the concept of the pastoral role being "core business." Controversial and politically divisive debates should take place under the umbrella of a different organization.

An important way forward would be the development of more websites prepared by both medical experts and support groups working in collaboration. All material published on such a website would be peer-reviewed and professionally edited to ensure the use of plain language approved by people with the condition. At the same time, the Internet is no substitute for direct, human contact. For many people, the experience of having a chronic medical condition and the treatment required can be devastating and dehumanizing. They seek the reassurance of loving and compassionate human relationships, and these are best provided face to face. For this reason, meetings in cyberspace will never replace the experience of real meetings between real people.

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