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Although now retired, Brenda May still maintains an interest in CAH and publishes articles. The most recent research comprised two components; she talked to women with CAH aged between 18 and 34 years, each for approximately four hours to discover from them what life with CAH had been like. The second part of the research involved parents of young children with CAH. Questionnaires were sent to both mothers and fathers of these children to see if things had changed since the older group of women had attended paediatric clinic. However, the issues that the older group of those with CAH brought up were extremely similar to those of the current parents. These issues and experiences appeared to be understood as being centred round the development of a 'skeleton -in-the-cupboard'.

A 'SKELETON IN THE CUPBOARD'

What is this skeleton? It is the difficulty of understanding what is the matter. Why is it necessary to go to the hospital for check ups? Why do they have to take medication? What is the problem 'down below'? These women had difficulty talking about these issues and in discovering what it was that was really wrong with them. It was hoped that today's parents would have found out more about CAH, however from the questionnaire it was obvious that there is still a problem in talking to other people about what is wrong with their children.

THE SKELETON IS STILL THERE

The problem has partly arisen because of the difficulties with communication. The women in the study had no idea what it was they were seeing the doctor about. They didn't know why they had blood tests and wrist x-rays and grew up worried about the unknown. Even though they were in their 20's and 30's they still weren't really sure what was wrong with them, even though they were now under an adult endocrinologist. One of the greatest concerns among the sexually inexperienced women, was whether they would be able to have full sex with their partners. In the event this was fine, but this is a concern and it is important that the issue is discussed and fears allayed.

WHAT EFFECT DOES THIS SKELETON HAVE?

Firstly the difficulties of pinning down their consultant and asking for an explanation in plain English about what was wrong with them, often made both children and adult patients become withdrawn about their treatment and to profess no interest. This in turn led them to feel shy and 'different'. This was distressing and worrying as they worried about making close friends and relationships in case others asked about 'it', for example, why they took tablets or went to hospital.

This led to a danger that young girls with CAH became separated from normal social developments. Not totally isolated or pathologically alone, but less able to make close friends, sharing intimate discussions normally part of social relationships. The worry about the 'skeleton-in-the-cupboard' becoming known appeared to be a big factor in these difficulties. Discussions help teenagers, of both sexes, to learn the social behaviours and roles relevant to their culture. A number of 'myths' are handed down across the generations and some of these may add to the difficulties experienced by those females with CAH.

MYTHS AND BELIEFS

There are some myths and beliefs held by people in our society, and these are learnt from many sources, including discussions and the media. One of these myths is that men and women are 'totally different'; a belief that there are two opposite sexes. Behaviours in girls that are thought to be only appropriate for boys, are known as 'being a tom-boy'. However, where there may be some initial doubt about the sex of the child as in CAH, it is all too easy to see these common behaviours as very odd and thus become a worry. The belief that behaviours are appropriate for EITHER boys OR girls, for EITHER men OR women is part of the belief that personality, behaviours, abilities and interests are 'programmed-in', that is individuals are born to behave in particular ways because it is in their 'genes' or due to their 'hormones'. Neither of these beliefs is true, all these things are learned. What is more, the research showed that women with CAH were NOT any more nor less feminine than any other women-on-the-street.

PLEASE TALK ABOUT CAH

Hopefully today's generation of children growing up with CAH will have the ability, opportunity and understanding to discuss aspects of their condition with appropriate others (with doctors, parents, close friends, family members, boy friends and partners etc.). It is important for them to understand why they have to go regularly to hospital throughout their life. If they ask you as parents questions that you are unable to answer, be honest and say you don't know and FIND OUT so that next time you can explain it to them. Perhaps write a list of 'unknowns and questions' before you go to the clinic and don't be put off - doctors also find it difficult to explain the complex things about CAH, especially those concerned with genitals and sex, and suffer from some of the same false beliefs as their patients! You as parents and your child are equal partners in the task of looking after the condition.