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*PSYCHOLOGICAL
ASPECTS*

Transcript prepared by Sue Elford. Although sent for checking by Dr Carmichael, at the time of printing alterations had not been received. We therefore accept there may be discrepancies.

PSYCHOLOGICAL ASPECTS

Great Ormond Street Hospital is extremely lucky to have the services of Dr Polly Carmichael as clinical psychologists are not available at all hospitals, yet it is recognised that they can be of invaluable help for children with chronic illnesses, such as CAH.

Dr Carmichael said that one of the questions she is regularly asked by parents is when to give information to a child about their condition. There is no real answer to that but it is important to answer any questions and concerns that a child may have. If you give too much information, it tends to just go over their heads but at least they will feel comfortable asking questions, even if it means you have to repeat the answers time and time again. It is important that a child does not worry. It was suggested that parents start with simple explanations in a low-key way and explaining things in more detail as the child grows older and understands more.

Secret vs Private

Some parents ask whether they should tell a child to keep details of their condition secret. With CAH, the genital surgery performed is referred to. Obviously not everyone needs to know all the intimate details. Dr Carmichael prefers to use the word 'private' as opposed to 'secret' as the interpretation of secrecy is more connected to shame. This should not apply but explaining that some things are 'private' is more appropriate and acceptable.

Children often do not know what to tell their friends when asked why they go to hospital so often, why do they need to take tablets? Whatever answer they give, they must be comfortable with so you need to come up with something they can remember and repeat over and over to friends by way of explanation.

Quite a few children are keen to meet others with the same condition, so they don't feel they are the only ones, especially with a condition such as CAH, which is relatively rare, and not many people have heard of.

It is also helpful for them to have someone else to talk to apart from parents and this is where seeing a psychologist can be an advantage.

There have been psychological studies, results of which show that the excess of androgens pre-natally could have an effect on behaviour. They suggest that girls with CAH may be more inclined to be tomboys and prefer to play with toys that are usually associated with boys. This can worry parents but it does not seem to have any effect on their gender identity or give them any problems with sexuality in later life. The research has also shown that girls with CAH have better visio-spatial abilities, which could be a benefit!

From a psychological perspective, the outlook for those with CAH is good. Making the most of opportunities to talk is advisable and beneficial.