Dealing with DSD

Julie Griffiths explains disorders of sex development and what midwives can do to help parents understand their child’s condition.

It can be difficult for midwives too, yet they are in a position to reassure and normalise, as much as possible, in those early days of uncertainty. A brochure has been put together to help parents understand and what midwives can do.

DSD STATISTICS

- It is estimated that there are around 350 to 400 babies born in the UK each year with DSD. (Personal communication, 2015)
- It is estimated that 15% of infants with hypospadias and cryptorchidism (the absence of one or both testes from the scrotum) will have a chromosomal anomaly. (Society for Endocrinology, 2011)
- It is estimated that 1% of infants with hypospadias and cryptorchidism will have a chromosomal anomaly. (Hoye et al, 2012)

- It is estimated that 13% of infants with hypospadias and cryptorchidism (the absence of one or both testes from the scrotum) will have a chromosomal anomaly. (Hoye et al, 2012)
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Ellie Magritte believes that midwives have an important role to play in empowering new parents dealing with DSD. Thirteen years ago, she gave birth to a baby girl by emergency CS and, after she and her husband shared the good news with family and friends, they learned that her little girl’s swollen labia may have testes in them. It was a long stressful 12 days after the birth that the couple agreed with the recommendation that they raise their baby – now a happy, confident and smart young teen – as a girl. Since then, Ellie has gone on to set up an online resource dsdfamilies.org to support parents and children affected by DSD.

In the period of uncertainty, social interactions both inside and outside the hospital can become very stressful. In most circumstances when a newborn baby needs special care, parents call on friends and family for support. With DSD, often the opposite happens and parents isolate themselves, with midwives often being the only contact they have. Ellie says that midwives can be a source of great comfort and support without being experts in DSD.

The brochure gives examples of what parents can say to friends and family, such as: ‘Our baby has a hormone-related condition that affects the genital development and we cannot tell you yet whether the baby is a boy or a girl,’ or: ‘It was a stressful birth, and we would be grateful for some privacy.’

Ellie says that midwives are in a good position to shield the parents within the hospital setting. While she understands the need to avoid giving the family conflicting information before all test results are back, Ellie says that this need not mean shunning the new parents. Midwives with a confident and relaxed attitude can make a fundamental difference.

No matter what gender, a newborn with DSD has the same basic needs as every other baby. Midwives can help new parents focus on this and help them and their baby with support on feeding, nappy changing, bathing and cuddling. Avoiding pronouns is helpful, instead use ‘your baby’, ‘little one’ or simply ‘baby’. The new parents are embarking on a lifelong journey on managing DSD, their child and the outside world’s lack of knowledge – Ellie says midwives can help set the tone.

‘Midwives are at the starting point and if they can project acceptance, then it sets the parents up for the long term. They can make a profound difference between parents feeling like they are facing trauma and feeling empowered and having a “can-do” approach.’

For more information, or online copies of the brochure, go to dsdfamilies.org or email info@dsdfamilies.org

Please email Midwives with your experiences of DSD at hollie@midwives.co.uk