AIMS For a better birth...

No tragedy to see here...

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Jane Ashwell Carter shares her experiences of the language used around Down's syndrome

Early in November 2016, I was one of a group of first year student midwives on our induction day at the maternity unit we would be training in for the next three years. The highlight of our day was to be a talk by the antenatal screening coordinator, a very experienced, incredibly knowledgeable and passionate midwife. We all listened intently, and I was not the only one who made a mental note to message and ask if I could have an extra placement with her for a couple of days to see this most fascinating side of midwifery. Then, she finished her talk with the phrase 'tragically, in the last two years six babies have been born with Down's syndrome in this area'. Later that day, I went home to my daughter, who is one of those precious six, picked her up and told her she was a tragedy. She gave me a big wet kiss and squalled to go back down and continue playing with her adoring brothers. Move along now people, no tragedy to see here.

The language that we use around Down's syndrome, (Trisomy 21), and any other diagnosis, is important, with families, to others, and between health carers behind the scenes in the staff room. Trisomy 21 is where a person has an extra copy of chromosome 21. A fetus or baby may be diagnosed with Trisomy 21, but they are not a 'Down's baby' and they do not 'suffer from' the condition. If it is relevant to the conversation, they are 'a baby who has Down's syndrome', and if not, they are simply 'a baby'.

NICE guidelines on Antenatal care for uncomplicated pregnancies 2017, state that women 'should be offered information and screening tests to check whether your baby is likely to have Down's syndrome'. Prenatal testing is offered to every woman, and the Fetal Anomaly Screening Programme Standards 2015-16 also state that 'high quality information should be imparted to enable women to make informed choices'. However, when the Down's Syndrome Association (DSA) ran a survey of new parent members, they found that 63% of respondents could not remember receiving any information on Down's syndrome before consenting to the test. Midwives at the booking appointment have a huge amount of information to impart and record in a short space of time, but it takes less than a minute to mention that the test being offered is screening and not a diagnostic tool, along with the basics as stated on the NHS Choices Screening webpage. Too often, the information is missing, although the negative language is not. Rather than the loaded word 'risk', NICE uses the phrase 'how likely' a baby is to have Down's syndrome. Other acceptable phrases involve 'chance' or 'possibility', as these do not put a value judgement on the baby. Giving parents a leaflet to go home with after screening tests have been carried out does not facilitate informed choice.

Many parents report that after receiving a 'higher chance' screening result, they felt rushed into invasive diagnostic testing, even though the risk of miscarriage from these procedures was often higher than the probability of a positive Down's syndrome diagnosis. In the event of a positive diagnosis, healthcare professionals may have the assumption that the pregnancy will be terminated. One mother reported that she received a telephone call to tell her of her son's prenatal diagnosis and to ask if she would like to make an appointment to 'interrupt the pregnancy'. She declined, and subsequently heard nothing more. She was given no counselling, no discussion or information on Down's syndrome, not even a leaflet in the post. She was not signposted to the DSA or local groups. In her own words 'I was completely left to it'.

There is no doubt that there are good practitioners, and sensitive, honest discussions are had in lots of places. Sadly, in others, parents may be rushed into decisions without time to process the news, and discussions often focus on all the things a child with Down's syndrome cannot do. It is not uncommon to hear of families who have had to sit through long spiels about disability, mental impairment, shortened life expectancy, social ostracism and heart problems while still trying to take in the news. It would be more honest to begin the conversation by explaining that many babies with Down's syndrome will be born fit and healthy, although some health conditions are more common for them and that some of these are serious. They will all have some degree of learning disability, but this varies considerably from child to child. This approach, together with questioning to see what the parents already know allows a chance for parents to ask questions and explore the issues with their care provider, rather than being told what to think. Offering contact with child development centres or local support groups may be helpful, and the Down's Syndrome Association helpline also welcomes calls from parents who would like more information with which to consider their options.

Ambiguous terminology and phrasing should be avoided as it can result in misunderstandings. A mother at a local support group recounted how she was told after an anomaly scan that she 'would not be bringing her baby home'. She understood from this that her baby was likely to need to stay in neonatal intensive care for a while. After her baby was born, she learned that the sonographer meant that her baby had a heart defect which meant that her baby was unlikely to survive past birth. Thankfully this diagnosis was wrong and her daughter is now a robust and happy three-year-old, who underwent open heart surgery shortly after birth, but this clearly underlines the need to be extremely aware of the language that we use.



Daisy Carter ©Jane Ashwell Carter

When Trisomy 21 is suspected at birth, the first thing that friends, family and health carers should remember is that the parents have just had a new baby. Congratulations are in order. Health carers, please do not draw lots to see who is going to 'break the bad news' – parents need factual information about their precious baby, not an opinion. The phrase 'I am sorry' is not appropriate, and nor are syrupy comments about special parents getting special babies. Just be positive and say the same things that you would say to any other new parent, because that's what these parents are – new parents.

It can be distressing for parents to be told their baby 'has to be' taken away for tests. All tests, including heart scans, can be done with the parents present, and it is important to remember that these tests are 'offered', not mandatory. We were pushed hard to consent to karyotyping (a blood test to count chromosomes), at birth, yet not being genetically diagnosed until the age of two in no way prevented access to services or care for our daughter. Be clear with the wording used when offering tests so that the parents know that they are the ones who are making the decisions. This empowers them at a time when they may feel quite overwhelmed.
Lucky parents will encounter professionals like the consultant paediatrician who performed a heart scan while I held our daughter. She discussed everything with us immediately, there was no anxious wait, and she assessed our level of understanding before explaining both her findings and the implications of these. Despite discovering our daughter had two heart defects, we came away reassured by her positive and caring manner. A far cry from the paediatrician on the children's ward who rolled her eyes, looked at the ceiling and tapped her foot when I tried to explain that I was unhappy to give formula. Please, always remember you are dealing with new parents who are short on sleep requiring support and family centred care.

Our personal experience of health professionals and their language has been varied. Daisy was born at home under the care of an Independent midwife who was a model example of how to talk to new parents. During all the emotions we went through, her language and attitude were always positive. It was clear that, to her, Daisy was a precious baby who just happened to have an extra chromosome, and she

celebrated the arrival of the first 'extra special baby' under her care. She kept a close eye on us for weeks until we had our breastfeeding established, completely supported us, and never once doubted that success was around the corner for us. This was in stark contrast to the midwife sent from the hospital who we called to arrange her postnatal check. Despite telling them we suspected trisomy 21, she had not been told. Immediately, she lowered her voice and began to list all the things that could be wrong with her, saying she had to go to hospital immediately as she would be unable to feed (despite the fact she was clinically well and breastfeeding beautifully). Her student sat silently, appearing horrified and refusing to look anyone in the eye or reply when spoken to. It was a strange and disconcerting encounter.

Too often we hear that children with trisomy 21 'don't breastfeed', or 'have trouble' breastfeeding. Babies with Down's syndrome may indeed have some extra challenges to feeding if they have heart issues, hypotonia (weak muscles) or other conditions related to Down's, but almost all of these can be overcome with excellent support and determination. Formula may be recommended, further undermining parental confidence and autonomy if they have chosen to breastfeed. Breastfeeding offers many important benefits for all babies and especially babies with Down's syndrome. For example, breastfeeding is important for a healthy immune system, and some babies with Down's syndrome are more prone to infections, especially respiratory infections. The action of breastfeeding encourages optimal jaw development, which can be helpful as some babies with Down's are born with a high palate and small jaw. Instead of saying that babies with Down's syndrome cannot breastfeed, it is more helpful to explain that these babies can get immeasurable benefits from breastmilk, and while it may sometimes be more challenging, there are many organisations which can offer support and information. As with all breastfeeding support, it is a case of supporting women who DO wish to breastfeed with positive language and practical support, without alienating or antagonising those women who choose not to.

Babies with Trisomy 21 might need medical care, but so do many babies. We, their parents, may need specific support, but so do many parents. How we are supported, and the language used when speaking to us, can make a huge difference to how that journey begins.

Jane Ashwell Carter

Support networks and links:
Down's Syndrome Association www.downs-syndrome.org.uk Breastfeeding support is available fromthe breastfeeding charities such as The Association of Breastfeeding Mothers, La Leche League, NCT and International Board Certified Lactation Consultants (IBCLCs).