‘A family member sent me a sympathy card’

Parents of children diagnosed with Down’s syndrome share their experiences

For parents, the birth of child is a very special occasion. But for parents of babies with Down’s syndrome, the experience can be fraught with worries. Some are unaware of what everyday life with Down’s syndrome holds, and for some the experience can be marred by unintentional discrimination.

Professional lead for learning disability nursing at University of Nottingham Helen Laverty says that times have changed drastically since her training days. ‘It almost seemed like dinosaurs ruled the earth. The textbooks we were given to learn from presented a bleak and stark picture of what it was like to live with a learning disability.’

Yet despite the progress made over the years, Ms Laverty says more needs to be done to challenge public and healthcare professional’s perceptions. She became aware of continuing misconceptions after being asked to join a closed online forum of parents of children with the condition. A thread emerged asking parents to comment on the myths they were told about their children. Even if people are not prejudiced towards people with disabilities, the forum highlighted that a climate of misunderstanding and misinformation surrounding Down’s syndrome continues.

Many new parents on the group felt blamed for having a baby with Down’s syndrome because they were older mothers. One parent recalls being told: ‘It was because your eggs were old.’ While the risk of having a baby with Down’s syndrome does increase with the age of the mother – a woman who is 20 has a risk of one in 1,500 compared to a 45 year old who has a risk of one in 50 – babies with Down’s syndrome are born to mothers of all ages.

Family accusations
Many parents faced accusations from family members that the condition was hereditary: ‘It must be from your family because there aren’t any disabled people in our family.’ Some family members were even accused of ‘causing’ the chromosomal abnormality because of the ‘funny cheese you like’ and being asked whether their ‘funny hormones’ affected the baby.

Considering that Down’s syndrome is not limited to one race, culture or social group, and that there is no evidence to suggest that anything done before or during pregnancy increases or decreases the risk, these comments are misinformed.

‘Someone said “He doesn’t look like he has Down’s,” as if everyone with Down’s is supposed to look like each other’

Parent

Many parents vented frustration at the often-expressed sentiment that ‘they are only given to special parents’.

While such comments may be well-intentioned, they only serve to emphasise the differences between Down’s syndrome children and ‘normal’ children. ‘What I needed was a dialogue, a positive narrative and some practical help – someone with up-to-date knowledge of Down’s syndrome. I didn’t need a membership form from a support group.’

And for parents who have other children, it can suggest that they’re not as special. As one parent said: ‘What does that say about my daughter who doesn’t have Down’s syndrome?’

For many parents, the outdated beliefs that their child would have no quality of life, that their lives would be ‘blighted’ and that they would have to give up their jobs turned out to be untrue.

Although people with Down’s syndrome will live with the condition throughout their lives, they are capable of leaving home, forming new relationships and gaining employment just like anyone else.

And with access to good healthcare, early intervention programmes and good relationships and family life, children with Down’s syndrome can and do thrive.

The misconception remains that living with Down’s syndrome appears to be a life...
sentence. One parent recalled how a family member sent her a ‘deepest sympathy’ card when her daughter was born.

Comments parents encountered included that the child with Down’s syndrome ‘will be a child for life’, that they wouldn’t be able to work and have a ‘normal life,’ and expressions of surprise that a child with Down’s syndrome would be able to attend a mainstream school.

‘Normal’ markers
One parent, who despite having a positive diagnosis experience when her baby was born, was still concerned about whether her baby would hit all the markers that ‘normal’ babies would: have friends, learn to roller-skate, drive a car and eventually get married.

Now, she says that she wishes she had not worried at all:

‘When we’re all round the table for Sunday lunch, I still think back to those first few days and wish I could tell myself that this is what family life would look like.’

BBC 3’s Things People with Down’s Syndrome Are Tired of Hearing video, effectively debunks the myth that people with Down’s syndrome are unable to live independently, have jobs or sustain relationships.

Sarah Gordy, who has starred in Call the Midwife and has had other jobs as an actor and dancer, says in the video: ‘I have a life, I go out with friends and have a nightlife as well.’

Another woman featured, Claire Minett, had several jobs in retail and office work, while Bafta-nominated actor Tommy Jessop is hoping to move in with his girlfriend.

‘We all lead an amazingly active life,’ says Sara Pickard, actor and project officer for Mencap Cymru.

While children with Down’s syndrome will have some degree of learning disability, the level of ability will be different for each individual. Yet many parents have become accustomed to comments from people not seeing each person as an individual, but rather as a homogenous mass.

‘The whole “they” thing, like a breed of dog: “they” all behave like this, “they” tend to have that,’ one parent noted.

Comments varied from assumption that all children with Down’s syndrome ‘suffer’, that ‘they are very musical, aren’t they?’, that they ‘have no quality of life’, ‘have heart problems’ and die young.

One parent noted: ‘Someone said “He doesn’t look like he has Down’s,” as if everyone with Down’s is supposed to look like each other.’
Another common belief, that people with Down’s syndrome are all the same, is related to the assumption that children with Down’s syndrome will remain children for life.

One parent recalls, when her child was 2 weeks old, being told by another mother: ‘He will be your child forever because he will never mentally progress past the age of eight.’

‘She tried to tell me in a reassuring manner but to be honest I went home and cried buckets. If I was told this now, I’d be much better prepared.’

As a consequence of these beliefs, many children and adults with Down’s syndrome are infantilised by strangers throughout their lives.

Healthcare professionals
For many parents who commented on the online group, fears of a limited future extended to worries about healthcare professionals.

One mother relates that a midwife burst into tears saying: ‘It’s every mother’s worst nightmare,’ as she entered her bedroom the day after a beautiful home birth. Another recalls a nurse offering comfort after her daughter’s heart surgery by saying: ‘they don’t feel pain like we do’.

Healthcare professionals have a role to alleviate anxieties for new parents of children with Down’s syndrome instead of using clichéd and misinformed language.

One parent recalls her first experiences in hospital emphasising the differences between her baby and others: ‘I personally didn’t need to be shuttled into a private room away from the other mums and babies because I didn’t want to feel that I was being pushed to one side not to upset the other mothers.’

She adds: ‘What I didn’t need when my boy was born was a horrible leaflet from the support group. I didn’t need people getting upset and sorry. I needed someone to give me a positive narrative, and yet I didn’t find it. I had to create my own. Everyone is different there is no “one size fits all” advice.’

‘Look at him, he’s strong, he’s beautiful, he’s bright as a button. You’re all going to be just fine’

Midwife

Fortunately, many healthcare professionals do know how to behave and communicate with parents, and one parent noted how a neonatal consultant helped with her confidence as a first-time mother.

‘When my daughter was five or six weeks old, I was so worried about knowing what to do and if it was “right” and he said to me: “She’s your baby, treat her like you would if she didn’t have Down’s syndrome, sing, play games, cuddle, love her and that’s the best thing you can do for her.”’

Another recalls how healthcare professionals set a great tone at the beginning of their baby’s life. ‘I remember a midwife popping in about midnight sitting beside my bed, holding him up in front of her and saying “look at him, he’s strong, he’s beautiful, he’s bright as a button. You’re all going to be just fine – trust me, I know babies”.

‘We were treated very well in hospital, they broke all the rules for us and we even had our own assigned midwifery assistant who doted on him.’

Another recalls: ‘The staff were all doting over my daughter and fighting to do her observations. She was treated like royalty’

These positive experiences highlight the need for health professionals to treat babies with Down’s syndrome in the same way they treat all babies, and Ms Laverty says learning disability nurses have an important role to play.

She says that she is fortunate that her position means she is able to influence the language used and also nurture nursing students to use a more proactive and positive approach to sharing information with families.

She encourages nurses to think how language can ease anxieties and change public perceptions of the condition.

‘Words count. The way a profession responds to a new family has the potential to make or break that family, and the relationship they will have with a healthcare team.’

She says healthcare professionals should question their own thinking about Down’s syndrome. ‘Reflect on the things you have said about babies within your social circle. Remember to say “congratulations”. It’s such a simple word that means so much in the days after a baby is born.’

Ultimately, Down’s syndrome does not define the person. Children born today with Down’s syndrome can realistically expect to benefit from good healthcare, to find a job, live a comfortable life into old age and set up home, perhaps with a partner.

Coupled with changing attitudes, parents no longer need to be concerned that they and the whole family will endure low quality of life. As one parent from the group aptly says: ‘Life is what you make it.’