

Positive about Down syndrome

Nicola Enoch set up PADS to give other parents the information and support she never had

Most parents who have had a baby with Down syndrome (DS) can vividly recall being told their child has the condition, whether the news was broken or shared, and whether the medical professional commiserated or celebrated, looked away and avoided eye contact or looked straight on and smiled.

When my son Tom was 24 hours old, a locum paediatrician accompanied by a junior doctor stood awkwardly by Tom's crib. They said that staff had concerns and asked if I thought Tom "looked normal". She wouldn't use the words Down syndrome – she wanted me to say whether I thought my precious newborn baby looked normal, the inference being they considered him abnormal.

No parent should be asked this. Despite being on a ward full of new mums, I was alone. Visiting time arrived, my husband and our three-year-old daughter Emily walked in. The medics couldn't cope, so left, and I had to try to explain to John, without letting on to Emily, that all was not as expected. Our world fell apart and we were offered no support to rebuild it.

We live in a society that suggests no one wants a child with DS; after all, that's why everyone screens, and medical professionals refer to the 'risk' of having one. Since I'd had a C-section, I was committed to staying in hospital and was subjected to several days of unadulterated negativity. Tom became a medical exhibit as junior doctors queued up to examine him and spot the markers. One midwife told me how her cousin has "one of them" who, she said, during the holidays "drives her mad". A social worker came to meet with us to discuss the possibility of adoption. I kept asking for information about life with DS, but none was forthcoming. Completely irrelevant comments were made – I was advised that Tom wouldn't be able to go on a trampoline and if he played football



Nicola (centre) with Dr Yana Richens, deputy head of maternity services at NHS England, and Professor Jacqueline Dunkley-Bent, chief midwifery officer, NHS England

that "he'd never play for England". This was 2004, before the internet, and I was overwhelmed by fear of the unknown perpetuated by medical staff.

Eventually, a booklet produced in the 1970s was found and presented to me. Images of young people in flares and tank tops compounded the outdated stereotypes I already had. Would Tom be a burden to Emily for the rest of her life? Would he go to a normal school? Would Tom be holding my hand as a teenager waiting to cross the road? Would I forever be identified as the mum of the 'Down syndrome boy'?

Everyone was reluctant to engage – we'd been put in a side room, out of the way. This was a relief as I couldn't cope with seeing all the 'normal babies' with their happy families while we grieved for the baby we'd hoped for.



Don't say you're sorry to parents –and never cry

On the third evening a midwife said to me: "You have a beautiful baby boy." Those six words were the only positive comment made during my stay.

Fifteen years on, nothing has improved. I conducted a short survey to establish what support is offered when news is shared pre-birth that there is a high chance of baby having DS. NICE guidelines stipulate: "If a pregnant woman receives a screen-positive result for DS, she should have rapid access to appropriate counselling by trained staff." Of 138 expectant women who were advised there was a high chance of DS and who continued with their pregnancy, 67% were not offered any counselling or support. Those who were referred to counselling reported that it was negative, outdated and not particularly useful.

One mum wrote: "They said most people don't decide to keep their baby with DS so they were not prepared for what to tell me for support."

Another said: "The only info I was given was a booklet by ARC [see arc-uk.org] but it only spoke about termination, nothing about having a baby with DS, which is what I expected and needed. Hospital staff need to give both sides, not just push mums to termination. I was strong, but I know a woman who had a termination and now can't cope. She struggles badly when she sees me and my daughter."

A survey I conducted in 2018 of 1,410

UK women who've had a baby with DS since 2000 showed that of 206 women who were given a positive result for DS, 69% were offered a termination in the same conversation. And of 271 women who had received a high-chance result and declined further testing, after advising they were continuing the pregnancy, termination was still mentioned to 50% of them, with many saying they were repeatedly offered an abortion.

Parents deserve better

It is rare for a medical professional to convey a positive attitude when informing parents their baby has DS or a high likelihood of DS. Of 205 expectant women being given the definitive results of a diagnostic test, just 9% considered the manner to be positive, the same figure (9%) for the 269 given a high-chance screening result. And for 710 women who discovered their baby has DS after birth, just 13% reported the news was given in a positive manner.

Within hours of birth, the new parents of a baby with DS are presented with a long list of problems their child may encounter, illnesses and conditions they may be more susceptible to, perhaps told their baby won't know them, won't walk, won't talk, not to expect much... The reality is that no one knows, and scaremongering does nothing for expectant or new parents' mental health.

Given the language and attitudes expressed by many medical professionals, it's no surprise to me that more than 90% of expectant women who receive news of DS go on to have a termination. Attitudes hark back to the 1960s when life expectancy for those with DS was

Voice of a mother

just 15 years, and those who lived long enough were put into institutions. People with learning disabilities were not entitled to an education until 1970, and didn't enter mainstream schooling until 1981. Medical advances, particularly in cardiology, have pushed life expectancy to beyond 60 years. And pioneering research by Professor Sue Buckley showed that people with DS make academic progress throughout their lives. Those with DS are now living longer healthier and more fulfilled lives. Yet medical attitudes haven't caught up.

Here's how to change that

When telling expectant and new parents about DS, congratulate and be positive. A new life is due/has arrived and you have the power to help a parent to bond and love the baby. Never underestimate the influence of your words, your body language, your attitude. There's nothing wrong with having a baby with DS; the baby has the same needs as any other – to be loved, fed and looked after.

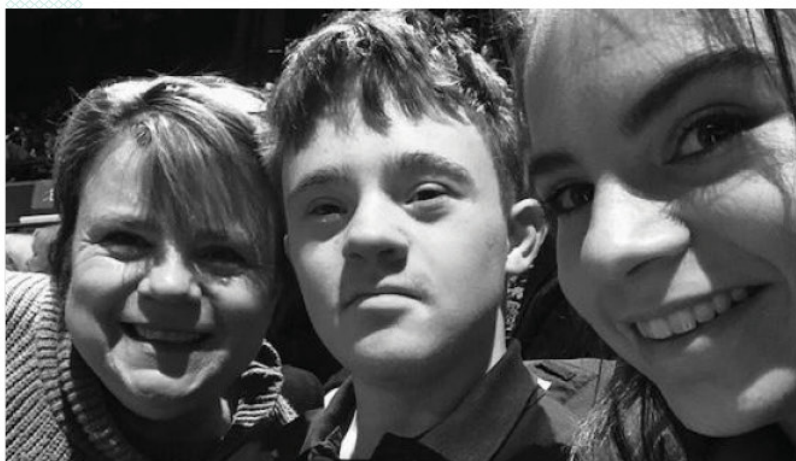
Be confident in the knowledge there's nothing to be sorry about. Don't be awkward or uncomfortable – parents look to you for support and understanding. Keep things in perspective – the baby will do the same as most other babies, maybe just a little later. Having DS is no longer a life-limiting condition.

Give parents time to digest the news. Assuming there are no immediate health concerns, allow parents time to bond, to relax, to enjoy getting to know their baby. Restrain yourself from talking about associated medical problems. Just let the new parents enjoy their new baby.

Refer parents to sources such as PADS and local support groups who can provide them with accurate, relevant contemporary and useful information.

Be considerate. Wait for Dad to be present. Of 687 new mums advised their baby has DS, 20% were told without the father there. Consider that the news may come as a shock and respect parents' responses – don't say you're sorry and never cry.

Don't label someone by their condition – a baby has DS, they're not a 'Down's baby'. And don't generalise



Nicola says Tom and Emily (above), "have the best relationship a parent could hope for"



– "they're always happy, they tend to be floppy, they struggle to latch". Focus instead on the individuality of each baby.

Don't ask new parents about what screening tests they had. So many new parents recount how medical professionals asked, "Didn't you know?" inferring that had you known you'd have had a termination. This is insulting and yet it happens frequently.


Unfounded fears

Tom is now 15 and I couldn't be prouder. He has just started Year 10 at our local secondary school. He can read very well and has exceptional spelling. He loves football and has a season ticket at West Bromwich Albion. He goes to Explorers (grown-up scouts), and enjoys playing golf, kayaking and snorkeling.

Tom and his sister Emily have the best relationship a parent could hope for. Parenting is a challenge, every child has strengths and weaknesses, a child with DS is the same. Both my children make

my heart burst with pride, both give me sleepless nights.

I know hundreds of families with a member with DS: our children and young people are valued, loved members of their families and communities. After college, we see Tom working in a primary school; his reading, phonics skills and enthusiasm will enhance any classroom, he is well mannered with a tremendous sense of humour and a love of people. I see no reason why he won't one day have a meaningful relationship, live in a semi-independent setting, and continue to travel and enjoy his love of the outdoors.

As one counsellor told a mother: "Don't worry, she's still going to be your baby. She'll hit milestones in her own time, she might look a little different than you expect, but she'll be your baby and you're so excited to meet her. Don't let this label scare you – just pick her up, feed her, love her, change her and she'll take care of the rest. Everything that should happen will happen, right when it's supposed to." 

MORE INFO

PADS is a website written by parents and young people with DS to share their experiences. Midwives feed back how invaluable a resource it is and new and expectant parents regularly making contact for advice and support. PADS literature is available from Nicola: call 07814 929306 or email contact@positiveaboutdownsyndrome.co.uk