

# ‘Before this happened to me, I didn’t even know what pro-choice meant’

We ask women who proceeded with or terminated pregnancies what they did and why

Sat, Jun 17, 2017, 06:00



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Róisín Ní Chonchúir with her son Connell Gallagher (8). Photograph: Nick Bradshaw

When Róisín Ní Chonchúir’s youngest son, Connell, was diagnosed with Down syndrome, two days after his birth, she was given a list of the possible characteristics and complications. “One hundred and fifty five characteristics, and not one of them was positive,” she said. Now eight, Connell attends mainstream school, makes friends easily, loves hurling, and is the apple of his parents’ and six elder siblings’ eyes. “When a child falls in the yard, it’s Connell who rushes over first to see if they’re all right,” his mother says. Despite the dire list of negatives, Connell’s contribution to their family is “positive in every way. If I’d known then what I know now, I’d say bring it on. I know we’re lucky and he has very few issues. But everyone has challenges in life – the difference is that we just knew from birth what some of his were likely to be.”

The arrival of new non-invasive blood tests – which are available privately in Ireland from around €350 – means more women are being told as early as 10- 12 weeks, with 99 per cent accuracy, whether their baby will have Down syndrome, or another chromosomal condition such as Edwards syndrome, sometimes known as Trisomy 18.

In the past, prenatal diagnosis relied on the mother's age, ultrasound markers, and blood chemicals to estimate the likelihood of chromosomal anomalies, which could then be followed by amniocentesis or chorionic villus sampling.

Some women opt for the tests simply because they want to be informed; others will choose, depending on the result, not to continue with their pregnancy. Because of this, advances in risk-free testing have led to claims that we may be heading towards “a world without Down's”.

Theoretically at least, such a prospect is possible. In England and Wales, 90.1 per cent of pregnancies end in termination following a diagnosis of Down syndrome. In Denmark in 2014, it was 98 per cent.

The issue has taken on a particular urgency here in the context of the debate on the Eighth Amendment of the Constitution. At the recent Citizens' Assembly, Prof Peter McParland of the National Maternity Hospital expressed his concern that “the science has got way ahead of the ethical discussion. As a society we have not reflected on what the implications are.”

Figures released this week show that, in the past year, 43 women who travelled to Britain for abortions did so after tests showed the baby would have Down syndrome. Some 100 others had terminations related to fatal foetal abnormalities such as Edwards syndrome and anencephaly, a neural tube defect that causes abnormal development of the brain.

## **‘Not a black and white issue’**

Laura Mulcahy, who is from Ireland and now lives in Switzerland, prefaces her comment by saying that she is “pro-choice”. However, as the parent of a daughter, Emer, who has Down syndrome, Mulcahy is concerned that people may be making the decision to terminate without really understanding what the diagnosis means.

“I would never say this is a black or white issue. The only thing I feel right in saying is that based on our experience, having a child with Down syndrome has been a really positive experience,” she says.

Inspired by the Irish “Here I Am” project, a collection of photographs of people with Down syndrome, Mulcahy put together an exhibition entitled *Moi Aussi* to raise public awareness, understanding and acceptance of Down syndrome in Switzerland.

Switzerland is often cited as bucking global trends. There, the number of children born with Down syndrome more than doubled between 2003 and 2012. But Mulcahy dismisses the notion that this is due to greater acceptance of the genetic disorder.

“Unfortunately, I don’t think Switzerland is very accepting at all. When we’re out in public, people would look away from Emer out of a misguided sense of politeness. One of the aims of this project was to give people the chance to really look at someone with Down syndrome. So I think if there’s an increase in the birth rate, it’s only because the testing until now wasn’t as good as it could be,” she says.

Iceland tends to be placed at the other extreme. It is frequently cited as a country on its way to “eradicating” Down syndrome, and where no baby with it has been born in the past five years.

But once again, the reality is not quite so cut and dried, says Katrín Árnadóttir, the mother of a 17-month-old daughter with Down syndrome born in Iceland.

Árnadóttir says that in her country, the social and cultural attitude to Down syndrome is actually “very positive. People with Down syndrome are integrated into the system [and] go to public schools.”

However, “the problem lies in educating what it means to have a child with disabilities. There needs to be a public debate on what kind of society we want to live in, and if we really want to eliminate Down syndrome and downgrade life with disability.”

Árnadóttir’s friend, the photographer Sigga Ella, recently held an exhibition of portraits of people with Down syndrome, entitled *First and Foremost I Am*. “It’s not a disease or a flaw. Parents of children with Down syndrome wouldn’t exchange them for anything in the world,” Ella says.



Oskar (60). Image from the ‘First and Foremost’ photograph exhibition tackling misperceptions of Down Syndrome in Iceland. Photograph: Sigga Ella Árnadóttir adds that in the past, children with disabilities in Iceland were often hidden away because of a lack of understanding and education. “Maybe even now doctors and nursing staff lack the proper information to deal with questions from young parents, and the easy way out is to suggest an abortion,” she says.

### **‘Ciaran wouldn’t get the support in Ireland’**

Educating medical professionals about how to talk to people who have had a prenatal diagnosis is crucial, says Susan Searle, a UK-based Irish mother. “They need to stop handing out leaflets listing all the negative characteristics. A child with Down syndrome is like every other child, their level of ability varies hugely,” she says.

But Searle points out that while it’s important to have discussions about greater understanding and better education, practical help is vital too.

Searle’s 11-year-old son Ciaran has Down syndrome and Duchenne Muscular Dystrophy, a muscle-wasting disease. She says she would have liked to return home to live in Ireland from the UK one day, but believes Ciaran’s needs make that “lovely dream” – or even a brief holiday – impossible.

“I need a hoist. I need wheelchair access. I need a wheelchair-accessible vehicle. Our house is really his house – it’s got a through floor lift into his bedroom, a wet room, [and] a hoist in his bedroom.”

She could not have coped without the support she gets from the British state, which includes a disability living allowance of £141 (€160) a week that goes towards a wheelchair-accessible car, an hour and a half’s respite a week, free nappies, and frequent appointments with heart specialists and neurologists. “Ireland is very socially accepting, but Ciaran wouldn’t get the same level of support.”

Searle is opposed to the introduction of free non-invasive testing. “I refused all testing when I had Ciaran, even though I knew there was a risk because I was 39. But Down syndrome was never an issue for us. He was diagnosed within hours of his birth and I thought ‘that’s fine. So what?’”

But better than most, Searle understands how complex and personal the debate about testing and choices is. Four years after Ciaran’s birth, she became pregnant again. Then aged 43, she had an amniocentesis and discovered she was carrying a son with Edwards syndrome.

It is a subject that is still clearly difficult for her to talk about. “I made the decision not to continue with the pregnancy. I resent the word abortion. I gave birth at 17 weeks to our son. It’s not a decision to be taken lightly, and it’s not a decision by which anybody should be judged.”

## **‘I didn’t want the baby to suffer’**

Here, discussions around the issues of termination and Down syndrome “have been focused on the images of high-functioning people. But it’s a spectrum disorder,” says Gerry Edwards, of the organisation Termination for Medical Reasons (TFMR).

Edwards points out that it’s insulting to families of people with Down syndrome to suggest that better testing will automatically lead to more terminations. In many of the cases where women choose not to continue with the pregnancy, there are likely to have been additional problems.

“Some women undoubtedly do travel [outside the State for an abortion]. But it’s never an easy decision. There’s the diagnosis, the prognosis, the mother, the family, their competence and ability to undertake the lifelong commitment; and there’s also the role of society and the State, all of which has to be taken into account.”



‘A child with Down syndrome is like every other child, their level of ability varies hugely’.  
Photograph: Getty

One woman who made the “heartbreaking” decision to travel following a devastating prenatal diagnosis was Laura McGlynn.

During routine screening on her first pregnancy, it was discovered her baby had a very large cystic hygroma – a cyst or group of cysts on the baby’s head or neck, and sometimes indicative of an underlying chromosomal disorder. She opted not to go straight for an amniocentesis test, which is invasive as it requires amniotic fluid to be taken and tested, and instead to have a non-invasive Panorama test.

“When we got the diagnosis of Down syndrome, I said to my partner “are they just telling us it’s Down syndrome?” Because that wouldn’t have bothered us at all.

“I remember walking past the Rehab facility [a disability service provider] and seeing adults and kids with Down syndrome going in and out and just wishing that my baby would get that chance. I was holding on to the hope that they could fix the cystic hygroma, but when the measurements went up past 7mm, the hope dropped off the scale,” she says.

“They couldn’t say definitely that he wouldn’t survive, but you had to read between the lines, and you had to learn what questions to ask. I decided when I was 18 weeks that I didn’t want the baby to suffer.”

When she was 20 weeks pregnant, McGlynn travelled to Liverpool with her partner and her mother. “When I got on the plane, I still thought I might change my mind. And when I got

into the taxi and said ‘Liverpool’s Women’s Hospital’ I was sure the driver was going to judge me.

“But once I finally got there and talked to the nurse, it was like somebody put an arm around you. A nurse said to me she thought it was a total disgrace that Irish people are forced out of our own country and have to go there to get some empathy.”

McGlynn went through with the procedure. Back home, she continued to have heavy bleeding and complications for months afterwards. “It was exacerbated by the break in my care. If I had stayed in the UK I would have been entitled to a scan afterwards, but I didn’t get that. It was just a nightmare. I never thought I’d come out the other side of that.”

She has since given birth to a healthy daughter, who is now 10 months-old. “Before this happened to me, I’d never have judged anyone, but I didn’t even know what pro-choice meant. Now I want to share my story, because I don’t want my daughter to have to go through what I had to go through. Nobody will ever tell me what I did was wrong. You have to do what’s right for you – it’s your baby, it’s your body, and it’s a very personal decision.”

## **‘What type of society do we want?’**

In the UK, the debate has focused on whether, as screening becomes more freely available, British society will sleepwalk into a world without Down syndrome. In Ireland, as McParland said at the Citizen’s Assembly, we’re a long way from that.

But now is the time to start the conversation about what kind of society we want to be, says Ni Chonchúir. “I wouldn’t judge anybody, but I do think society needs be guided. If a woman is told with certainty that her baby will not survive after birth, I do think it should be her choice.

“But for me, it’s about what type of society do we want? Do we all want to be the same? How do we have the right at birth to say who’s going to add value in society? Where do you stop? It’s not people with Down syndrome who are causing all of the problems we have in the world.”

Árnadóttir says there has been too much focus on the testing, and not enough on the wider societal issues. “We should not stop progress in science. There will indisputably be better ways to test for a number of things. We just need to answer the ethical questions.”

Beyond the ethical questions are, as Searle points out, some very practical ones: if we’re going to encourage women to have children regardless of their special needs, then we need to put better supports in place for those already here.

Mulcahy agrees: “I heard someone say recently that Ireland is a pro-life society, but it hasn’t given enough thought to what happens next, to what happens after the babies are born.”



Sigrun (10). Image from the 'First and Foremost' photograph exhibition tackling misperceptions of Down Syndrome in Iceland. Photograph: Sigga Ella