



# Hard choices – birth and termination

It may be the hardest choice of all. The 20 week scan indicates your baby is disabled.

One thing's for certain. No one else can or should tell you what to do.

Three disabled women tell **Annie Makoff** about how they made and lived with their choices

In October last year, a Bedfordshire hospital hit the headlines in a six figure payout after they failed to pick up a spina bifida diagnosis in an antenatal scan. The mother of the disabled boy told the court that had she known, she would have undergone a termination. It is all too easy to condemn her comments. Indeed, the case raises a lot of questions, not least how will this child feel about his mother's comments when he is old enough to understand? It also raises ethical questions: is it "right" to have a termination following a prenatal diagnosis? Yet, as experience tells us,

it is never quite as clear-cut as "right" or "wrong".

Under current law, a termination can be carried out no later than 24 weeks, unless a "severe handicap" has been diagnosed, in which case, a termination can be carried out right up until full term.

This may seem unethical on the surface, but there are those who argue that taking various factors into consideration (the mother's situation, the difficult decision the parents face, the time for second or third opinions) it can give women the time and space to make an informed choice that is

right for them, their unborn child and their families.

But there are also those who say that doctors and other NHS professionals are too ready to rush to judgement and offer terminations, even pressurize mothers with an antenatal prognosis of disability into ending their pregnancy.

Demonstrating just how unhelpful it is to make judgements as to the rights and wrongs of termination, three women spoke to *Disability Now* about the difficult decisions they had to make following an in utero diagnosis.

## ELENA'S STORY

When I became pregnant at just over 40, my husband and I knew there could be a risk with the pregnancy. Neither of us felt that we lived in a world into which we could bring a disabled child comfortably.

I've worked with people with learning disabilities since 1985 and I've worked in care management and disability teams, but I had to stop recently because of the pressure I felt from emotional trauma. My clients were often refused vital services and support that they desperately needed and I found it very difficult seeing this denied to them. I experienced first-hand the distress some carers felt who weren't coping and the guilt they felt because of this.

I couldn't bear to bring my precious



SUPRIJONO SUHARJOTO

**“When we received the diagnosis of Down's syndrome, it felt like a death knell. I thought 'so that's it' and I cried and wept”**

daughter into this awful world where the services are nil. So when we got the diagnosis of Down's syndrome, it felt like a death knell. I thought “so that's it” and I cried and wept.

I know our decision will be countered by people who don't agree

with what we did, but because of what I'd been through as an employee, the thought that I may have to deal with services like that in the future – that my daughter may suffer – was horrific. So, following counselling, we decided to go ahead with the termination.

At that point, we didn't think we had much time. We didn't know then that we could have delayed things – we could have had further tests and taken longer to make our decision. But even so, I don't regret anything. I miss her, but I don't regret it.

I gave birth to Jessica a few days after the termination procedure which happened at 18 weeks.

Strangely, it felt very peaceful. I still look at the pictures we took of her, and look at her beautiful face. She's my baby girl and I love her.



MIROSLAV BENEDA

## JULIE'S STORY

I'd already decided that I didn't want a formal scan to test for Down's syndrome. If my unborn child had a disability, I'd deal with it – I knew it wouldn't make any difference to me. Despite my feelings, the hospital performed one anyway. They noticed Theodore had fluid on his lungs which is symptomatic of Down's syndrome.

From that moment I was treated as a leper. I was put into a side room by myself that had leaflets about bereavement and termination. They

left me by myself for several hours. I wasn't even allowed to sit near the other mothers – they thought it would be too upsetting for them. Eventually I saw the consultant who was adamant that I should have the termination immediately. I burst into tears. I told him I wanted to go ahead with the pregnancy. He said, “he'll have no life”.

I had to go back every six weeks to see this consultant and every time, he'd say, “have you thought any more about a termination?” I was under tremendous pressure – it felt like brainwashing. I was a single, older mother, therefore I was wrong to even consider going ahead with the pregnancy. But I knew a termination wouldn't have been right for me, I wouldn't have lived with myself. I was told that my son had less than 50 per cent chance of surviving past 24 hours as I had to have an emergency

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Caesarean at 35 weeks. But he's a strong lad and he pulled through – he's two years and nine months now.

I felt very isolated during and after the pregnancy – we never really had the support – even our health visitor told me I had to move as the area wasn't suitable for a child with a disability. But I found a lot of support from online forums. So yes, it's been hard at times, but you get there. And I wouldn't change Theodore for the world.

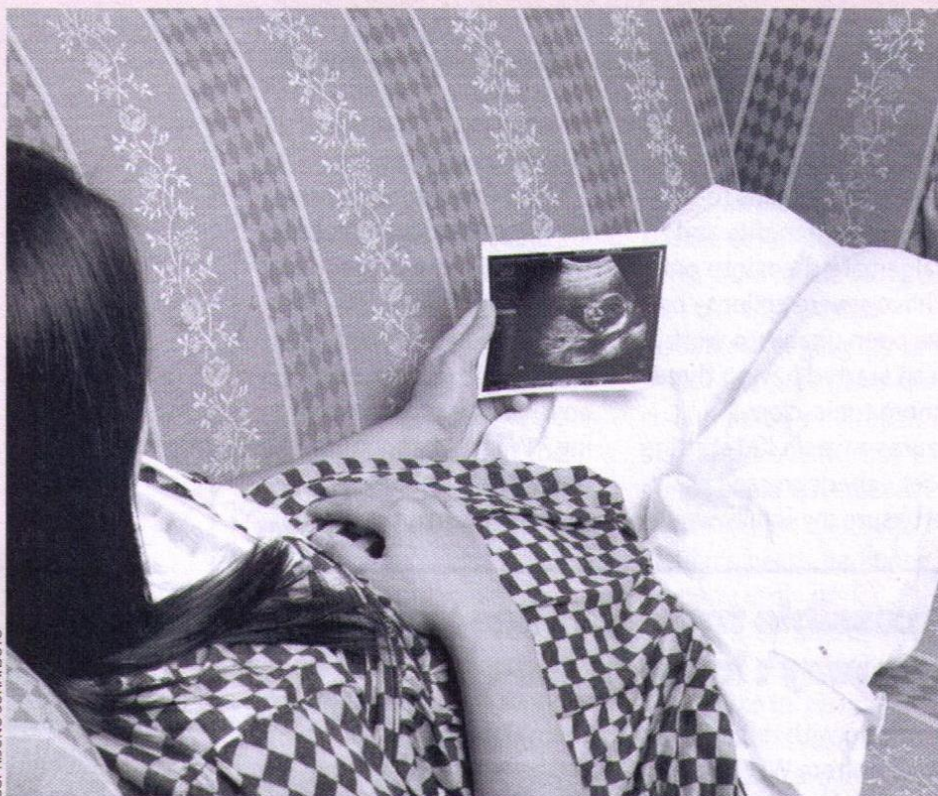
## ANDREA'S STORY

Jack wasn't unwanted. I would have given anything to keep him. I didn't want a perfect baby, I just wanted a baby that wasn't going to be in pain from the moment he was born. But we were told at our 20 week scan that Jack had osteogenesis imperfecta – a severe brittle bone disease. A second opinion told us that Jack might survive but it would be touch and go. They went through a list of what would be wrong with Jack and the problems he would have.

My husband and I agonised for weeks about what would be the best for Jack, but we knew that interrupting the pregnancy meant I could save him from future pain.

I carried Jack for an extra five weeks because I didn't want to lose my baby. Every scan showed that Jack had more broken bones. If we did go ahead with the pregnancy and he survived birth, he probably wasn't going to leave hospital and would eventually break every bone in his short life.

We decided to interrupt my pregnancy at 26 weeks and 4 days. The consultant inserted a needle through my stomach and into Jack's heart. I lay there for an hour while she tried to stop Jack's heart. I went into induced labour on the Thursday and Jack was born in the early hours of Saturday morning.



SUPRIJONO SUHARJOTO

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We spent time with him afterwards. We had him blessed and the nurses dressed him in the little

outfit we'd given him. My family visited and we took pictures. Eventually the nurse advised us to let him go because he was changing and his skin was tearing from where we were holding him.

We hadn't realised there were exceptions to the termination law – but we were the exception because of the severity of Jack's condition. I am grateful we had that time – I would have given anything to stop Jack's pain. He'd already suffered enough. We are going to miss him forever: he will always be our first-born baby boy. ■

• *Some names have been changed.*

## FURTHER HELP AND SUPPORT

**Contact a Family:** For families with disabled children.  
Helpline 0808 808 3555 Textphone 0808 808 3556  
Email: [helpline@cafamilly.org.uk](mailto:helpline@cafamilly.org.uk)  
Website: [cafamilly.org.uk](http://cafamilly.org.uk)

**ARC (Antenatal Results and Choices):** Non-directive support to expectant and bereaved parents throughout and after the antenatal screening and testing process.  
Helpline: 020 7631 0285 – Mon-Fri, 10am-5.30pm  
Email: [info@arc-uk.org](mailto:info@arc-uk.org) Website: [arc-uk.org](http://arc-uk.org)