‘Having a single twin is a bittersweet experience’

Thrilled to be pregnant via IVF, Martha Roberts suffered ‘emotional meltdown’ after one of her twin boys was diagnosed with a life-limiting condition. Here she talks about the conflicting feelings that come with simultaneously loving a newborn and mourning his brother’s death

By Martha Roberts
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'Is he your only child?' An innocent enough question, but one that always makes me catch my breath. It may be that I'm at our local playgroup, drinking tea and chatting with another mum as our children play together.

Do I simply say yes and feel I haven't done justice to the truth, or do I explain the situation and risk opening up an emotional can of worms?

The reality is that our two-year-old son Ezra is our only living child, but he is also a surviving twin. His brother Oscar died shortly before their birth.

As a family, we are not alone in suffering this kind of loss. In the UK, multiple births are on the increase, largely because of fertility treatment (10,334 sets of twins were born in 2007 in England and Wales, compared to 5,859 in 1978).

But the babies are more likely to be born early and to suffer from conditions such as cerebral palsy and respiratory problems.

‘Each year, about 600 families with twins, triplets or other multiples lose one or more of their babies in a variety of ways, either before or shortly after the birth,’ says Carol Clay, who runs the support groups and Twinline at Tamba (Twins and Multiple Births Association). ‘So an enormous number of people are left facing this unique, bittersweet experience of mourning death and celebrating life at the same time.’

It’s for this reason that HFEA (the Human Fertilisation and Embryology Authority) is asking clinics to try to reduce the numbers of multiple births. Its policy is currently just advice, but it could eventually be made law.

Despite the risks, most mothers – including me – opt to have two embryos implanted (three are allowed over the age of 40) because they want to increase the chances of success in expensive IVF cycles (each of our four rounds cost £10,000).

When my husband Simon and I found out we were pregnant with non-identical twin boys following fertility treatment, we were ecstatic.

But 20 weeks into the pregnancy, we discovered that Oscar had a severe brain condition which meant he was unlikely to survive long after birth, if he didn’t die in the womb. We were told his condition wasn’t caused by his being a twin, but was complicated by it – a singleton would probably have been terminated at 20 weeks and, although traumatic, his loss at that stage would have made it easier for us to mourn and try to move on.

In our case, the advice was to carry out the procedure at around 30 weeks to give Ezra a better chance of survival, since if it was carried out any earlier there was a risk that he would be born too early to survive. (The termination involved a needle being inserted into my stomach and a substance injected into Oscar’s heart to stop it beating.)

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The ten weeks that followed our decision were a living hell as we prepared for a birth and a death, with the two boys growing inside me. Talk of birth plans and newborn baby equipment for Ezra was tempered by discussions about how we would collect mementos of Oscar.

Simon and I had named our boys after an 18-week scan when we found out their sex.

We agreed upon which twin would have which name when we discovered Oscar’s condition – Oscar sounded like a gentle name (in the womb, Oscar seemed like the quiet one, probably because of his condition), whereas Ezra, a lively
boy even then, seemed like a solid name for a boy we hoped would be strong once born.

Ezra also means helper and his middle name, Raphael, means healer – I thought that when they were born, Ezra would help us to heal, to get over Oscar’s death.

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I worried that he’d feel lonely and bereft, knowing that he should have had a brother. I tried to do everything I could to collate information and joint experiences for him, such as playing the piano for them because I thought that hearing classical music in the womb would help them to feel calm and contented.

I also kept a diary while they were still together inside me, telling them about places we’d been together. I wanted Ezra to know that good things happened in my pregnancy (I imagined him one day saying, ‘What did we do when I was in your tummy?’).

But whatever I did, it didn't feel good enough, because I couldn’t give them a future together.

Oscar died on 10 August 2006 – Simon watched the monitor as Oscar’s heart slowly stopped beating, but I couldn’t bear to look. The thought of it still makes me cry to this day. It was so clinical, yet all we could think about was the emotional meltdown of everything that mattered to us.

As anticipated, the procedure led to my waters breaking and just hours later, at 30 weeks and six days, in the early hours of 11 August, our two sons were delivered by caesarean.

As I came round from the general anaesthetic, I was told that Ezra, tiny at three pounds, had been taken to the neonatal intensive care unit. The nurses brought me Oscar, wrapped in the quilt I’d made him, and we lay there together.
For those first few hours, Simon and I both felt unexpectedly calm, as we sat in a room with Oscar and were able to marvel at how beautiful he was. Simon says it was like spending time with someone we felt we’d always known. We felt humbled by his presence.

Congratulations cards and gifts poured in for Ezra. Some people mentioned Oscar in Ezra’s birth cards or sent them one each, but most people didn’t mention him at all, no doubt unsure of what to say.

In the meantime, Simon organised both birth and death certificates, and made arrangements for Oscar’s funeral, as well as managing our house renovation and his new mobile-phone business.

Just after the birth, some friends bought us two bird cherry tree saplings (so called because birds love the fruit) to plant – as they put it: ‘One for your son who has roots, and one for the other who has wings.’ I remember frantically scouring the garden for pots to plant them in and saying, through tears, to Simon, ‘I can’t find two the same!’ ‘But they’re not the same,’ he said. I knew they weren’t but it didn’t stop me wanting to redress the balance.

People would tell me that I now had ‘twice the love’ for Ezra and that Oscar’s death was ‘for a reason’ or ‘meant to be’ (especially when we found out that Oscar also had congenital heart failure and a systemic infection that could have infected Ezra too if they’d spent longer together in the womb).

I now appreciate that they were making real efforts to soften the blow. To the outside world, perhaps it did seem as if I’d ‘won’, because I had at least come out of it with a baby, unlike a mother who has lost a singleton. But it was never ‘buy one, get one free’. We were expecting two babies and we ended up with one – we lost 50 per cent of our children when Oscar died.

Jeanne Kirkwood, my supportive listener at the Tamba bereavement support group, says: ‘When you lose a twin, whether before birth or after, there are terrible dichotomies between loving and grieving, all at the same time. Most people think that if you focus on the joy the grief will go away, but it doesn’t work like that.’

In her book *Twins & Multiple Births*, Dr Carol Cooper even says that the loss of a twin is ‘harder to bear’ than the loss of a singleton because of the need to care for the surviving twin and carry on with family life while your natural reaction is to mourn – something that has certainly rung true for us.

In the weeks and months after the birth, I felt something was missing, that a part of me had died. I was also irrationally terrified of losing Ezra.

Jean Kollantai, founder of the Center for Loss in Multiple Birth (Climb), and herself a bereaved mother, says this is normal. ‘That’s how I felt when my son’s twin died. I spent the first year being afraid of losing him,’ she says. ‘He’s now 21 and I think I still feel like that in some way. It’s always with you.’

Being in the neonatal unit for five weeks while Ezra continued to grow enabled me to avoid the happy world of ‘normal’ new mums exchanging birth stories. But it also compounded my loss – designed for high-risk babies, these units are full of twins and multiples.

My heart broke when I put my breast milk into the neonatal unit freezer to be stored for Ezra’s tube feeding and saw batches of milk with labels such as ‘Jones twins’ – I had enough milk for twins, too.

We took Ezra home at around 36 weeks, still tiny but healthy despite his prematurity. Back in the real world, I was terrified of bumping into twins, of seeing twin prams or buggies, or even hearing the word ‘twin’.

I was sensitive to plurals – I was given a mug that said, ‘Mothers of little boys work from son up to son down’, and I couldn’t use it because it reminded me of the fact that I now had ‘a little boy’ rather than ‘little boys’.

Ezra was also given an outfit that said, ‘Number 1’, which I gave away because his and Oscar’s hospital files and wristbands were marked ‘Twin 1’ and ‘Twin 2’ and I didn’t want to be reminded that we had ended up with only one.

I’ve had fantastic support from a range of people, from consultant psychologist Dr Rosie Hurlston at Hammersmith Hospital through to a handful of very close
friends whose capacity to understand still floors me to this day.

Most of all, Simon has been beyond incredible, not least because he’s been dealing with his grief as well as mine. He’s demonstrated a strength that I couldn’t have survived without. I once read that love is the sum total of your joint experiences. If that’s the case, we are more in love than ever.

I live in an area where there are twins galore — and seeing them is becoming less painful. I have also come to realise that what looks like a set of twins may be triplets minus one.

Vicky Burley Smith, who lost Coran, one of her twin daughters, 27 weeks into the pregnancy, later went on to have twin boys, and now says, ‘People see three lovely children, but Coran is still important to us today.’

We often talk about Oscar and go to his grave. I frequently contemplate how we’ll tell Ezra about his brother, which we will as soon as he’s able to handle the information. I have to trust that we’ll know when the time is right.

When Ezra was about eight months old, I asked Jeanne Kirkwood, ‘Can you ever feel happy again after losing a twin?’ because I felt my joyful days had gone for good. Every good experience was tempered by memories of Oscar.

I remember people saying, ‘Aren’t you lucky you’ve lost all your baby weight,’ and I wanted to say, ‘I’d rather be fat and have them both here!’

‘You will be happy again,’ Jeanne told me. ‘You’ll still feel pain but as time goes by the pain will be surrounded by more joy.’ She also reiterated what other people had said, which was that Ezra would increasingly help us to heal. I remember saying, ‘I’m looking forward to that time because I can’t imagine it.’

Jeanne gave me hope and she turned out to be right. Ezra, who is now two, has been my salvation. He has been like a tornado, sucking me back into real life.

Living with a single twin is truly bittersweet, a constant reminder of what you’ve lost as well as what you’ve gained. When people ask if Ezra’s an only child, I generally tell them about Oscar because he is part of our collective reality.

When Ezra was recently seen by the paediatrician, I told him we felt very lucky because we have a child, and he answered, ‘Yes, but you’ve been very unlucky, too.’ We definitely feel both.

Perhaps that sums up twin loss best of all — good luck and bad luck, all in the same package. The trick is learning to live with the joy and the pain.

Advice for friends and family

- Avoid platitudes, particularly any sentence that starts, ‘At least’ (‘At least you’ve got another baby’). There may be a reason for the death, but for the parents there will never be a reason why their child has died while others live.
- To tell the parents ‘it’ll be OK’ is to misunderstand the situation. Despite medical advancements, some things can’t be fixed.
- Be prepared to listen to whatever the parents want to talk about, which will include the child they’ve lost. If you can’t do this, practical help — cleaning, cooking meals or looking after other siblings — can be much appreciated in the early days.
- Admit that you don’t know what to say — it’s the truth and it’s so much better than trying to rationalise the situation.
- Don’t compare the loss to your own experience. Losing a parent, sibling or friend, however painful, isn’t the same as losing a child.
- Don’t consign the lost twin to history. Asking about the lost child will show you continue to acknowledge their loss.
- Help the parents find support, such as Tamba’s bereavement support group (tamba-bsg.org.uk).
- Seek guidance yourself. The Climb website has advice on supporting bereaved parents (climb-
support.org).

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