## features

Zoë Clark-Coates was determined to use her own experience of miscarriage to help others. She talked to *Sarah Meyrick* 

WHEN Zoë and Andy Clark-Coates were 32, they decided that they would like to start a family. Although Zoë became pregnant easily, the baby did not reach full term. The couple then lost two more babies before the safe arrival of Esme, now aged eight. A fourth baby died in the womb before Zoë became pregnant for the fifth time — unexpectedly — with twins. Then Zoë became seriously ill

Then Zoë became seriously ill with gall-bladder problems. One of the twins died before Zoë underwent complex surgery. And, although the operation was initially thought to have been a success, it emerged that a gallstone had lodged in her bile duct, necessitating further surgery. It was touch and go whether she or the remaining baby would survive.

"We felt helpless, but knew there was one thing we could do. We could pray — a lot," she writes in her recent book, *Saying Goodbye*. "All I could do was pray for a miracle, that the stone would be gone and no surgery would be needed." Miraculously, the final scan showed that the stone had vanished, and Zoë was spared the second operation. Finally, in spite of a last-minute hitch with further medical complications, their second surviving daughter, Brontë, was born safely. She is now six.

ZOË and Andy found the experience of baby loss traumatic — for them and for their families — and were not helped by the response of some of those around them. Finding out how many people were like them was hard. This week, the Health Secretary, Jeremy Hunt, spoke of 1000 cases a year in the UK where babies die or are brain damaged unexpectedly at birth. Add to this the number of miscarriages, many of which go unreported, and the Clark-Coates reckon that up to half a million parents might be affected each year in the UK, and more than 70 million globally.

"When Brontë was six months old, I decided we needed to do something to help others who had gone through loss," Zoë says. "I spent weeks looking at what would have helped us in our darkest hour, and that is when the idea of 'Saying Goodbye' was born."

In 2012, the couple set up the Mariposa Trust, also known as Saying Goodbye: a charity to support people who have been affected by the loss of a child at any stage of pregnancy, at birth, or in infancy. It started off as a not-for-profit division of the events business that the couple ran, but has now become a charity in its own right, and their full-time work. In a typical week, the charity's resources are accessed by more than 50,000 people across the world who are touched by baby loss.

A key initiative is the programme of services of remembrance in cathedrals. Since the first such event — held in Exeter Cathedral, in 2012



## Permission to grieve

— there have been services in cathedrals around the country. The 100th took place in Westminster Central Hall last Sunday, coinciding with today's release of a Christmas single, "Symphony of Light", which Zoë describes as "a beautiful song of hope".

The services meet a real need, she says. They are for anyone who has lost a baby, whether recent or decades ago. Although Zoë and her husband are Christians, the services are designed to be accessible. "We are a secular charity; so we needed to be open to people of all faiths and none. There are Christian elements, because we are in a cathedral, but they also include secular music, poetry, acts of remembrance, and other elements."

It took a great deal of planning to get the services right, but there is now a well-established format. They include lighting candles and ringing handbells — a chime for every life lost. "It took a good few months, and we've tweaked it since. But it's important that wherever you attend a Saying Goodbye service, you experience exactly the same thing, and you know what to expect. That's really helpful if a family member attends a service in a different part of the country, because there's so much fear surrounding this."

It took time to build trust with the cathedrals, she says, but it helped that the couple were used to running events. "They knew we were reputable," she says. "We work in partnership, and have been able to say, 'This is what we'd like to do,' and they were welcoming."

It soon became apparent that the services also had resonance for people who could not conceive: "People can be grieving even if they've never carried a child. They are for anyone who wants to say goodbye. The template really works, and leads people through the grieving process, whether they've come straight from the hospital or had a loss 60, 70, even 80 years ago. They leave smiling, not broken."

LAUNCHING the charity meant going public with their personal story, as did the publication of the book. Saying Goodbye, subtitled A personal story of baby loss and 90 days of support to walk you through grief, recounts their experience and offers a series of reflections for those coming to terms with their loss.

The book has been well received, she says. "I always knew it would do well, but didn't expect it to be in the bestsellers, alongside books on pregnancy and childcare. That's a wonderful surprise; but perhaps I shouldn't be surprised when the volume of loss is so great."

It did not take long to write, she says, because it is based on "everything I say daily to hundreds of people". Two more books are in the pipeline: one aimed at supporting those who are going through pregnancy having suffered loss, and a second on grief in general. In the autobiographical section of the heat she are in general bet to write

In the autobiographical section of the book, she is careful not to write about the stage at which each baby died. "When we launched [the charity], one of the main gripes was, that it was as if the world tells us how much you are entitled to grieve, depending on the stage of loss. It's as if you've got more reason to take time off work if your baby has reached 24 weeks, as if the depth

'To be told your baby has gone to a better place is not helpful' of your grief could be measured. We decided never to talk about it."

ONE of the aims of the charity is to overcome the taboo that Zoë and Andy experienced. She says that they have seen a change. "We've gone a long way in five years. We've seen a massive difference. Is baby loss still a taboo? Andy and I can be on TV or radio up to five times a week. We're not fighting to get heard in the same way."

This is important to those who have been through it. "People tell us that their families don't want to talk about it, in case it upsets them. But it upsets me more if the family don't talk about it."

Some of the reluctance to talk about it comes through the fear of saying the wrong thing. "As a society, we really struggle with all loss and grief and death — anything a person is afraid of, or that triggers pain for themselves."

It is one of her hopes that the book may be a useful gift. "This is something people can give that is thoughtful, and a resource. I hoped it would be a way of giving love and care."

THE charity also has a campaigning arm, with the aim of improving the care and support of grieving parents. "We've got a Bill going through the House of Lords at the moment — it's had its first reading — to bring in a national loss certificate. If the baby is lost prior to 24 weeks, you don't get a death certificate, and parents have been saying for a long time that it would make the world of difference. [Such a certificate] shows the baby did exist, and that's important for them as a family, and also for future generations."

Some of the less than helpful comments Zoë and Andy experienced came from church leaders, she says. "We were supported by family and friends, but not so much by church leaders. They didn't know what to say to us. To be told that your baby has gone to a better place ... As a grieving parent, that is not helpful. It just brings more pain. We're working with church leaders to offer them the right words."

The book is written for a wide audience, and does not particularly focus on the couple's faith. "I wanted it to be something that everybody felt comfortable reading; so it's my journey through loss. There's enough in there to show that I have a personal faith, and I will write a Christian version with lots of scripture, but I knew I couldn't for the first book."

That is not to suggest that her faith is unimportant. "I hung on to my faith," she says. "It brought me closer to God. I didn't resent God. I didn't ever think 'Why me?' I thought, 'Why not me?" For God as Father the pain of the

For God as Father, the pain of the loss of his son really resonated, she said. "There's no greater loss. I felt more completely connected with God than ever before, and that carried me through a traumatic time."

The work of the charity continues and expands, especially overseas, where they work as Mariposa International. "We feel really called by God to this, and want to see it grow. If you'd asked me seven years ago, I'd never have thought my life would be like this, but I certainly don't regret anything. It's the greatest thing I've ever done.

"Walking alongside so many broken people is an honour and a privilege. I'd never change that but I never expected it."

Saying Goodbye: A personal story of baby loss and 90 days of support to walk you through grief by Zoë Clark-Coates is published by David C. Cook at £12.99; (CT Bookshop £11.70).

www.mariposatrust.org