

Even now, the tragedy of stillbirth is all too real, writes **ZOE TAYLOR**

# Silent anguish bears new hope

Emma Kirkwood carries a photograph of her beautiful baby daughter Olivia in a gold locket always worn around her neck. It's a constant reminder of those few precious moments spent with the baby girl, and of her full cheeks and rosy lips.

But it also gives Emma the opportunity to talk about a subject many still prefer to shy away from.

Olivia was stillborn.

She died inexplicably 36 weeks into an uneventful pregnancy.

Now, the courage of Emma, and parents like her, in talking about their loss could help other families avoid enduring a similar tragedy.

A group of NSW parents, whose grief brought them together, has formed a foundation to promote awareness and research into stillbirth—including a world-first study by Sydney researchers, which could offer clues to preventing stillbirths.

Staff in many maternity hospitals will gently encourage parents of stillborn babies to record as much as they can about their baby.

It is common for photographs and ink prints to be taken of tiny fingers and toes and these "little feet" were the obvious choice for the emblem of the new Stillbirth Foundation.

About one in 100 babies in NSW is stillborn, and almost half of these deaths occur near to term and with virtually no explanation.

While medical advances have contributed to vast improvements for the survival of babies in the first 28 days of life, there has not been a decline in stillbirths—the loss of a baby after 20 weeks' gestation.

In 2003 there were 732 neo-natal deaths nationally, but 1288 stillbirths, according to the Australian Bureau of Statistics. And while the neo-natal death rate was down 6 per cent on the previous year, stillbirths were up by almost 4 per cent.

What is most difficult for parents is that there is often no explanation as to why their baby has died.

Olivia was Emma's second child and she was nearing the end of an uncomplicated pregnancy when she was told her baby had died.

Obstetrics social worker Deborah de Wilde says Emma's story is tragically typical. Into the final weeks of her pregnancy, Emma, 37, just did not imagine there would be a problem when she went to the Mater Hospital, on Sydney's North Shore, for a check, prompted because she hadn't felt her baby move.

She took her young son Hugh, then two, with her and didn't think it worth bothering to call her husband Chris, to let him know.

So, when she heard the words "I'm sorry, your baby has died" from a midwife, Emma's first reaction was to assume that there must have been some kind of mistake.

That was followed by a fear of giving birth to something that was dead—most women are advised to go through a labour and vaginal delivery when a baby has died.

Emma was induced, and Olivia Kate was born silently on July 31 2002. Initially, Emma was reluctant to even look at her baby.

"I remember saying please take it away. I was so frightened about what it—I didn't know it was a girl—would look like," she says.

But when she saw her daughter she looked perfect.

"There was no fear then—I had this desperate longing to hold her and to love her and cherish her.

"I counted all her fingers and toes, adored her little rosy lips and her tiny eyelashes.

"I kept watching her chest hoping it would start to rise and fall with breath. We bathed her, dressed her, wrapped her, cuddled and kissed her.

"We introduced her to her family and said goodbye to her as we put her gently in a casket.

"It still causes me much pain that something so perfect could have died," Emma recalls.



**Tiny steps:** Emma and Chris Kirkwood with Hugh, 5, and Lily, 2. The family is celebrating a new member, but has honoured the memory of Olivia

Her mother had a stillborn daughter 30 years prior, but it had never occurred to Emma that she would have problems after passing the 12-week mark.

"Particularly when you get close to delivery, you naturally presume that your baby is going to be born alive and, even if it is a little early, it will be saved," Emma says.

"The pain will last forever, you never forget it."

But after gaining strength from a support group at the Mater, also open to families across the state, Emma was determined to draw a positive out of her experience.

She was inspired to establish the Stillbirth Foundation.

Emma explains: "While living with the grief of my beautiful Olivia, I was not only horrified to learn of the high statistics, but amazed to realise that little research was being done specifically into stillbirth."

The foundation also aims to raise public awareness and support families affected by stillbirths.

Almost a year after Olivia was born, Emma had another baby girl, Lily, who is now two years old.

And, at 3pm last Friday she gave birth again, to a baby boy, Oscar.

The Mater also runs support groups for couples who are pregnant again, following the death of a baby.

They may not necessarily be con-



sidered as being at higher risk of having a stillborn baby, but do need specific support, Deborah de Wilde, a patron of the Stillbirth Foundation, says.

"There's a lot of pressure on them to feel happy and excited, but wom-

en often feel so emotionally bound-up with the little one that died. It's incredibly complex," she says.

"This is something that affects people, often for the rest of their lives. The public perception around any kind of loss is that if a certain amount of time passes, then people get over it. What people do is learn to live around it."

One of the hardest questions parents ask is why their baby died. "A lot of people think the death of a baby or a mother is something that happened when our grandmothers had babies," de Wilde explains.

"They want to know why it happened, particularly if it was a completely normal, well-nourished baby after an uneventful pregnancy, and the baby inexplicably dies."

A post-mortem examination can sometimes offer clues, such as a problem with the cord or placenta.

A research project, starting this month and following 300 pregnancies in four Sydney hospitals, could provide more pieces of the jigsaw.

National Health and Medical Research Council researcher Adrienne Gordon will analyse the pregnancies of 100 women who have stillborn babies over the next three years, and compare those pregnancies to the experiences of mothers

who have live babies. It could lead to changes in ante-natal care—particularly around the monitoring of movements during the later stages of pregnancy.

"Women are told that fetal movements slow down, but they are still a really good predictor of well-being," de Wilde explains.

Emma kept a daily record of movements through both of her subsequent pregnancies.

She says de Wilde's support group was absolutely vital in helping her cope with the process.

"I'm quite happy to wear my Olivia round my neck all the time. Some people might find that odd, but it's about the personal grieving process," she says.

"But when I was pregnant with Lily, I was finding it so difficult to separate the two, that I had to take it off and put it away."

This week Emma and Chris are celebrating the birth of their fourth child. And Olivia will live on through the work of the foundation.

Emma says: "In the memory of Olivia, I promised I would establish an organisation to fund and improve research into stillbirth. If just one family can benefit and not live through what I went through, then it will be a success."

For donations or information about their work, contact the Stillbirth Foundation on 9900 7596

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