

# The Lost Children

Rebecca sits in the emergency department for five hours bleeding and crying, feeling a life and the hopes that accompanied it drip out of her.

Claire stares at an ultrasound screen in shock, having trouble understanding why the sonographer is telling her there's nothing there.

Sam bursts into tears at shops when she sees a mother and baby, hating the other woman for having what she worries she'll never have.

Fiona sits wrapped in a hospital blanket, waiting for a doctor to come and take the dead part of her away.

Miscarriage is one of the final taboos in an age where every aspect of life is shared. The silence around grief leaves many women feeling alone, isolated by the experience. But they find when they open up about their lost children, other women share their own miscarriage stories. That invaluable support makes many question the sense in hiding their grief and pain.

High profile people have started telling their stories — including Hugh Jackman and Deborra Lee-Furness, Beyonce, Gordon Ramsay and Scottish First Minister Nicola Sturgeon — and October 15 is marked internationally as pregnancy and infant loss remembrance day.

Bears of Hope founder Amanda Bowles says there's been a distinct shift towards openness over the decade since she started the support service.

But while there's more discussion about miscarriage, Bowles says there's still a disconnect stopping people from seeking support.

“Some people can have a miscarriage and, whilst usually fairly upset at the time, can work through that and rationalise it, sort of piece it all back together and continue on,” she says.

“But there’s a large proportion of families who need some more support ... and that too is OK. It does not make them unusual or different, it just is the way it is.”

Claire (not her real name) says the loss of a baby is still very much a taboo subject, enshrined in the expectation of not announcing a pregnancy until after 12 weeks.

“To me it feels like this is because if something does go wrong then you can quietly deal with it and no one has to know,” she says.

“People want to celebrate with you but commiserate, not so much. This feeling of having to deal with it in secret is isolating and makes it harder to reach out for help.”

The culture of silence led her to believe most people dealt with miscarriage pretty quickly and she was surprised to find herself grieving.

Claire, now 31, learned she was pregnant with her second child just before Christmas 2014. She and her husband spent the holiday period thinking about the big year ahead and tossing around names.

But at their dating scan the sonographer said to Claire, “It doesn’t look like there’s anything. It looks like there’s a blighted ovum.”

Her first baby had been a “textbook pregnancy” and Claire never expected everything could go so wrong.

“I thought, well, we did it once and it was pretty straight forward. So when they said there was no sign of the baby growing it kind of took a second — like, are you actually talking to me because I did this once, doesn’t it happen the same way again?”

A second scan confirmed that although her body continued as if it was growing a baby, the baby wasn't growing. Given the choice of waiting for a natural physical miscarriage, having an induction or undergoing a dilation and curettage (D&C), Claire chose the latter. Looking back, she says while doctors gave lots of information about what to expect medically, no one prepared her for the emotional impact.

“Despite not having a baby I still ended up with postnatal depression, which I didn't expect, and then also found out I was suffering from anxiety and stress,” she says.

“I didn't really think that hormones would be still running wild and (how) that would escalate the emotions of grief. It also felt that, given how little it was talked about, grieving over an early miscarriage wasn't a normal thing to do.

“I felt a little embarrassed that I was so upset over a baby I never met.”

Claire felt isolated and struggled with not knowing what to tell people. Some were very uneasy at finding out, changing the topic or saying unhelpful things like she would have another baby or at least she hadn't seen its heartbeat. She lost friends who couldn't understand why she wasn't around for big events while dealing with postnatal depression and anxiety.

Eventually she found people who had experienced miscarriage and offered support, reassuring it wasn't her fault.

The gap in support available between her miscarriage and her next pregnancy felt like limbo.

“When you think about it, when you have a baby you have all the medical support — midwives, doctors, et cetera — during labour and then after you have (maternal

health) nurses to check on you, access to the community clinics as well as family and friends,” she says.

“With my miscarriage I was lucky enough to have medical staff present for the surgery. But after that you are left to deal with it on your own.

“No one contacts you to let you know what services are available to you or where to find support. I had my Bears of Hope bag but beyond that I was left to search the internet for services, ways to remember my baby or even support groups.”

Australia doesn't collect statistics on how many babies are lost before a pregnancy reaches 20 weeks. A commonly accepted figure is one in four pregnancies end in miscarriage, suggesting almost 100,000 children lost each year.

However, obstetrician Professor Stephen Robson says the one-in-four statistic is based on a study from the early 1990s and the situation is more nuanced. In younger women it's maybe one in eight but for women in their late 30s and early 40s it could be as high as one in three.

The demographic shift towards women having babies older has probably made miscarriage a more common experience.

“I think it's something we're seeing more and often the stakes are higher. Because of their career or they haven't met the right person or it's just not the right time, they delay it and then are often more desperate to get pregnant,” Robson says.

“You just feel that sense that time is beginning to slip away from you, so when you have a pregnancy loss it can be really devastating.”

Bowles says the statistics don't matter; every loss counts.

“Yes, miscarriage is common but so is breast cancer and nobody’s patting anyone on the back saying it’s OK ... you’ll deal with it. There’s a lot more respect,” she says.

“Just to say it’s common and you can have another one or you can move on or you’ll be OK is not an acceptable response to anybody.”

Sam Blandford thinks part of the “massive taboo” is because people are scared if they say anything, “you’re probably going to implode in front of them”.

“When I went through it, it was terrible, there was no support,” she says of her miscarriage in 1997.

“I’d love for things to be different for other people going through it.”

At the time, Sam felt like people dismissed her loss and she had to hide her devastation.

“Because they didn’t physically see a baby, you weren’t out there with your stomach and things like that, I think they went she must be fine, it will be OK ... it was so early it doesn’t matter,” she says. “I wasn’t feeling that way at all.”

Sam didn’t know if she would be able to fall pregnant because of her history of anorexia but when fertility treatment worked when she was 25 her first thought was, “Fantastic, we’re going to be able to do this.”

An initial scan showed she was pregnant with triplets but a couple of weeks later Sam started bleeding. One of the triplets had died.

“I thought all was lost but we had twins and that was really fantastic. We had heartbeats as well, so that was really good,” she says.

A month later, Sam was the matron of honour at her sister’s wedding when she started miscarrying again and lost both twins.

“I could not stop crying and I just thought this is it, I’m never going to have children. I cried and cried for two weeks non-stop,” she says.

“Mountains of devastation would just keep coming over me.

“In shopping centres if I would see a pram, I would just burst into tears.

Sometimes I hated women and their babies. It sounds like a horrible thing because I’m not normally a hateful person but I just hated what they had and I thought, ‘I can never have that’.”

Rebecca Klemke studied biology and knew about miscarriage in a medical, abstract sense, but wasn’t prepared for the reality.

“If people talked more about it, it wouldn’t be such a shock for women,” she says.

“Most people know about (postnatal depression service) PANDSI ... or when you walk into hospital you see a lot of those support things all around the place. But you don’t hear about anything specifically about when things go bad.

“You have to go look for (information), it’s not readily available, it’s not plastered on the walls. No one gives you a little book afterwards to go here you go, this is about miscarriage.”

Her husband David says it’s also tricky to know how to make a miscarriage public knowledge — it’s hard to speak about, like any trauma.

When Rebecca, 32, fell pregnant in late 2015 she had one close friend who was midway through a pregnancy and another who’d just had their first baby.

“I thought I might very well be on maternity leave at the same time as two of my good friends, this is fantastic, all our kids will be able to grow up together,” she says.

“That was probably one of the most devastating things, because I got all excited about that.”

She and David started planning for their new baby, toured the local hospital and put their name down for antenatal checks.

Then she got cramps, followed by bleeding.

“By the time we’d gotten out the door and started going to emergency, it was extremely painful and then began the long five-hour wait to see someone in emergency.

“You’re sitting amongst everyone else waiting, worrying, not doing anything, bleeding more. Finally you get in to see someone, waiting another five hours for blood tests, waiting more hours, more hours, more hours for results, and then being sent home.”

The morning brought more bleeding, another hospital visit and another obstetrician, who told her to remember humans are really bad at reproduction and it was nothing she had done wrong. Rebecca says her study meant she took that medical approach relatively well.

“Despite being absolutely devastated and in tears, I could tell myself it’s OK, whatever it was it wasn’t viable anyway,” she says. “‘This is a good thing’ is what I kept telling myself.”

David had a friend whose wife had miscarried who checked on him daily but says Rebecca didn’t have have that support and was in meltdown.

“For me, it was easy to get over it because it wasn’t physically happening to me,” he says. “But we’d be watching a TV show when something baby or miscarriage related happened and I’d look at Bec and she’d be crying.”

The next time Rebecca fell pregnant she didn't believe it and was scared to share the knowledge even with her husband. On David's part, he says this second time he tried to keep himself distanced from the idea of having a baby.

Rebecca had family history of difficulty with pregnancy hormone levels and pushed her doctors to check, leading to a stressful day of driving from clinic to clinic chasing referrals and blood tests.

At the end of this, she went to the bathroom and found she was miscarrying.

"Emotionally I just kind of broke, just crawled into bed and tried to keep it together. David walked past and saw I was crying and asked me what's wrong and I ended up wailing that I was bleeding and can't deal with it any more."

They were about to go on a six-week holiday and it took that entire time for the bleeding to stop. But Rebecca says being away helped put everything on pause.

"I've thought about it every day, not intentionally but it has popped into my head every day. I'm constantly trying not to think about it," she says.

"This second time has been a lot harder emotionally, I've definitely fractured."

She and David say one of the most frustrating things was being told by doctors they weren't in the demographic where fertility problems are expected and to just keep trying. Rebecca was told no medical investigation could happen until after three miscarriages.

Days after we spoke she miscarried a third time.

Robson believes it could be easy for medical staff to underestimate just how devastating miscarriage can be, particularly if a woman has ended up in the emergency department.



“It’s very easy to be part of what seems like just a bit of a production line. They may not even see a doctor after the procedure, they may be told by the nurses to just go and see their GP,” the Australian Medical Association ACT president says.

“I can see how there would be a strong perception that you just get through the curette and shoot off home and the problem goes. It can be a very lonely experience for a lot of women.”

He says it’s important for doctors to offer the opportunity to talk about what’s happened and why and what it may mean for their next pregnancy.

Women find their approach to pregnancy changes after experiencing a miscarriage.

Sam Blandford hated every minute of her pregnancy with her oldest daughter because she was terrified of losing the baby again.

“I did almost nearly lose her as well and I was in the deepest depression that day and when I had the scan and she was still there and had a heartbeat — I don’t think there was anything I wouldn’t have done to make sure that that pregnancy went through,” she says.

Claire remembers never being able to look at the ultrasound until the sonographer confirmed a heartbeat.

“I kind of switched from the mentality of knowing that miscarriage happens to one in four to suddenly, well, I’m one of those statistics, if it’s happened once it could happen again.”

When we speak, Fiona Wilson is three days overdue with her “rainbow baby” (one conceived after a pregnancy loss). Previously she had approached every pregnancy wanting to tell the people important to her immediately, but this time she and

partner Jarrah waited until after seeing the first ultrasound to know everything was fine.

“I guess it was partly me not actually fully embracing this pregnancy until I felt more safe,” she says.

A year earlier Fiona was excited and terrified at the thought of having a second child.

“We’ve decided over the last 12 months that any decision to have any child is a moment of madness,” she says.

She went to her first obstetrician visit with “blind faith” everything would be fine. A fortnight later she returned for another ultrasound and her baby had no heartbeat.

“That was instantaneously devastating.”

As a nurse, Fiona knew the statistics on miscarriage and also had several colleagues who had lost babies. She thought she’d be fine but, when confronted by the reality, “fell into an entire heap”.

“Once I knew that our baby had died, I really felt like there was something dying inside of me. I felt emotionally drained in a way I’ve never felt before and it was a very strange feeling of not wanting to let go of my baby but also actually feeling like part of me was dying.”

She decided to have a D&C and says logistics took over until she reached the hospital and found herself alone in a ward.

“(Hospital) tends to be a place where you end up waiting a lot on your own,” she says. “You end up sort of tucked up in a blanket watching the clock and watching what’s going on around you, trying not to think about why you’re there.”

All these women speak of the importance sharing their story and hearing the tales of others made to their grieving. Miscarriage is part of Australian life but it's hidden and likely to stay so unless more women speak out and share their stories. Only then can there be greater community understanding of the grief families feel for their lost children and support to remember them.

Claire keeps the Bear of Hope she got in hospital on display in her family room and lights a candle next to it at Christmas, Easter and the anniversary of her surgery. She also has "Charlie's rose" planted in a pot outside her window.

The teddy Fiona got in a Bears of Hope package has slept in her bed every night, "and probably will until my current baby is out of my tummy safely". Baby Lilian was born healthy four days after we spoke.

Rebecca and David are still trying for a baby and have made sure they keep talking with their friends about what's happening, keeping their support network strong.

Sam marks her twins' due date every year and keeps a picture of a mother and baby giraffe she bought for their nursery.

"People think you can just dismiss it forevermore but it doesn't work that way. I still to this day think, 'did I do something wrong?'" she says.

"It doesn't stop me moving on in the world and getting on with things but it never leaves you.

"People don't realise that's how much impact it can have on your life."