

Inconceivable Dilemma

by Rosemarie Milsom

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Carolyn Martinez is trying not to cry. "I'm a strong, independent woman," she says, smiling through tears. "I'm sorry, I really didn't want to get upset."

This courageous, warm-hearted 40-year-old has nothing to be sorry for. After enduring seven cycles of IVF in the past three years, her tears are entirely appropriate. We are sitting in a New Lambton café and Martinez is outlining her and husband Saul's next attempt to have a much longed-for baby.

"Our doctor has said that it's well and truly time to move on to donor material," she explains. "My cousin Lisa has offered to donate eggs, but ideally we wanted to use donor embryos. We really like the idea of using an embryo that is already here and giving it a good home."

One of Martinez's long-time friends, Lisa Lumer, who has had three children through IVF and has three unused frozen embryos, has raised the possibility of embryo donation. But it is a highly emotive issue. "Prior to giving birth," Lumer says over the phone from her Queensland home, "the embryos were just cells, a means to an end. But now that my family is complete, I find it hard not to think of them as my children, as siblings to my three boys."

Ideally, Lumer would attempt another couple of IVF cycles in the hope of having a daughter, but she is also step-mum to her husband Richard's four children from a previous marriage. Financially, another child would be crushing. "I emailed Carolyn the other day and asked if she'd consider it (using her unused embryos) and she sent me a long list of considerations, the emotional and ethical. Of course it's something she'd love to do, but I'm still working through things."

Lumer is one of the estimated 30,000 Australians who have unused embryos in storage. She has three options: discard them, donate them to research, or donate them to another infertile woman. Like many aspects of the IVF journey, the dilemma is fraught.

"We know that not every embryo makes a baby, but people think, "We have little Susie from that batch of embryos, maybe little Johnny is there as well." IVF counsellor Vivien Hart says, "It's really important for people to have finished their family before they make a decision and that in itself is a significant decision.

"Some people reach the point where they have finished with their family, and they don't want to keep paying for the maintenance of the embryos, but they also don't want to discard them."

After deciding not to have more children, the next challenge many couples confront is reaching agreement about what to do with their embryos, which are stored in vials immersed in liquid nitrogen.

Twice a year when the \$250 storage fee is due, Lumer is reminded of her dilemma. Her husband is more than happy for the remaining embryos to be donated to Martinez, but his four children, aged 15 to 20, aren't. "Now they've got three half-brothers, they are dead-set against the possibility of another sibling living with someone else," Lumer says. "But I feel selfish for not allowing the embryos a chance at life, especially because I know how hard it is to want a child and not be able to fall pregnant. I really feel for Carolyn."

The most recent statistics about frozen embryos – referred to as "snow babies" in online forums – date back to a 2006 survey by the National Perinatal Statistics Unit based on information supplied by 57 Australian IVF clinics. The survey found there were 119,000 embryos on ice, the majority of which were earmarked for future patient use in another cycle; 5.6 per cent were earmarked for donation to research; 2.7 per cent for disposal; and only 1 per cent for donation to another couple.

What becomes clear when talking to women who have embryos in storage, as well as the fertility specialists whose job it is to guide them through an IVF program, is that most people at least consider all three options, a fact not gleaned from the final figures.

"What generally happens is that most couples go through all these options and, in the end, the majority reach the point where they decide to get the clinic to allow the embryos to succumb naturally with thawing," Associate Professor Peter Illingworth, a medical director of fertility clinic IVF Australia, says. "You can't underestimate the importance, or the emotion, of the decision. A lot of people express emotion about the embryos being the unformed siblings of the children they already have.

"Many reach a decision that is very different to what they had planned in the beginning."

The heart and mind are entwined through the decision-making process, and couples who have had to confront the sadness of infertility find it confronting to be in the position where they are discarding embryos.

"When couples first come into the clinic, at the forefront of their minds is the fear that they will end up childless and it worries them enormously," Illingworth says. "The mental leap to a situation where they've got enough children and don't want any more is something they just cannot imagine at that early stage. A huge change in their life and attitude occurs.

"Every time a couple considers IVF, we work through all of this. We let them know that there may be stored embryos, more than they need, and they tend to say, "Wouldn't that be wonderful!" But when they find themselves in that situation, their feelings are often very different."

In NSW as of last year, the length of time embryos can be stored has increased from five to ten years. Pragmatism usually steps in before the deadline because of the storage fees, which start from \$30 a month, though many couples fail to act until they are informed by the fertility clinic that their deadline is approaching.

Some couples simply ask the clinic to discard the embryos for them whereas others feel the need to have a much more personal goodbye. “People come in wanting to acknowledge that it’s the end of their journey,” says Hart, who counsels couples at Genea (formerly Sydney IVF Newcastle) during the decision making if they feel the need for support. “We take the embryos out of cryostorage and we put them in a nice box and they take them home. Whether they bury them or put them in the cupboard, it’s a way of helping them finalise that part of their life.”

Sandra Dill, of the national infertility network Access Australia, knows of a couple of women who chose to have the remaining embryos transferred at a time of the month when it was highly unlikely they would be fertile. “They felt a strong need to return the embryos to the place they should be rather than discard them another way,” she says. “I think it’s very important that we respect the wishes of those who created the embryos. No one values those embryos more.”

Lumer is open to this option, even at a cost of \$1500. “It seems like the right way to go, but Richard isn’t 100 per cent about it,” she says. “I’m not sure why, but he also says that he’ll support whatever I decide.”

When Claire Brandt* was diagnosed at 32 as infertile because of endometriosis, she was stunned – and then devastation set in. “I was a healthy young woman who had always taken good care of myself,” she says. “I was fit, had never smoked or taken illicit drugs. I couldn’t believe I was in this situation.”

The only way she and husband James could have a baby was with the help of IVF. “Our IVF doctor advised us at one of our early appointments that our chance of success was very high, and those words definitely kept me going.”

Fast-forward five years and the couple have a daughter, Amelia, who is five, three-year-old son Charles, and are expecting their third child. Amelia was conceived after their first round of IVF, which also produced six other embryos. Charles was surprisingly conceived naturally, but when the couple were planning a third child they opted to use one of their frozen embryos.

“We felt very strongly that we shouldn’t even try to conceive naturally,” Claire explains. “These embryos were there and were produced using considerably younger eggs than I have now. We felt we should go back for one more of them.”

And although Claire and James have a few years to make a decision about what to do with their five remaining embryos, they have already thought long and hard about the options and have agreed they will be donated to IVF research. “After our daughter was

born, I couldn't help but view our frozen embryos as our unborn children," Claire says. "But having just gone through the process of a frozen embryo transfer that didn't work straight away, we now have a different perspective. We realize that not all of our remaining embryos can become children."

Like the Lumers, Claire and James considered donating their embryos to an infertile couple but could not look past the implications for their family given that at 18, a donor child is entitled to details of its genetic origins and may choose to make contact.

"As much as we feel incredibly sad and have huge empathy for other infertile couples, the reality is we'd be constantly looking at children and wondering whether they might be ours," Claire says. "We also considered donating to friends, but I just know that I'd want to take the baby home with us and I'd find it very difficult to accept that I have no say in the child's upbringing."

The decision-making process hasn't been easy and Claire says if she were to go through IVF now, she would do it differently. "If we had a similarly large haul of eggs from a cycle, I think I'd request to have a percentage frozen and only fertilise enough to produce the total number of children we'd be willing to have," she explains. "When we started IVF, the technology to successfully freeze and thaw eggs hadn't been developed so it wasn't an option."

Illingworth says people are now moving away from creating a high number of embryos. "A few years ago we used to create a lot of very early embryos. Now, we take them to blastocyst stage – day five – before transfer and because of this, fewer embryos are stored. A natural selection takes place, reducing the number of viable embryos."

Hunter IVF director and fertility specialist Dr Steve Raymond says cultural and religious beliefs also affect a couple's decision about how many embryos are created. "A few couples make a point of not generating many embryos," he says. "There are others who say that they will use all the embryos in storage, even if that means having three or four children."

Raymond oversees a small number of embryo donations a year and they usually always happen between couples who are related or close friends. "It's happening more and more, and becoming more acceptable," he says. "They tend to be known donors. It's not our role as clinicians to go out looking for frozen embryos."

Both parties are counselled and undergo appropriate medical testing. (Under federal law, embryos cannot be bought and sold in Australia). "Some people just don't make good embryos and they've exhausted all avenues," Raymond says of a couple's decision to use donor embryos. "Eighty per cent of the time, IVF leads to a baby. We have world-class results in Australia considering we do single embryo transfer 70 per cent of the time, but it's still not a guarantee that you will have a baby."

Carolyn Martinez is admirably positive given her ordeal. “We are open to adoption and fostering,” she says. “We know we will have a family, one way or another.”

Stamped in capital letters on a geometric silver pendant given to her by her cousin Lisa are the words REACH CREATE BELIEVE. The necklace is a more feminine, arty version of a military dog tag and Martinez has earned it after enduring her gruelling battle with infertility.

“In seven cycles, we got three embryos and none of them took. It’s been a nightmare,” she says, her wide smile fading. “When you start out with IVF you’re convinced you’re going to fall pregnant after the first cycle. Everyone is.”

Riding a dramatic roller-coaster of emotions has been confronting and led to a decision by the Lake Macquarie City Council employee to take a year off from full-time work. But instead of lolling about, Martinez has produced a book aimed at helping others cope with the IVF experience. In *Inspiring IVF Stories*, 24 women and men from throughout Australia, including her good friend Lisa Lumer, recount their dramatic highs and lows in candid detail. Their stories are harrowing and surprisingly humorous.

“Every story is completely different, but you feel normal when you hear about other people’s experiences,” she says. “You don’t feel as isolated. When you start out, you’re overwhelmed with medical information, scientific information, with financial details, emotions. It’s a minefield.”

While receiving donated embryos is high on her wish list, Martinez is inexpressibly grateful for the offer of eggs from her cousin. How would she feel if more embryos using her cousin’s eggs were created than she was comfortable using? ‘We’re not sure,’ she replies. We’d happily have four children if we can. If there were more embryos than that, could we give away our own embryo? It’s too big a question to answer now.”

**Name has been changed by request.*

Inspiring IVF Stories, by Carolyn Martinez, will be launched at Wallsend Library today at 11am. Some of the couples featured in the book, which is available from hawkeyepublishing.com.au, will attend and answer questions. All welcome.

Inspiring IVF Stories is available for \$26.95 at www.hawkeyepublishing.com.au (postage included), or in all major e-book stores for \$12.99.