

SILENT SUFFERING

BY TRUDIE McCONNOCHIE

Amid the cheerful disorder of a household buzzing with three lively girls under five, west Auckland mum Emily Campbell can still be seized by a wrenching sadness at unexpected moments. The trigger could be someone's well-meaning query about whether she had ever

wished for a son, the dawn of a significant day – perhaps Mother's Day, or the anniversary of the day she lost him or the day he was due – or it might be something of no significance whatsoever. A profound ache clamps around the 34-year-old's heart and overpowers her all over again, as if her miscarriage were only yesterday.

Though few of her friends can ever fully understand it, even after five years the loss of any child – irrespective of whether it lived to take a breath – is a sorrow that never goes away.

"It just sneaks up on you," Emily says. "In my day-to-day life I don't think about it anymore, but it's always there. It doesn't consume me anymore but sometimes I'm caught by surprise."

For 32-year-old Aucklander Pieta, the pain – which she describes as "a blanket of grief" – is raw and fells her more frequently. Last year she endured three consecutive, progressively more soul-destroying miscarriages, shifting her dreams of motherhood onto shaky ground. Getting pregnant is not a problem for her – she conceived easily each time, following her obstetrician's advice to wait two full cycles after miscarrying. But despite spending eight months of last year pregnant, Pieta still does not have a much-yearned-for child; Mother's Day 2012 should have been so very different.

"Mother's Day is that hard day where, if everything had gone to plan, I would have had a baby," Pieta says. "I would have been celebrating Mother's Day like

every new mother. The reality is it may never happen."

Intensifying this bewildering grief for the children she didn't get to meet is the fact that her suffering is, for the most part, behind closed doors. Yet in truth, neither Pieta nor Emily should feel isolated – miscarriage is cruelly common. Among confirmed pregnancies in New Zealand, 15-20% will result in a miscarriage, says Dr Karen Buckingham, an obstetrician and gynaecologist who works in private practice and at Auckland's recurrent pregnancy loss clinic.

"Because it's so common we don't tend to investigate unless they've had three miscarriages in a row or two second-trimester miscarriages; otherwise we'd be inundated with couples to see," Dr Buckingham says. "The most common cause of sporadic miscarriage is probably a chromosomal problem with the embryo. There's nothing a woman does that's going to make a difference to that."

And because human pregnancy is a relatively inefficient process, she says, approximately 50% of all conceptions fail – with most miscarriages unrecognised because they occur before or with a woman's next expected period.

LACK OF UNDERSTANDING

Despite its frequency, miscarriage is not an easy topic to broach. In fact the stigma is so great that Emily was the only woman NEXT spoke to who consented to having her surname published. Emily, who lost her baby son at 16 weeks, and Pieta, whose miscarriages occurred at eight, 12.5 and nine weeks, recall how friends and family, failing to understand the depth of their pain, offered well-meaning but unhelpful comments. Even more upsetting was when people wouldn't address it at all.

"It'd be dismissed with, 'It was barely bigger than a seed, what are you going on about?' or people didn't know what to say so they didn't say anything," Pieta says. "It completely shifted my life in a different direction, so for people to pretend that it didn't happen is pretty hard. Unless you've

been through it, it's very hard to relate."

She is grateful to her circle of supportive friends and family for gently checking in on her from time to time, and she leans heavily on a group of women she met through an online miscarriage support forum who understand all too well that her anguish is ongoing.

"If I'm not up to going to a friend's child's birthday party or baby shower, I will be completely honest and say I can't do it," Pieta says. "Some people have made me feel like, 'Aren't you over it yet? Surely you should just get over it and go?' This is not something you just get over."

Wellington mum-of-one Naomi, 33, was almost 20 weeks pregnant with her second child in 2010 when doctors delivered the heartbreaking news that her baby had died. Frightened by the prospect of giving birth to a deceased baby, she opted to have a D&C (dilation and curettage) under general anaesthetic, where the cervix is opened and the uterus gently scraped with a curette (an instrument with a long handle) to remove any tissue which could become infected if left. Because she was in the second trimester, meaning her pregnancy was very visible, Naomi found it easier to talk about than a miscarriage in the first trimester, which usually results in a hidden grief.

"When I told people, everyone was really uncomfortable, which I understand," says Naomi, who has a two-year-old son. "But I think the fact that no one talks about it makes it worse for people when it does happen, because even though it's really common, people don't feel like it is," she says. "And we have this culture of 'don't tell anyone you're pregnant until you're 12 weeks' in case you have a miscarriage, and obviously you don't want to tell everyone, but you would be better off if you did tell some people so you have some support if you do miscarry."

With so much focus on the woman after a miscarriage, the man's grief is not always recognised.

"It's harder for the guy," Pieta says. There's the whole thing of the >>

OFFERING SUPPORT

The usual grief comments often don't come to mind when there is no picture in your mind of a baby, or you didn't know the person was pregnant. When you're not sure what to say, a simple "I am really sorry about your loss" is fine. Here are some ways you can help:

HOW TO SHOW YOU CARE

- Acknowledge her pain with something like, "I know how much you wanted that baby". Don't be anxious if you make her cry – this is how she works through her grief.
- Ask questions about how she is feeling.
- When you ask her partner how she is doing, don't forget to ask him how he is.
- Often people are sympathetic the first time, then never mention miscarriage again. Parents may be grieving for weeks or months, so it is reassuring for them to know your support is ongoing. Say something like, "Can I call you back next week to see how you are doing?"
- Reassure them it wasn't their fault.
- Grieving is a physically exhausting process and she will probably need to rest during the day; help her get uninterrupted peace to do this.
- Do something practical such as the washing, shopping or providing a meal.
- If you are worried about her behaviour, seek professional advice. As a rule of thumb, as long as she is not damaging herself, another person or property, you probably don't have anything to worry about.

BEAR IN MIND WHAT REALLY DOESN'T HELP...

- Ignoring her because you feel helpless or you find the situation uncomfortable.
- Thinking that miscarriage is easier to cope with than a stillbirth or neonatal death. Her baby has just died, and it doesn't really matter how pregnant she was.
- Putting on a bright cheery front or confusing offering support with 'cheering her up'. Grief needs to be released not repressed.
- Having expectations about how long it should take her to recover. Losing a baby is one of life's most difficult experiences.
- Saying something like, "She's so lucky to have the other kids." Her pain is for this baby and her other children don't take that away.
- Telling her, "You can always have another one". She and her partner didn't just want any baby, they wanted this baby.
- Assuming there will be another pregnancy.
- Offering platitudes which minimise her loss such as, "You're young enough to try again", or "it was nature's way of getting rid of an imperfect baby".
- Saying, "At least you didn't know the baby – it would have been much worse if it had happened later". It is not the length of the pregnancy, but the strength of the parents' attachment that determines the intensity of their grief.



Miscarriage is remarkably common among Kiwi women, yet we rarely discuss the ongoing heartbreak of this loss. We take a look at this oft-ignored subject

husband always protects and looks after you... he can see all this grief you're going through and he can't stop it. There's a lot for them to process - it was their child too. I think it's something that will either bring a couple together or drive them apart. I'm very fortunate it's brought us together."

CAUSE UNKNOWN

Sadly, Pieta, Naomi and most women will never know why their babies died; the vast majority of miscarriages are deemed 'unexplained'.

For Emily, post-miscarriage tests revealed a blood clot problem which caused the baby's placenta to break away from the uterine wall. Sadly, this starved the baby of oxygen, causing a hormonal change that brought on labour and resulting in

slightly later period."

For a referral to the public recurrent miscarriage clinic Dr Buckingham works at, women must have had at least three consecutive miscarriages, be younger than 40 and be patient - there is a waiting list of around three months.

As well as clinical services such as early pregnancy monitoring, it offers counselling, relaxation training and support. As a result, 70% of patients with unexplained recurrent pregnancy losses go on to have a successful pregnancy.

"There are very few patients to whom we would say, 'Look, it's never going to happen; your chance of miscarriage is so high it's not worth trying'," Dr Buckingham says. It's not uncommon for her patients to have



"It's always there," says Emily Campbell of the pain of losing her baby son at 16-weeks gestation.

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her giving birth to her dead son while away on holiday.

It was during these tests doctors noted the baby was "most likely" a boy, based on the way the genitals had started to form. Knowing the gender helped Emily move forward in her healing journey when she later gave her baby a name, Jacob William. During her three subsequent pregnancies she took aspirin to thin her blood and everything went well.

Dr Buckingham says miscarriage is becoming more common due to advancing maternal age - oocyte (an immature ovum, or egg cell) quality is one of the few known contributors.

"Women are leaving it later to conceive, and when they are in their 30s and 40s we would expect to have a high miscarriage rate in that group," she says. "I think too with the tests we've got now we can detect pregnancy even before we have missed a period - 20 years ago you would have just thought [a miscarriage] was a

MYTH BUSTING

Much misinformation prevails about what factors can adversely impact on a pregnancy, and after a miscarriage many heartbroken women wonder wrongly whether they could have somehow caused it. Dr Karen Buckingham sorts fact from fiction.

HEAVY LIFTING "There's very little evidence that avoiding heavy lifting makes a difference."

WEIGHT "If someone's considerably underweight or overweight they're much more likely to miscarry. We're seeing more and more women who are overweight having recurrent miscarriages."

SEX "There is no good evidence that having sex makes you more likely to miscarry."

FOOD "We do ask women to avoid eating things that can contain listeria, which can cause sporadic miscarriage, and have no more than two cups of coffee a day - there's evidence that if you have more than that it increases your risk."

AGE "As we get older our eggs get fewer in number and poorer in quality, and that increases the risk of miscarriage."

EXERCISE "If a patient's pretty fit and healthy we don't want to discourage exercise, but we wouldn't suggest starting exercise that's new or excessive in the first trimester."

PAINKILLERS "It's perfectly fine to take most painkillers during your pregnancy."

GENETICS "There's an anomaly called translocation where one partner has the correct number of chromosomes but they are rearranged differently, so when the chromosomes divide in the formation of eggs [gametes] and sperm, the gametes may have 'unbalanced' amounts of DNA - making the embryo more likely to miscarry. It doesn't mean they'll never have a baby, but it means they might have quite a few miscarriages before they get there. We only find it in about 2-3% of cases of consecutive miscarriages."

You have lost something huge but the world goes on; it's not like we've got that funeral or the wake

had as many as six miscarriages and one woman on file had an incredible 16. Pieta, who has taken a break from trying to conceive, doesn't plan to go that far.

If the worst outcome comes to pass and she doesn't have a baby in her arms within five years, she has vowed to step off the emotional rollercoaster of recurrent miscarriage.

"We're just waiting, I guess, until my desire to have a child outgrows my fear of having another miscarriage," she says.

"Each time you have one is exponentially worse than the last. Because I get pregnant so easily - and I'm really fortunate that I don't have that side of things as well - people say we can keep trying until I'm 40, but we will run out of the strength to continue before we run out of fertile years. There's only so long you can do it, because it consumes you."

Despite all the agony, she and her husband have not given up on their dream of having a family just yet.

"You've got to have hope, and the day the hope disappears I'm not going to try anymore. There are other things that we'll end up planning in our lives. I'm not going to let this rule my life."

MOVING ON

Each of the three women NEXT spoke to has marked her child's (or children's) death in private ways. Naomi and Emily each planted a tree in their garden - in Emily's case, on the five-year anniversary of her son's passing. "We named him then too," she says, unable to hold back the tears. "It was eating away at me that I hadn't done enough to acknowledge him."

Pieta released helium balloons and she wears a pendant around her neck

featuring two angel wings and this inscription: 'An angel in the book of life wrote down my baby's birth, then whispered as she closed the book 'too beautiful for earth'.

A gallery of family photos hanging on her lounge wall has a secret component - inside the top layer of three ceramic hearts hanging alongside is the last scan of each baby.

"I think it's helpful to do something because it's not like other deaths where you've got a grave or ashes," she says. "It's such a silent thing. You've lost something huge but the world goes on; it's not like we've got that funeral or the wake."

Navigating the labyrinthine grief of miscarriage can be a dark journey, but Naomi says the pain does lessen.

"I feel at peace with it now," she says. "You can't change it, and it's a shitty thing that happens, but shitty things do happen in life. At the time you feel devastated and particularly having to deal with it - the having to tell people, and going to have the baby removed, and that's really horrible to deal with. But it does get easier."

Naomi is now pregnant again and though she feels anxious for her unborn baby's survival, her 12-week scan showed no cause for concern and she is determined to remain positive about this pregnancy.

Emily believes she appreciates her daughters more than she might have done if she had not suffered a miscarriage, but stresses that being blessed with three beautiful, healthy girls does not take away the loss of the first and all that was lost with him.

"We want our girls to grow up knowing they had a brother," she states. "He will always be a part of me, and always be a part of my family." □

RECURRENT PREGNANCY LOSS

Recurrent pregnancy loss (RPL) usually refers to the occurrence of three or more consecutive losses of clinically recognised pregnancies. The majority of RPL cases are deemed 'unexplained', but in some cases it can be due to a structural abnormality of the uterus such as a septum, fibroid or polyp, or medical conditions such as severe thyroid disease, diabetes or a thrombophilia (an inherited ability to form blood clots which may be associated with miscarriage). Less commonly, a woman can have a condition called the antiphospholipid syndrome which makes her more likely to miscarry.

In his report Recurrent Miscarriage published in medical journal *The Lancet*, UK obstetrician Professor Gordon Stirrat wrote: "The risk of miscarriage increases with each successive pregnancy loss, but some studies report a pregnancy ending in live birth reduces the risk of miscarriage in the subsequent pregnancy." His report gives the risks as: 14-21% after one miscarriage; 24-29% after two miscarriages; 31-33% after three miscarriages.

TYPES OF MISCARRIAGE

- Very early miscarriage (or biochemical miscarriage) - a pregnancy is detected by blood test but the levels never rise high enough or last long enough for a pregnancy to be detected on scan.
- Missed miscarriage (or missed abortion) - the in-utero death of the embryo or fetus prior to the 20th week of gestation, with retention of the pregnancy for a prolonged period of time. Treatments are: conservative (await spontaneous miscarriage), medical management (tablets taken to induce uterine contractions and miscarriage), or surgery (D&C).
- Threatened miscarriage - develops days or even weeks before the baby is lost with symptoms such as bleeding and cramps. The term "threatened" is used because pregnancy loss does not always follow vaginal bleeding in early pregnancy.
- Incomplete miscarriage - this is when some placenta remains inside the uterus, requiring a D&C or medical management.



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