



stillbirth in australia

when a baby dies...

The death of a baby is shocking and painful. As parents, we hold close to our hearts many hopes and dreams for our baby. When a baby dies, those hopes and dreams slip away. Many parents feel overwhelmed by feelings of confusion, isolation, intense sadness and despair.

If you are a parent whose baby has been stillborn, or if you know someone who has experienced a stillbirth, we offer you our heartfelt sympathy. We recognise the importance of your baby and acknowledge the loss that you are feeling.

While the Stillbirth Foundation Australia does not offer direct bereavement support, it is hoped that the information in this brochure will bring you some comfort by providing you with information about the possible causes of your baby's death and in assuring you of the Stillbirth Foundation Australia's efforts to support research aimed at reducing the incidence of stillbirth.

The Stillbirth Foundation Australia operates to reduce the incidence of stillbirth in Australia by:

- ∞ Funding and encouraging research into stillbirth, and
- ∞ Increasing public awareness about stillbirth



Thank you to Paula and Daniel Benmayor for sharing the photo on the front cover of their first daughter, Isabella, who was stillborn on 26 September 2004.

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The Stillbirth Foundation Australia, the first charity of its kind, was launched by Emma McLeod in October 2005. Olivia, Emma's second child and first daughter, died unexpectedly in utero and was born still on 31 July 2002.

At the time, Emma was shocked and dismayed to discover that so little was invested in researching the possible causes of stillbirth. Emma resigned from her corporate career to establish a charity dedicated to stillbirth with the aim of raising awareness and to help answer why it happens.

Today, the charity represents the voices of thousands of Australian families who have been touched by stillbirth and who seek answers. Since inception, Emma has overseen the fundraising efforts of a growing network of committed volunteers, and the charity has supported the country's premier researchers and universities.

The Stillbirth Foundation Australia is recognised nationally as a leading voice on stillbirth, and strives to deliver current and vital information to the state based health networks. It is a parent-driven organisation which emphasises the opinion that it is the onus of every member of the Australian community, parent or not, to work towards radically reducing the tragic number of stillborn children each year.

'You never get over stillbirth,
you just learn to live with it.'
Emma McLeod



When my daughter Caroline was stillborn, so many people expressed sympathy, but also surprise that stillbirth "still happens." Not only does stillbirth happen, but it is more common than many other complications in pregnancy and far more common than Sudden Infant Death Syndrome.

I didn't know any of that when it happened to me and my daughter. I just felt like I was joining a club I never knew existed, and of which I did not want to be a member.

In just a few generations, we have grown as a society in our understanding that stillbirth is a genuine loss, the death of a person. Gone are the days when stillborn babies were whisked away and the mother sent home with instructions to forget about the birth. Today, we celebrate the lives of these babies, cuddle them, bless them, and often hold memorial services – giving not just mum, but the whole family the chance to mourn the loss.

But where we haven't particularly grown as a society is in our understanding of stillbirth. The rate of stillbirth is largely unchanged, and research into the causes or ways to prevent stillbirth is only just beginning.

Yet research does hold the key. Research into SIDS led to the simple yet effective "Back to Sleep" campaign, which has seen the rate of SIDS drop significantly. Early results suggest there may be some lifestyle and other changes in pregnancy that could similarly reduce the chance of stillbirth.

The Stillbirth Foundation is working to raise awareness of stillbirth and money to fund important research. Thank you for taking the time to read this booklet. Your support could make a lifetime of difference to a family.

The Hon Kristina Keneally MP

what is stillbirth?

Stillbirth is when a baby dies before or during birth and can occur at anytime from 20 weeks until full term (40 weeks) or later. Six babies are stillborn each day in Australia. These deaths are a tragedy. It is disturbing that, in an age of enormous technological and medical advances, the rate of stillborn babies is not declining nor well understood.

Today:

- ∞ 1 baby is stillborn for every 135 live births – this means over 2,000 stillborn babies every year in Australia¹.
- ∞ Each year, 3 million families worldwide will experience a stillbirth², with 2.65 million stillbirths occurring in late pregnancy³. Of these, 1.46 million occur prior to birth and another 1.19 million occur during labour.³
- ∞ For every baby that dies of Sudden Infant Death Syndrome (SIDS), 35 are stillborn in Australia^{1,4}.
- ∞ Globally, stillbirths have only declined by 1.1% each year since 1995².

stillbirth risk factors

Risk factors for stillbirth can be separated into two broad areas – medical or societal.

Maternal medical conditions such as diabetes and high blood pressure, can result in stillbirth. However, in today's modern age of good maternity care, this rarely happens in Australia.

Societal risk factors, as identified in a Literature Review funded by the Stillbirth Foundation Australia, include pre-pregnancy obesity and smoking especially during pregnancy. It is important that any woman who plans to fall pregnant maintains a healthy lifestyle, takes folic acid, stops smoking and loses weight prior to falling pregnant. Older women (over 35 years) and those having their first baby were also identified as risk factors, and whilst these cannot be avoided, women who are pregnant for the first time over the age of 35 years should ensure that they receive good maternity care during their pregnancy.

What are the preventative measures?

Potential interventions for the prevention of stillbirth vary from the time before conception up until labour. Some potential measures, as outlined in a recent series on stillbirth published in leading medical journal *The Lancet*⁵, are:

- ∞ Preconception care to ensure a healthy lifestyle and promote adequate folic acid intake
- ∞ Regular antenatal care including an ultrasound in early pregnancy
- ∞ Folic acid, iron, calcium and vitamin supplementation
- ∞ Fetal monitoring, particularly in regards to fetal movement counting
- ∞ Fetal growth restriction and pregnancy risk screening
- ∞ Early detection and management of diabetes and hypertension
- ∞ Induction of post-term pregnancies as well as consideration of planned caesareans for babies in breech presentation

what causes stillbirth?

We don't always know why a baby dies but there are a range of problems known to either increase risk or be a cause of stillbirth. The following are commonly reported risk factors for and causes of stillbirth in developed country settings like Australia and are ranked by order of importance^{6,7}:

- ∞ **Congenital anomalies:** These describe conditions where the development of the baby has been affected and are present from conception or early in pregnancy. They may involve problems with chromosomes or important structures such as the brain, heart, spinal cord or kidneys.
- ∞ **Premature birth:** 7% of women in Australia deliver their baby preterm. Although the majority of preterm babies now do well with modern obstetric and neonatal care, if the birth is extremely early, the baby can be too immature to survive and can be stillborn. Underlying reasons for preterm birth are not well understood but include infection and maternal medical conditions necessitating earlier delivery.
- ∞ **Problems with the placenta or cord:** A variety of issues may lead to placental problems including conditions such as diabetes and high blood pressure. These can impair placental development and mean the placenta is unable to nourish the baby and can result in stillbirth. Placental abruption is a relatively common cause of stillbirth and occurs if there is bleeding between the placenta and the wall of the womb which can acutely reduce blood supply to the baby. Rarer placental problems such as vasa praevia and fetomaternal haemorrhage can also affect blood supply to the baby. Cord "accidents" are often implicated in stillbirth but the diagnosis should be made with caution as cord problems are often seen in healthy liveborn babies. A baby's death should not be attributed to a cord accident unless there is both evidence of true obstruction and exclusion of other problems⁸.
- ∞ **Fetal growth restriction:** This term refers to babies that do not reach their full growth potential. This is associated with a significant increase in risk for stillbirth with up to half of babies who are stillborn being smaller than expected. It can be secondary to impaired placental function, chromosomal problems with the baby, smoking and maternal medical conditions such as high blood pressure. It can be very difficult to diagnose these at risk babies during routine antenatal care.
- ∞ **Maternal medical conditions:** Pre-existing medical conditions are associated with increased risks of stillbirth. Commonly reported conditions are diabetes, renal disease, thyroid disorders, cardiac disease, systemic lupus erythematosus and obstetric cholestasis. Although regular antenatal care can help reduce the risk of stillbirth, sadly stillbirth can still occur.

- ∞ **Hypertensive disease/preeclampsia:** High blood pressure can be pre-existing or pregnancy associated. It is often associated with poor placental function and fetal growth restriction. It is a major contributor to pregnancy problems including stillbirth and is routinely screened for in antenatal care.
- ∞ **Congenitally acquired infections:** In developed countries like Australia infections that cause stillbirth are more commonly seen in premature babies however can also be a cause at term. Infections known to be causally associated with stillbirth include parvovirus, rubella, listeria monocytogenes, toxoplasmosis and group B streptococcus.
- ∞ **Smoking:** This is associated with a number of adverse pregnancy outcomes and contributes increased risk for stillbirth mainly via poor placental function, placental abruption and fetal growth restriction. There are interventions available to help women who smoke to cease during pregnancy with much of the risk being reduced if they are able to stop smoking by the last trimester. All women attending antenatal care should routinely receive advice and support about stopping smoking.
- ∞ **Multiple gestation:** The stillbirth rate among multiple pregnancies is 4 times higher than singleton pregnancies. This is due both to complications specific to multiple gestation e.g. twin to twin transfusion as well as increased risks of common complications such as advanced maternal age, congenital abnormalities and fetal growth restriction.

There are a number of tests that are recommended following a baby's stillbirth to try and establish the cause. These include blood tests collected from the mother, examination of the placenta, and tissues sent for chromosomal analysis.

One examination that is important that families are offered is called a post-mortem or autopsy. This is a detailed and thorough external and internal examination of the baby. Some parents understandably find this request overwhelming at such a difficult time. It is important to understand that the decision for the examination is entirely voluntary and that there is no pressure for families to agree to a request.

It is equally important to understand that families should be offered this opportunity to discover more information. Experience shows that a post-mortem examination adds important information in up to 40% of stillbirths. The examination is performed in such a way that parents can still hold and nurse their baby following the completion of the post-mortem, which is usually performed within 48 hours of birth.

Finding out we were pregnant was such a beautiful day for Aaron and I. Already the parents of Noah aged 4 and Max aged 18 months, we were excited at the prospect of adding to our family while wondering whether the planning to conceive had brought a little girl into our family. At our 19 week scan, it was confirmed. We were to welcome a much loved little girl into our family. We have wonderful memories of sharing our excitement with family and friends.

Although this was my 5th pregnancy, we didn't have any reason for concern as we already had 2 healthy children. My previous pregnancies were each very different. When I was pregnant with Noah, I was restricted to bed rest from 28 weeks until delivery at 38 weeks, while my pregnancy with Max was very straight forward, also delivering at 38 weeks. Although I suffered extreme morning sickness until 26 weeks with Evie, everything seemed to be going well until 5th August 2009. The day that would change our lives in more ways than one.

I distinctly remember Evie's movements the previous night as she was always extremely active from around 7pm each night.



On the evening of 5th August, after settling my sons into bed I remember thinking I hadn't really felt any movements and sat down for a while to encourage her to move. After an hour and a half of resting and trying to provoke some movement, I called the hospital to arrange a CTG scan. Never for a minute did I think there would be anything to worry about, so I told my husband to stay at home with our boys. Once at the hospital, my concern grew with each minute as I realised they couldn't find a heartbeat. My worst fears were confirmed when my obstetrician was called. Alone and heartbroken, I called my husband to break the news.

Together we made the decision to go home that night, and return the following morning to deliver our daughter. Heartbroken and frightened, we made our way back to hospital to induce labour and meet our longed for baby girl. Once an official ultrasound was performed to confirm she had passed away, we then began the induction at 9am. I had previously had very fast labours, so I assumed that my little girl would be the same. Although there are few words that can explain the emotions you feel when you are giving birth to your "sleeping" child, I wanted to bring her into the world the same way as her big brothers.

At 5pm, we welcomed Evie Angela. The fact that she was born on my birthday, is a gift I will hold dear. At 32 weeks our daughter was beautiful and perfect. Our little angel weighed in at 1,694 grams and 46 centimetres. We spent every minute holding and telling our daughter how much she



was loved and missed. Those few days we spent with Evie have given us wonderful memories to treasure. The day we brought our sons to the hospital to meet Evie was a mix of emotions. They may not completely understand what has happened, but they now have memories and

Each day is a mixture of extreme hurt, sadness and loneliness, but there is also an incredible amount of love for our daughter and family.

photos to remember their sister. Our immediate family also met Evie, telling her how much she was loved. It was important to us to share this time with family, so they too could remember her beauty and have memories of their own.

Each day is a mixture of extreme hurt, sadness and loneliness, but there is also an incredible amount of love for our daughter and family. This journey has brought us closer together as a couple and family. The days since losing Evie have been incredibly difficult, however the memories and the keepsakes keep her memory alive as she will never be forgotten.

“In global health policies, the high burden of stillbirths seems incongruent with global action to prevent them. Stillbirths have been the invisible losses.”²

Stillbirth is typically an under-investigated, commonly overlooked or even ignored health issue. Many parents of babies who die during pregnancy will never get a definitive answer to their question of why their baby has died. About half of stillbirths at full-term remain unexplained.

Currently, stillbirth research is focused on an array of known or suspected stillbirth risk factors like maternal obesity and nutrition, gestational diabetes, anaemia, caesarean sections, advanced maternal age, smoking, alcohol, high blood pressure, sleeping positions, infection, fetal growth restriction and poor, or no access to maternity care, particularly in rural communities where the chances of stillbirth can triple⁹. The Stillbirth Foundation Australia, true to its goal of funding and promoting stillbirth research, supports studies that investigate:

- ∞ risk factors which may predict stillbirths in the later stages of pregnancy when the reasons for stillbirth are frequently unknown
- ∞ known and potential risk factors with a focus on what may be modifiable
- ∞ the functioning of the placenta during the latter stages of pregnancy
- ∞ molecular testing for viral infections
- ∞ how cytomegalovirus infection may be transmitted to the unborn baby as well as preventative measures to stop this from occurring
- ∞ the perception of expectant mothers regarding their baby’s movements in late pregnancy
- ∞ how Obstructive Sleep Apnoea, that is both partial and complete obstructions of the airway while the mother sleeps, can seriously impact on the health and growth of the baby

For more information on the Stillbirth Foundation Australia’s current research projects please access our website: www.stillbirthfoundation.org.au

Stillbirth is a true life changing event and, at the time of a baby’s death, it is hard to imagine that life will go on. But it does, somewhat differently than planned and with new and unexpected challenges.

Many parents are anxious about whether they can ever have a healthy baby in the future following stillbirth. Generally, there is much reason for hope looking forward.

In some circumstances, tests will suggest that there may be increased risks in a future pregnancy, particularly if a genetic cause is found or suspected. At some time within a few weeks after a baby’s birth, it is usual to review all the investigations with your doctor or health care team to discuss what they mean for the future.



The Stillbirth Foundation Australia needs your help to continue funding stillbirth studies in new directions and, hopefully, to raise \$1 million each year to produce greater advances in stillbirth research.

My pregnancy was a dream. I was the happiest and healthiest I'd ever been. My due date passed without a flutter. But at 1am the next day, labour started. Later, we went to hospital but were told labour was not established, and much to our disappointment, we were sent home.

We then spent three days at home, waiting for my body and my baby to get the show on the road. Labour was slow, and confusing. Not at all what I'd expected.

Four days overdue, we went back to hospital for a check up. As we left, I realised I hadn't felt our baby move for about half an hour. We were worried, but tried not to make too much of it. When we got to hospital the worst was confirmed. Our baby had died. The world as we knew it ended in that moment when we heard the words "I'm sorry" and saw that horrifying "still" ultrasound screen.

The next day I was induced and gave birth to our eight pound daughter at 4.35pm. She was perfect – with my nose and Daddy's toes. We named her Hope, and spent the night with her trying to pour a life time of love in to the briefest of moments. We thought we might die from our broken hearts.

We waited nine long months for her. We decorated a nursery. Bought a pram. Installed the car seat. Washed her clothes. We were so ready, only to have her snatched away when we thought we'd past the finish line.

The world as we knew
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that horrifying "still"
ultrasound screen.



The next day we returned home empty-handed to our quiet home, littered with evidence a baby was supposed to be with us. Five days later, her funeral was held. 200 came to say goodbye to the baby girl they never met.

The months after our daughter's death were the most intense and gut-wrenching of our lives.

The silence from some family and friends was deafening. The harmless but insensitive comments from well-meaning people cut deep. Everything that was once good in our lives was

so devastatingly wrong. The pain overwhelmed us. It is a pain like no other, and we could never wish this on anyone.

In those early days, we wondered how on earth we'd ever go on. Parents, yet not. Childless, yet not. We had no idea where we fit in anymore.

It was so difficult to learn just how common stillbirth was, especially when it is not talked about during pregnancy or in society in general. But we hope the wonderful work the Stillbirth Foundation do can help shed some light on this tragically silent topic.

As a parent-driven organisation, the Stillbirth Foundation Australia welcomes donations in memory of babies who have been stillborn. Many families, their friends and work colleagues gain comfort in knowing that their contribution will support research which may ultimately reduce the incidence of stillbirth.

please help make a difference

There are a number of ways you can help the Stillbirth Foundation Australia achieve its goal to reduce the high incidences of stillbirth and ultimately save babies lives. You can:

- ∞ Make a tax deductible donation
- ∞ Raise funds for the Stillbirth Foundation Australia through a race, ride, walk or by holding your own event
- ∞ Request that friends and family donate to the Stillbirth Foundation Australia in memory of your baby at a celebration such as a birthday, anniversary, wedding or christening
- ∞ Donate goods and services so that the Stillbirth Foundation Australia can continue to operate at minimal expense
- ∞ Join a fundraising committee or volunteer to assist at a Stillbirth Foundation Australia event
- ∞ Attend a Stillbirth Foundation Australia event with friends and family

Should you have any questions relating to the Stillbirth Foundation Australia, please do not hesitate to contact our office:

Stillbirth Foundation Australia
PO Box 9
Willoughby NSW 2068
Telephone: 02 9967 3229
info@stillbirthfoundation.org.au
www.stillbirthfoundation.org.au



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donation slip

Thank you for your support of the Stillbirth Foundation Australia. Your donation will directly assist us in our aims to reduce the incidence of stillbirth by funding and encouraging research into stillbirth and increasing public awareness about stillbirth.

My Details

Dr/Mr/Mrs/Miss/Ms _____

Address _____

Suburb _____ Postcode _____ State _____

Telephone _____ Email _____

Please do not include me on your mailing list

I would like to donate: \$500 \$250 \$100 my choice \$ _____

My donation is made in loving memory of: _____ DOB _____

Payment Details

Please make cheque/money order payable to Stillbirth Foundation Australia Trust

OR

Debit my Visa Mastercard AMEX

Card number _____ / _____ / _____ / _____ **Total \$** _____

Cardholder's name _____

Signature _____ Expiry date ___ / ___ CCV _____

OR

EFT to the following bank account —

Account name: Stillbirth Foundation Australia Trust | Bank: Westpac Banking Corporation

BSB: 032 123 | Account number: 246445 | Customer reference: Your full name

Once you have completed this form, please return to:

Stillbirth Foundation Australia
PO Box 9
Willoughby NSW 2068

Stillbirth Foundation Australia ABN 86 132 740 937 as trustee for Stillbirth Foundation Australia Trust ABN 35 823 795 120

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Reviewers:

Sheila Bryce-Sim MAASW

Social Work Clinical Manager, Royal Hospital for Women

Dr Adrienne Gordon MBChB MRCP (UK) FRACP MPH (Hons)

Clinical Senior Lecturer, University of Sydney

Professor Caroline Homer MScMed(ClinEpi) PhD

Director of Centre for Midwifery, Child and Family Health & Director of Midwifery Studies, University of Technology Sydney

Emma McLeod OAM BPharm (Hons)

Founder and Director Stillbirth Foundation Australia

Professor Jonathon Morris MB ChB MM FRANZCOG DDU CMFU PhD

Associate Dean of Sydney Medical School, Northern, University of Sydney

Deborah de Wilde OAM BSW RGN CM

Obstetric Social Worker

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