The death of a child at any time is a devastating experience for parents, with lifelong physical, psychological and spiritual sequelae. The death of a baby before birth presents its own particular challenges. This article is written by mothers whose babies have died. Our daughters, Olivia and Annie Rose, were stillborn at 36 weeks after uneventful pregnancies 15 years apart. In this article we describe the reality of stillbirth expressed by parents in sadness over their lost hopes and dreams and in the loss of a social identity that would validate the individuality and significance of those little lives. Over the last 10 years, we applaud the improvement in and the more humanised approach to the care of stillborn babies and their parents; however, concern now exists around the levels of awareness about stillbirth in the community, before, during and after any pregnancy.

“I’m sorry but your baby has died” are the hardest words for any parent to hear. With stillbirth, these words introduce parents to a death and grief that is not well understood and is poorly accepted by the community. Stillbirth is emotionally complex, with long lasting symptoms of grief and significant struggles to find meaning 1. Stillbirth is an event that happens often completely unexpectedly to a happy couple, who then commence a journey travelled without consistency of care that is typically far removed from any previous life experience. In such circumstances, much information and support is needed from the medical community, family and friends.

In Australia, one in every 140 babies is stillborn; in the scheme of things, stillbirth is a relatively common form of death (Table 1) 2,3. In an age of enormous medical and technical advances, it is surprising that the number of stillborn babies has not reduced over the last decade. We live in an age of great technology and information; however, stillbirth remains an event cloaked in mystery. In most cases, the first time a family hears of stillbirth is when it happens to them.

A plethora of extreme emotions is felt at the time a baby dies – incomprehension, disbelief, intense sadness, crying, anger, anxiety, guilt, loneliness, fear, grief, love, joy and pride. The emotional and physical shock and trauma associated with stillbirth requires personal sensitive care. It is a confusing time; not only does one mourn the death of their baby and ask why did their baby die, but parents will also wonder and marvel at the child they have created. Parents need privacy and information. There are many considerations, including what they will experience during the birth, pain, blood loss, lactation, along with guidance and information about seeing their baby, registering the birth, planning the funeral, as well as life beyond this time.

The first time parents meet their baby, he or she is dead; this may be the first time they see a dead person. Parents may feel frightened about how their baby will look 4 and may find it challenging to accept that their baby has really died. They may need assistance in both facing and separating from their baby 5. Although the value of parents seeing their stillborn baby is still debated, the choice is for the family to make.

Table 1. Deaths in Australia 2005 2,3.

<table>
<thead>
<tr>
<th>Number</th>
<th>Cause of death in Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>2946</td>
<td>Men died from prostate cancer</td>
</tr>
<tr>
<td>2736</td>
<td>Adults died from breast cancer</td>
</tr>
<tr>
<td>1979</td>
<td>Babies were stillborn</td>
</tr>
<tr>
<td>1273</td>
<td>People died from skin melanoma</td>
</tr>
<tr>
<td>884</td>
<td>Women died from ovarian cancer</td>
</tr>
<tr>
<td>87</td>
<td>Babies died from SIDS</td>
</tr>
</tbody>
</table>

Under the Microscope
Stillborn babies are born into a void of silence and into the love and desperate longing of their parents. Parents love their stillborn baby as they do their other children. Yet a stillborn baby, and to an extent its family, is defined by the word stillbirth which in itself can bring a conversation to an abrupt halt.

Parents must learn to live with their loss in a society that defines the value of a person through life. Many bereaved families, and in particular mothers, struggle with this for many years. Despite the fact that stillborn babies do not breathe, their existence is very real to their parents, who are left with unfulfilled plans, hopes and dreams for their future lives. For many parents, creating an identity around their child and gathering mementos of their brief time together is enormously important.

Whilst there have been great advances in the care of stillborn babies and their families over the last 20 years, consistency of care remains an issue today. The care received by families whose baby is stillborn varies greatly between hospitals and staff, and is dependent on the skill, experience and empathy of the caregivers. Caregivers need to support parents in moments of chaos and at other difficult times, while knowing that their every action and piece of advice will be remembered in clear and accurate detail by the parents. Caring for families who have experienced the stillbirth of their baby is challenging and demanding for the medical, nursing and allied staff.

Once trust is established, parents value the guidance of caregivers. Many parents speak fondly of the facilitated care and support they received during the precious time spent with their stillborn baby and will forever treasure this memory. There is no fear, just love and a desperate longing to cherish and get to know this beautiful person. The short period of time spent with their baby must give opportunity and allow for every detail to be etched in each parent’s heart and mind. To have the opportunity to collect mementoes, such as locks of hair, footprints and handprints, take photographs and to bathe, dress, wrap, kiss, and introduce him or her to family and friends is important for many bereaved families.

Loneliness and isolation are two very great emotions that parents of stillborn babies experience, along with intense pain and sadness. These are felt at the time of the birth and thereafter, with some parents forever reporting a sense of isolation. Whilst there is no evidence from randomised controlled trials that there is or is not a benefit from providing specific psychological support or counselling after perinatal death, meeting with others is anecdotally beneficial for many families.

Death is not accepted well or wholly in today’s western society, and the death of a baby is even more challenging for family and friends, particularly if that death is unexplained. Condolences and suggestions that it is “God’s will” or “not the right time” are not supportive for the grieving family. Parents need to be able to normalise and comprehend their grief and loss, and the task of educating friends and colleagues about stillbirth is an additional and unfair stress. The best way to describe stillbirth and to make it real has not yet been elucidated or promoted. Perhaps the use of the more accurate term, “deadbirth”, coined by an 8 year old boy when describing his little sister to his friends, is more informative and honest.

At the time of their baby’s birth, families wish to know why their baby died and most will desire to save others from living the same tragedy. For many families, the cause of their stillborn baby’s death will never be determined, despite a full post mortem investigation. Consenting to an investigation of their baby’s body is unthinkable for many parents and the guidance and expertise of senior, knowledgeable carers is required. Any decision made at the time of a baby’s death is challenging; even normal everyday decisions are not easy such as when to take a shower, have a drink or eat! Therefore, the monumental decision to allow investigations on their baby can only be made with the provision of accurate, honest information about every aspect of post mortem. All examinations of a baby’s body must be conducted with dignity and respect of both the baby and the parent’s values. Results must be provided in a timely and sensitive manner to parents.

Today, the collective community does not know, yet should, what families learn at the time of their baby’s death. The facts about stillbirth, including the incidence and what is being done to reduce it, as well as risk factors and support services available, are important public health messages. The death of a baby is a massive life changing event and parents, along with health professionals, must work together to reduce the stigma of stillbirth. It is not a scary word. For us, stillbirth describes two very real, beautiful and beloved little girls who have entirely shaped our lives and those of many others.

References

Guidelines for Clinicians: Perinatal Mortality Audit Guideline incorporating Psychological and Social Aspects of Perinatal Bereavement can be found at http://www.psnzpmnsm.org/guideline.html

Emma Kirkwood’s second child, her first daughter, Olivia, died unexpectedly in utero and was born on 31 July 2002. At the time, Emma was amazed and disturbed to discover that little funds were being spent on stillbirth research and therefore resigned from employment within the pharmaceutical industry to establish the Stillbirth Foundation in 2005. Today, on an entirely voluntary basis, Emma runs the Stillbirth Foundation which operates to reduce the incidence of stillbirth in Australia through funding in addition to encouraging research into stillbirth and increasing public awareness about stillbirth.

Ros Richardson is the General Manager of SIDS and Kids NSW. Ros is a bereaved parent and has a background in nursing and public health. Her service provides support for families who experience the death of their baby or child during pregnancy, birth and infancy. Ros has particular interest in access to care and support for bereaved families, and in increasing awareness and preventative public health campaigns in perinatal and infant death.