



# Hand in Hand

**sids** and **kids**<sup>®</sup>  
ACT

Edition 1, 2010 —  
Mother's Day

The newsletter of SIDS and Kids ACT Bereavement Support Services

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## Thinking of you on Mother's Day

WELCOME to our first edition of *Hand in Hand* for 2010, and our warmest wishes to all our mums and grandmothers this Mother's Day.

As one of SIDS and Kids ACT's new Bereavement Services counsellors, I was impressed with what a great resource a newsletter can be for bereaved families, and found my hand going up to make sure it goes out each Mother's Day, Father's Day and Christmas. I'd like to thank those of you who contributed in any way to this edition and encourage any reader who discovers a story, poem or article they found helpful to use our newsletter as a way of sharing it with others.

Our counselling team — Mandy, Fiona and me (Janine) — each feel privileged to be working in an organisation where there is such a long history of compassion, respect and hard work for bereaved parents. Like your former counsellors — Jenny and Helen — we will be doing our best to meet your needs as we step into the roles they performed so well. Please feel free to call for a chat any time, or let us know if we can pay you a visit. Due to the generous donation of two new cars to our team, we are feeling particularly mobile and just as happy to visit you, as we are to have you visit us.

It has been a real pleasure to get to know the members of our peer support program. Our peer supporters are bereaved parents who have been willing to undertake a significant amount of training in order to provide compassionate and effective comfort for those who seeking help with their own grieving process. For those who would like to receive more information about these wonderful mums and dads, please call Fiona, to learn more about the valuable service they provide.

I have asked Mandy to introduce herself



to you in this issue, and Fiona and I will do the same in the next two issues.

Inside this issue you will also find tips for "getting through" Mother's Day from Erin, one of our peer supporters, and a moving speech that another peer, Lyndall delivered at our fund-raising ball in March. Attendees were very moved by Lyndall's courage in describing her family's story.

By the time our next newsletter comes out, we expect to be busy working from our new offices in Chifley. We look forward to the new possibilities a ground floor premises allows us to provide for parents with children, and are open to any suggestions any of you may have about what is most important to you when you visit us.

As many of you already know, it is an important part of SIDS and Kids' philosophy to provide support for all those affected by the death of a child, including grandparents and siblings, and we hope to make our new offices a welcoming space for parents, family members and friends of all ages.

Warm Regards,  
Janine Brissett,  
Bereavement Support Team.

## May 2010

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# Tools to help you get through Mother's Day

ONE of the most difficult days to get through following the loss of a child is Mothers' Day.

Reminders of this special occasion are everywhere. Stories, magazines, and flower shops all have advertisements and brilliant displays showing ways to honour mothers.

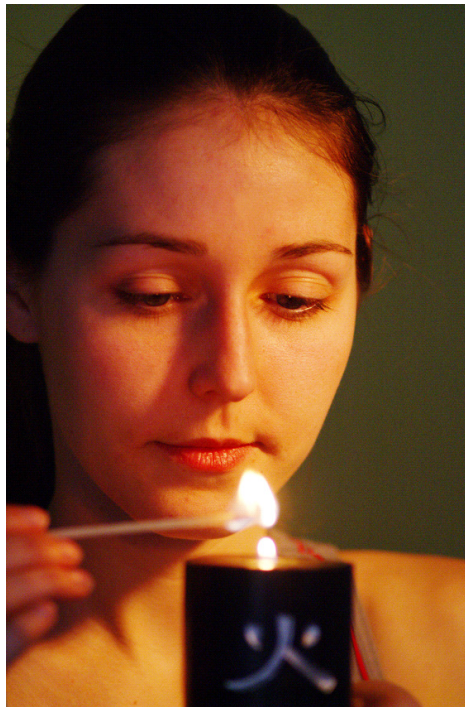
For a mother that has gone through the pain of having a child die, these reminders continue to add to the pain already felt by a mother's heart that has been left aching for the child she loves so much.

There is no way to completely avoid Mother's Day, but there are things that can be done to lessen the pain.

Often, the most important thing a mother can do is to communicate her feelings to those who are part of her support system. Don't be afraid to be honest. Come up with a plan that best suits you and share that plan with others so that they know how to best help you get through Mother's Day.

It is vitally important for a mother to take care of herself physically by eating nutritious meals and by keeping herself well hydrated in the days leading up to Mother's Day. Also, it is important to get as much rest as possible.

Grief work is very real and requires lots of attention. Grief is a drain



It can be comforting to do something to honour the memory of your child on Mother's Day.

Many mothers have found that journaling their thoughts is healing for Mother's Day. Others have found that it helped to plant a special flower in memory of their child. Some mothers want to be acknowledged in church on Mother's Day, even though their child is not here with them.

Others choose to avoid all social gatherings on Mother's Day, and instead choose to take a quiet, reflective walk. Do whatever is best for you. Remind yourself often that you can make it through Mother's Day. Do all that you can gently and in a way that is healing to you. Remember that tears are cleansing and are not a sign of failure.

By preparing for Mother's Day you are paying attention to your grief work before the day arrives. You will find that when Mother's Day comes and you have a plan in mind, you will experience less grief and those around you will be able to support you through the day that has been so heavy on your heart.

Most times, the anticipation is far worse than the actual day. With some thought and careful planning, you will make it through Mother's Day and you will be one step closer to finding healing in this difficult journey called grief.

*(Hinton 2006, Sids and Kids WA.)*

## A day to cherish and celebrate your partnership and your child

WHILE every bereaved parent is likely to have experienced the challenges that Mother's and Father's Day present, some parents find that these special days also offer an opportunity for healing.

While you and your partner have shared an incalculable loss, the value your intimate partner holds for you may have been overshadowed in the long and painful days of grief since your child died.

A question you may wish to reflect on is, "Is there a way I can honour this person for what s/he means to me,

minus the baby, as well as the person that helped create our precious child?"

Mother's Day gives fathers the opportunity to offer a great deal of comfort and strength to the mother of their child, as well as lifting your spirits as a couple as you reunite spiritually and emotionally.

Though your child may never have taken a breath on its own, or only lived for a short time: this holiday is a day to cherish and celebrate your partnership, the parents you are forever, and your child.



Mother's Day gives fathers the opportunity to offer a great deal of comfort and strength to the mother of their child.



## Erin shares memories of her first Mother's Day

*Erin is a member of our Peer Support Program. She is one of a number of mothers and fathers who offer support to our members.*

**Q: Do you remember a particularly comforting thing a friend or family member said or did for you on Mother's Day?**

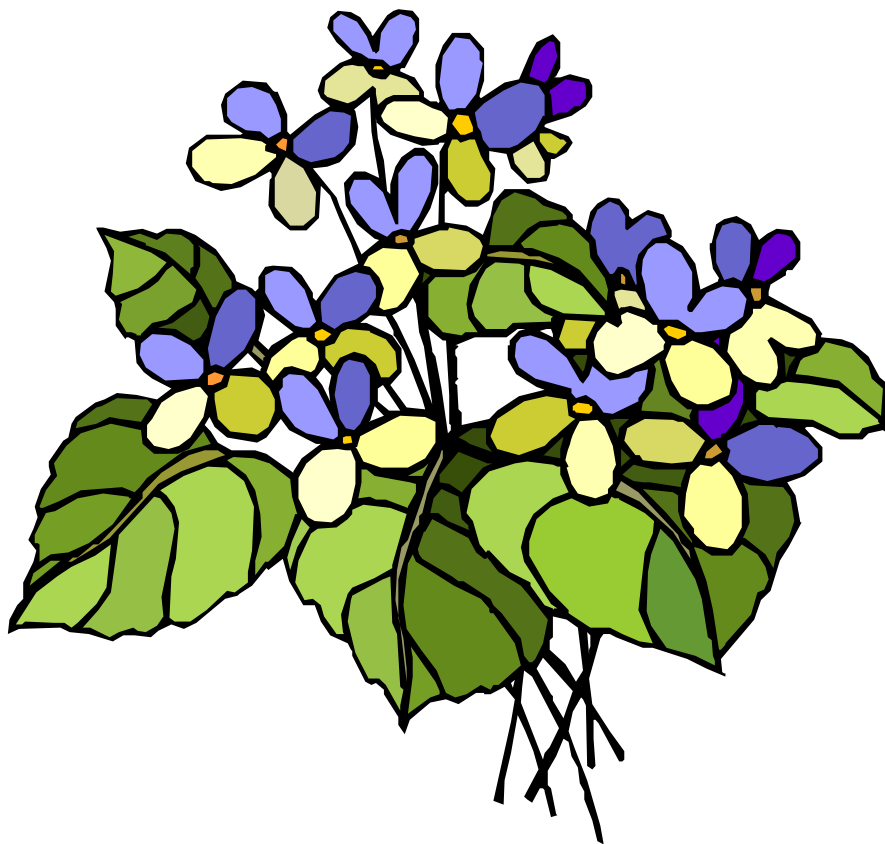
**A:** Just "Happy Mother's Day!" Just acknowledging that I am a mother even though my child was not there on my first Mothers' Day. Since having children it has always been nice to see my son's name on the card along with his brothers and sister.

**Q: Is there a special thing you have done for yourself on Mother's Day since your baby or child died?**

**A:** It is very much a 'me time' as it is still difficult not having my child with me. I usually do my own thing to allow a meltdown if I need it. My mother is very understanding of this. She too finds it difficult when she thinks of the grandchildren she should have around her.

**Q: Do you have any words you would like to say to a newly bereaved mother whose first or only child has died.**

**A:** My first Mother's Day without my son I had nothing planned. I didn't feel like I had to be somewhere so I had no expectations on myself. Be kind and easy on yourself. Do what feels right for you even if that means not getting out of bed. People tend to say it is just a marketing ploy ... that it is a cruel and horrible reminder of your loss and the dreams you had of spending Mother's Day with your child or children. It is hard, but if you want family or friends to acknowledge the day it helps to let them know that you're feeling down about the day coming up and you're worried you will get forgotten as a mother too. It helps you and your family or friends on the day and it is a good way to avoid disappointment as they may not know if you want to be acknowledged or not.



**Q: Can you tell us about a Mother's Day when you had the courage to ask a partner, friend or family member what was important for you on Mother's Day?**

**A:** My first Mother's Day was spent childless and I found the lead up very difficult with TV ads and other advertisements being thrown in my face. I had dreamt that my first Mother's Day I would be having breakfast in bed and I would get an African violet and a home made card. Just what I did with my mother. I had told my husband and parents that prior to Mother's Day. I think they could tell from my despair how much this day was going to hurt. I woke up that morning and my husband had surprised me with what I spoke about. It wasn't what I wanted, I wanted my son back but the Mother recognition was warming and the African Violet and my home made-card made by Daddy.

**Q: Can you let us know why this request was so important to you to have the person respond to your request.**

**A:** My first Mother's Day was an

especially painful time because I had no living children to share it with. Anything that got me through the day no matter how minor or ridiculous was important.

**Q: Would you like to share a special way you commemorate or connect with your baby who died on Mother's Day?**

**A:** I have my son's ashes at home. I usually wake up and lie in bed and hold them till I get a hold of the day. Being close to him is important to me. Every year my husband makes a card that has my son's hand and foot prints in it for me. This is a very special tradition for me and my husband and I hold these cards very close to us. It is a way to make him feel real again on the day. Finally I get that African Violet which, when I look at it, reminds me of being a mother to my son and my three living children.

***If you would like more information about our Peer Support Program, please contact SIDS and Kids ACT on 6287 4255***



# A grandmother reflects on her grandson's stillbirth

From *Quietus, A Story of Stillbirth* by Jean Gunderson and Donna Harris.

In this excerpt of her book, Jean Gunderson describes her experience when her much awaited grandchild was stillborn. Having worked previously with children with a multitude of needs, the absence of love in their lives had always been a source of intense grief to her. As she awaited her own grandchild's birth, she had felt such hope, knowing that this little one would be born to nurturing parents, prepared to offer him the security of loving arms, soothing voices, stroking and cuddling.

WE had this dream, my daughter and I. She loved the life blossoming inside her. She intuited the baby was a boy and talked about his character and his looks; how welcome he would be, what he would do with his life, and how their family would change. Later, he became Lief Olaf, her little son.

I shared his life with her as we walked together around the nearby lake. I knew he'd be a unique grandson born of devoted parents. I had so many plans for sharing life with this new child.

*"Death was absolute. We would no longer hold him."*

My dreams collapsed, too, when Lief was stillborn. I walked into the birthing room and became shrouded in the pain of my daughter. Memories of my anticipation of her birth, years ago, the love I felt for her when she was born, her 28 years as my child inundated my being and I felt an overwhelming grief.

She was propped up in bed, so helpless. Her dead baby lay in the bassinette. The quiet was intense. Jean, usually in command and control; Jean, nurse and caregiver, so needy now! She was facing toward the bassinette. Our eyes met as I entered the room and turned toward the baby. I rocked in my grief. I held Lief and rocked back and forth as if I

could make him breathe. The nurse asked me if I'd like a rocking chair and I said, "No", thinking how absurd to be rocking a dead baby. Immediately my body began rocking him again and the nurse slid a rocking chair behind me. I sat in it and cuddled and rocked Lief for two hours while I talked and cried with Jean. I walked to Jean's bed and we held him together and cried inconsolably.

Later the nurse suggested I accompany Jean to her sitz bath so she could cry with the flow of the water. This scene will always be imbedded in my memory, and I am grateful for the knowledge and understanding of the nurse. I helped Jean into the bath, washed her back, and cried at my helpless inability to wash away the pain for my daughter.

Hours later, Jean and I together dressed Lief, knowing we'd soon have to let him go. I still felt his perfect little arms would reach up to us and his little legs would move. We cried as he was taken from the room.

Death was absolute. We would no longer hold him.

Several times after Lief's death, as Jean and I walked or went to church together, people expressed their sympathy to her. No one said anything to me. My loss was never acknowledged. As I listened to people talk with Jean, my heart felt the loss of Lief as surely as if he were my own. I hurt for the loss of my grandchild. I needed to walk away. I knew people were not aware of my grief.

One of my unique experiences was the deluge of losses that surfaced with Lief's death. I felt my daughter's pain. I relived my own two past miscarriages, my brother's death in Vietnam, my father's death, grandparent deaths and personal losses that ran across my memory unceasingly. Tears would come unexpectedly while on a walk, in the car, and on the job. Nearly a year after Lief died I visited my hometown. The losses surfaced again as I entered the church of baptism and childhood/adult years for three generations of my family."



## A grandmother's tears

*A mother's poem to her daughter, a year after her grandson's stillbirth.*

Jean, my Love  
my tears flow yet  
in love for you  
at this midnight hour  
away from the fishbowl existence,  
free to keen  
away from the gape of outsiders.

Do you know ...  
... one year later  
my heart is squashed with sorrow.  
Incessant awareness of Lief's  
loss abounds  
I reactivate the memory of my  
pregnancy with you...  
the intense desire for your being.  
Has ever a baby in the womb  
felt more loved and desired?  
The joy of your birth...  
Prayers of gratitude.

We've been together you and I  
from womb to womb  
your love is my love  
your loss is my loss  
God, assuage her pain ... I can't.



## Living With Loss: Bereavement Support

# ‘Having a thought’ versus ‘buying into a thought’

THERE'S nothing wrong with thinking. Language and cognition have allowed humans to be enormously successful in the evolutionary sense, and people who are good at them do well in many professions as they reshape the world in many positive ways.

The problem arises when we can look only “from our thoughts” rather than “at our thoughts.”

This is particularly true for those experiencing internal, emotional pain because it is the thoughts that attach themselves to our experience of pain, that are far more entangling and debilitating than the actual experience of a distressing emotion.

To understand the difference between pain and suffering, it is important to recognise the difference between painful emotions, and the disturbing thoughts that can accompany them, and lead to ongoing suffering.

For a period of time, it is normal and understandable that those experiencing significant loss will have thought such as “This pain is unbearable”, or “I will never be happy again”.

The problem for some people, however, is that they unconsciously accept their thoughts as truths, and forget to examine them objectively.

Before they realise it, they have become enmeshed with a disempowering thought, and it has become their reality.

This is an important understanding for bereaved parents, who are facing what many would describe as the ultimate pain.

How is it possible that a person could continue to live a vital and meaningful life in the face of such loss and sadness?

Counselling research shows that it is that the choices we make in relation to our thoughts that will have a far more significant impact on our future lives than the enormity of our loss.



Counselling research shows that the choices we make in relation to our thoughts will have a significant impact on our future lives.

It will not be the degree of pain a bereaved person feels that will determine their ability to go on and live a meaningful life, nor even the degree of love and attachment she or he felt for a loved one who dies.

What matters more than both these things is that person's capacity to work through both the thoughts and feelings of their grief: allowing even the most painful feelings to ebb and flow, but noticing and questioning the validity of their thoughts.

To understand this a little better, let us consider the sadness of a woman whose child has died.

Because the pain she feels is the most intense she has ever experienced, the thought arises that it will never subside, and life has lost all its meaning.

At this point, she may become entangled in her thoughts, succumbing to them in depression, or struggling endlessly to distract herself from the kind of future her thoughts have presented her with.

In either case, it is the thoughts, and not the feelings that stand in the way of her healing.

While her feelings of sadness have given her valuable information about

how important her child's short life has been to her, it is the thoughts that have her doubting herself.

Fortunately there is another way for this mother to deal with her debilitating thoughts.

Rather than buying into the ideas or images they deliver of a miserable future, she can catch herself when her thinking process begins.

Rather than noticing a disturbing thought at the end of that process, and giving it the status of “truth”, she starts to recognise herself as a part of the thinking process.

Gradually, over time as she becomes more familiar with the way her thoughts and feelings overlap, she realises that she has choice about which thoughts she allows to influence her.

Even when thoughts creep up unexpectedly and frighten her, she comes to recognise the judgments they deliver as simply words and ideas, that she is free to question and replace.

It is up to her now, and not her thoughts whether she moves closer to or further away from life.

— Janine Brissett

*[Information from Stephen Hayes, Get Out of Your Mind and Into Your Life, (2005)]*



## Research update

### The Australian Institute of Health and Welfare released *Australia's mothers and babies 2007 in December 2009*

IN 2007 289,496 women gave birth to 294,205 babies in Australia. This included:

- 292,027 live births
- 2,177 fetal deaths

The perinatal death rate was 10.3 per 1,000 births (equal to previous year), which equates to 3024 babies.

The fetal and neonatal death rates were 7.4 per 1,000 births (equal to previous year) and 2.9 per 1,000 live births (previous year 3.0 per 1,000) respectively.

The state and territory fetal death rates ranged from 6.3 per 1,000 births in Western Australia to 9.6 per 1,000 births in Victoria.

The baby boom continued, with 12,036 more births (4.3 per cent) than reported in 2006 and 14.4 per cent more than in 2004.

The average age of women who gave birth in 2007 was 29.9 years, a year older than in 1998 and more than 14 per cent of first-time mothers were 35 or older, compared with 9 per cent in 1998.

### ACT figures

In the ACT a total of 5535 babies were born. This included:

- 5495 live births
- 40 fetal deaths

The perinatal death rate for the ACT was 11.6 per 1,000 live births.

The fetal and neonatal death rates were 7.2 per 1,000 live births and 4.4 per 1,000 live births respectively.

### Perinatal death (includes fetal and neonatal deaths)

Of the 3024 perinatal deaths, 72.0 per cent were fetal deaths. Perinatal death rates varied by socio-demographic, maternal and pregnancy risk factors. Young maternal age, maternal Indigenous status and multiple pregnancy were associated with higher rates of perinatal deaths. The leading category of perinatal death was

congenital abnormality (23.5 per cent). For term single pregnancy births the leading categories of perinatal death were unexplained antepartum death (25.3 per cent), congenital abnormality (16.7 per cent) and hypoxic peripartum death (14.0 per cent).

### Making Stillbirths Count, making numbers talk

(Froen JF, Gordijn SJ, Abdel-Aleem H, et al. *Issues in data collection for stillbirths. BMC Pregnancy Childbirth. 2009 Dec.*)

FREDERICK Froen of the Department of Genes and Environment, Division of Epidemiology at the Norwegian Institute of Public Health in Oslo and colleagues, which includes Vicki Flenady of the Mater Research Support Centre in Queensland, state that: "Stillbirths need to count. They constitute the majority of the world's perinatal deaths and yet, they are largely invisible."

Simply counting stillbirths is only the first step in analysis and prevention.

To guide efforts to prevent stillbirths and improve quality of care there is a need for information on:

- Timing and circumstances of death;
- Associated conditions and underlying causes;
- Availability and quality of care.

The authors:

- Assess how different definitions and limits in registration affect data capture;
- Discuss the specific challenges of stillbirth registration, with emphasis on implementation;
- Identify what data need to be captured;
- Suggest a dataset to cover core needs in registration and analysis of the different categories of stillbirths with causes and quality indicators;
- Illustrate the experience in stillbirth registration from different cultural settings;
- Obtaining high-quality data will require consistent definitions for stillbirths, systematic population-based registration, better tools for surveys and verbal autopsies,

capacity building and training in procedures to identify causes of death, locally adapted quality indicators, improved classification systems, and effective registration and reporting systems.

- Point out gaps that need attention in the International Classification of Diseases and review the qualities of alternative systems that have been tested in low- and middle-income settings;

### Nurses' attitudes towards perinatal bereavement care

(Chan MF, Arthur DG. *J Adv Nurs. 2009 Dec*)

MOON Fai Chan and David Arthur of the Alice Lee Centre for Nursing Studies at the Yong Loo Lin School of Medicine at the National University of Singapore conducted a questionnaire study among with 185 nurses and midwives to explore the factors associated with nurses and midwives' attitudes towards perinatal bereavement care.

The authors note that caring for and supporting parents whose infant has died is extremely demanding, difficult and stressful. In some situations nurses may experience personal failure, feel helpless and need to distance themselves from bereaved parents because they feel unable to deal with the enormity of the parental feelings of loss.

Regression models showed that nurses/midwives with religious beliefs and those with more positive attitudes to the importance of hospital policy and training for bereavement care were statistically significantly more likely to have a positive attitude towards perinatal bereavement care.

Nurses emphasised their need for increased knowledge and training on how to cope with bereaved parents and requested greater support from team members and the hospital.

The authors concluded that bereavement counselling education and preceptorship supervision are recommended to reduce this stressful experience, increase the confidence and expertise of novices, and lead to increased quality of care for bereaved parents.



# Invitation to attend international conference



AS a member of the conference organising committee it is a pleasure to be able to invite you to register for the joint International Stillbirth Alliance (ISA) and International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) on October 8, 9 and 10 this year.

The conference, *Precious lives: global collaboration in stillbirth and*

*infant death* aims to enhance international collaboration in addressing the global loss of lives through stillbirth and infant death.

It is only through the collective efforts of health professionals, researchers, support services and bereaved parents that the loss of these precious lives will be reduced and the support and care of families suffering this loss will be improved.

SIDS and Kids Australia, representing ISPID, and the Australian and New Zealand Stillbirth Alliance (ANZSA), ISA's regional office representing ISA are both honoured to be co-hosting this exciting event being held at the Masonic Centre in vibrant Sydney.

The program will bring together world class researchers, health

professionals and families from across the globe to share new knowledge and initiatives and to build collaborations towards our common goals.

Registration is now open through the Conference website.

You can find out more information on the conference and social programs and register at [www.isaispid2010.com](http://www.isaispid2010.com)

There is a concessional rate for bereaved parents of \$495 for the three days if you register before May 31, 2010.

We look forward to welcoming you to Sydney in 2010.

Karen Faichney  
(On behalf of the organising committee)

## More mobile than ever, thanks to Kia sponsorship deal

SIDS and Kids ACT, Hunter and NSW have entered 2010 with much excitement as KIA Motors welcomes us into their ambassador program.

In 2010, KIA is generously providing KIA Soul vehicles to all three offices to help our teams run our programs, services and outreach.

ACT's chief executive officer, Karen Faichney, says: "through our research we understand that parents who have experienced the unimaginable loss of their baby or young child are best supported in a comfortable and familiar environment.

"The generous provision of these six cars from KIA will enable counsellors and education staff from SIDS and Kids ACT, Hunter and NSW to more effectively support bereaved parents in their homes.

"It also allows us to provide further education to individuals, community groups, health and other



SIDS and Kids counsellors and educators will soon be getting around in sporty new Kia Soul cars, thanks to the generous support of Kia Motors.

professionals in their own communities," Karen said. This relationship with KIA would not have been possible without the valuable support of Jo Struck, a bereaved

parent and SIDS and Kids NSW supporter. Thank you to Jo and everyone at KIA Motors for your generous support.



## Poetry or prose — an important step in finding solid ground

JOHN Keats, the English poet, is regarded by many as one of the most sensitive and emotionally intelligent people in history.

He was only 26 years old when tuberculosis brought him to his death bed, and while his physical pain was great, far more difficult for him was the separation from the woman he loved — Fanny Browne.

In a letter to his friend just four months before his death, he wrote: “I can bear to die — I cannot bear to leave her! Where can I look for consolation or ease? I fear there is no one who can give me any comfort.”

In his next and final letter to a dear friend however, he still has his good humour, and makes a simple but important statement: “You must bring your philosophy to bear, as I do mine, really, or how should I be able to live?”

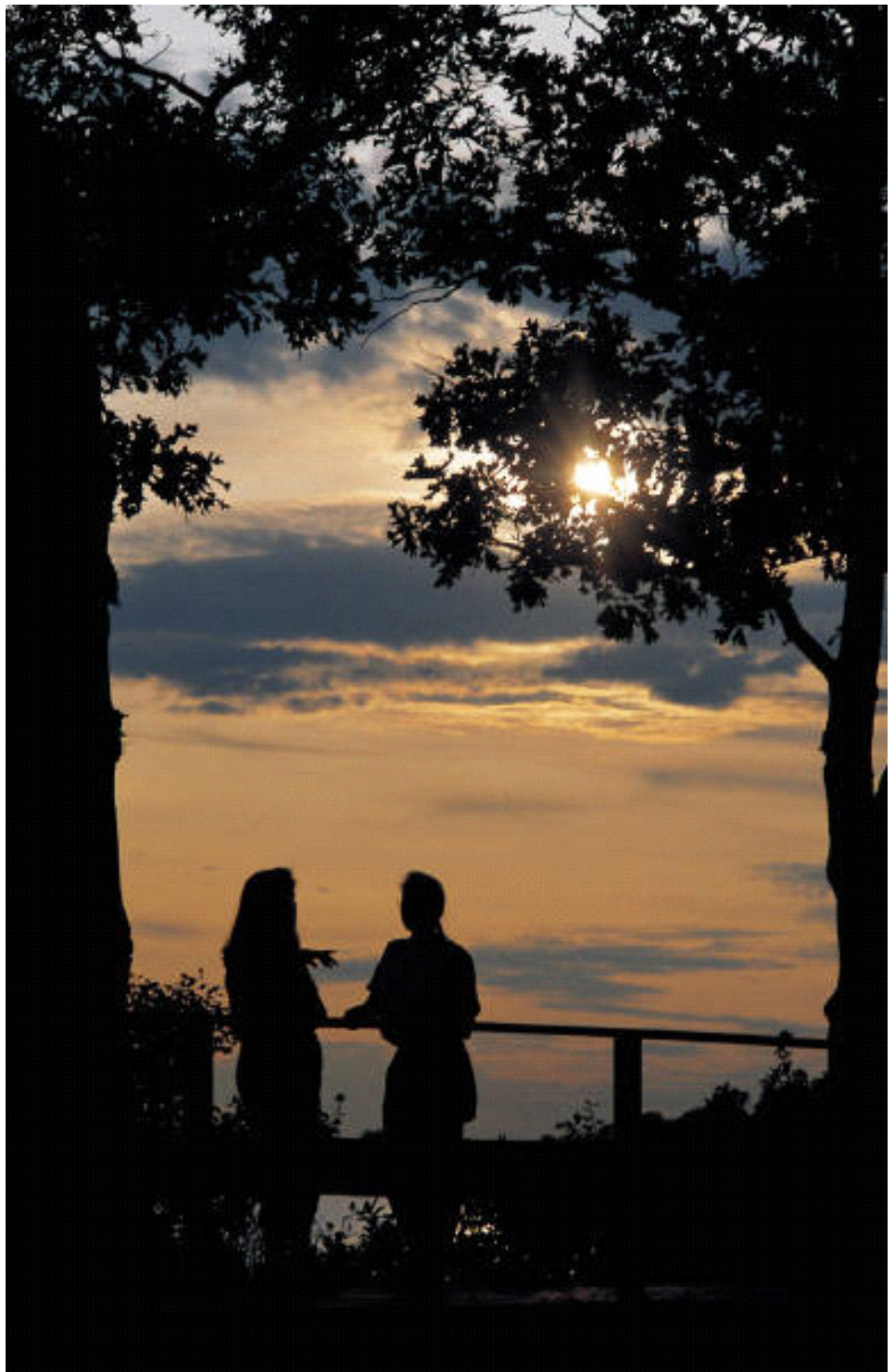
While facing death at such a young age, Keats developed a philosophy of life, that allowed him to live with uncertainty, mystery and doubts.

Like many people in the past, Keats used poems and letters, written thoughtfully and honestly, to transform the feelings that threatened to wash him away in their intensity.

In comparing life in our modern world with that of Keats, Thomas Moore states: “Creating a carefully constructed and passionate philosophy of life is not something modern people do. Today many blindly follow their clergy, their ideologies, their political leaders or even television and the press for guidance. They are informed, but they haven’t thought deeply enough...”

“A philosophy of life” he says, is a bundle of wisdom you have gathered from your reading and your experience. It is not a rigid ideology that allows no development and complexity.

“It’s a living thing, a developing idea about life that belongs to you alone. You may want to share your insights and may even wish that the rest of the world would adopt some of your



principles. But essentially it is your special source of comfort and understanding.”

For many bereaved parents, floundering in a sea of emotions after the death of a child, expressing themselves through poetry or prose,

is an important step in finding solid ground again. Or, as Keats found, the only way of holding on to life when there was no one who could give him comfort.

*From Dark Nights of the Soul: A Guide to Finding Your Way, and Through Life's Ordeals, Thomas Moore 2004*



## To family and friends

By Kate O'Connor, (NSW, 2010)

You know I had our Ellen,  
She was sweet and pretty and pure,  
We lost her oh so close to life,  
It cut us to the core.

I won't talk to you of milestones,  
Or of how her life has been,  
'Cause we lost her on her first day here,  
So though we love her she can't be seen.

She's up on high among the stars,  
She's waiting for us there,  
She's watching down with eyes that shine  
She's a baby that just can't be here.

I won't brag to you of first teeth,  
Or of walking, or of talk,  
But I'll tell you that we loved her,  
And I'll trust you know it hurts.

I won't ring you up on Sunday,  
And tell you this week she said "Dad",  
I won't laugh with you when she toddles,  
I'll just say missing this stuff is sad.

I won't wish she'd learn to eat,  
Without spreading lunch across her face,  
Or enjoy her splashing in the bath,  
'Cause she's a baby in a special place.

I won't tell you of her favourite toy,  
Or how she likes to play,  
Or how she says she's met a boy,  
And moons over him all day.

I won't tell you how she fell in love,  
Or tell you of her plans,  
Or tell you that she'll soon be wed,  
I'll miss seeing her wedding band.

I lost my baby early,  
And she passed away too fast,  
I cry of it almost daily,  
I have only memories to make her last.

But I imagine telling you all,  
That I'd wished for something more,  
I hope you'll understand my need,  
To remember her once more.

Think of these words when I'm chatting,  
Talk of Ellen whenever you please,  
Knowing that you remember her also,  
Will help keep my mind at ease.

So if I tell you of her,  
It's only so you know,  
That it's all I've got for my baby,  
And that she's in my heart 'till I go.

## Fingerprints

By Tom Krause, (2001)

Your fingerprints are on my heart.  
Fingerprints that teach me about caring.  
Fingerprints that teach me about love.  
Fingerprints that teach me about courage.  
Fingerprints that teach me about hope.  
Fingerprints that bring me closer to my loved ones.  
Fingerprints that bring me closer to myself.  
In the time I cared for you my whole life changed,  
Never to be the same again.  
All this from tiny fingerprints that touch my heart.  
You will live in my heart.  
You will live in my heart forever — never to be forgotten.  
I will always love you.  
You are my child.



## The sitting time

(From *Mourning Unlived Lives*, 1984)

Don't listen to the foolish believers  
who say, forget.  
Take up your armful of roses and remember them  
the flowers and the fragrances.  
When you go home to do your sitting in the corner by the clock  
and sip your rosethorn tea.  
It will warm your face and fingers  
and burn the bottom of your belly.  
But as her gone-ness piles  
in white crystal drifts,  
It will blossom on her moment,  
the warmth on your belly, the tiny fingers unfolding,  
the new face you've always known,  
*that has changed you.*  
Take her moment and hold it  
As every mother does.  
She will always be your daughter  
And when the sitting is done you'll find  
Bitter grief could never poison  
The sweetness or her time.





# Scientists say: “Shed a tear, it’s good for you”

DOCTOR William Frey, a biochemist in Minnesota, has researched the chemical content of human tears.

One of the substances found in tears was the stress hormone ACTH.

Thus it is possible that shedding tears helps to reduce excessive amounts of ACTH and perhaps other substances that accumulate following a stressful event.

Dr Frey has suggested that the purpose of emotional crying may be to remove waste products from the body, similar to other excretory processes such as urinating, defecating, exhaling, and sweating.

Dr Frey's conclusion is that: “we may increase our susceptibility to a variety of physical and psychological problems when we suppress our tears”.

Crying not only removes toxins from the body but also reduces tension.

Studies on adults in psychotherapy have found lower blood pressure, pulse rate and body temperature in patients immediately following therapy sessions during which they cried and raged.

Similar changes were not observed in a control group of people who merely exercised for an equivalent period of time.

Researchers have looked at the relationship between crying and physical health.

Studies have found that healthy people cry more and have a more positive attitude about crying than do people who suffer from ulcers or colitis.

Other studies have shown that therapy involving high levels of crying leads to significant psychological improvement.

Those patients who did not express their feelings in this manner during therapy tended not to improve, while those patients who did frequently cry in therapy experienced changes for the better.



Studies have shown that crying removes toxins from the body and helps reduce tension.

## Children and tears

Children cry spontaneously after having experienced any kind of stress or trauma.

The more stress there is in a child's life, the greater will be the need to cry.

Added to the major life stresses are all the daily separations, accidents, frustrations, disappointments and anxieties children experience.

In a single morning at nursery school, a child can have a toy grabbed from him by another child, fall from a swing, be served a snack that he dislikes, spill paint on his new shoes and have to wait for a late parent after all the other children have left.

Even happy occasions can be stressful if they are over stimulating.

It is not uncommon for young children to burst into tears during their own birthday party, for example.

While much of children's stress is an inevitable part of life, parents can reduce their children's stress level (and therefore the need to cry) by providing a sensitive, accepting, child-friendly environment that recognises children's needs.

Non-authoritarian approaches to discipline are much less stressful for children and also more effective than the use of punishment.

Finally, the entire family will benefit when parents look for ways to reduce stress in their own lives.

For further information visit the Aware Parenting Institute website at [www.awareparenting.com](http://www.awareparenting.com)



## Taking care of yourself after your tears

**SOMETIMES we need to leave the world for a while and let our tears wash over us. Then, after a good cry, we need something to help us find our way back to the world again.**

### *For puffy eyes and faces:*

After pouring yourself a chamomile tea, soak a man's large white cotton handkerchief in the tea, fold it in thirds and use it as an eye compress for your tender lids.

Add a slice of chilled cucumber to each eyelid and 'chill' yourself in a darkened room, listening to soothing music for another 15 minutes.

If you find yourself crying on and off, you may like to have this soothing mix on hand in the fridge.

### *Cucumber and tea rinse*

You will need:

½ cucumber, peeled and seeded  
¼ cup hot, prepared green tea,  
¼ cup hot, prepared chamomile tea

Puree cucumber in a blender and strain out the juice.

Mix the teas together and add the cucumber juice. Stir well and place in the fridge for at least half an hour.

Pat face with mixture.

Rinse face with cool water, and pat dry with your softest towel.

Ease the throbbing of a headache with a little aromatherapy by inhaling the scent of essential oils. A combination of two or three of the following will help — violet, peppermint, orange peel marjoram or lavender.

And, above all, be gentle with yourself.



## Legend of the tear jar

IN the dry climate of ancient Greece, water from one's own body, when crying tears for the dead, was considered a sacrifice.

They caught their precious tears in tiny jugs called 'tear jars' — small jars that were about four centimetres tall and two centimetres wide.

The tears became holy water and could be used to sprinkle on doorways to keep out evil, or to cool the brow of a sick child.

The tear jars were kept unpainted until the owner had experienced the death of a parent, sibling, child or spouse.

After that, the grieving person decorated the tear jar with intricate designs, and examples of these can still be seen throughout modern Greece.

This ancient custom symbolises the transformation that takes place in people who have grieved deeply. The ancient Greeks were not threatened by the grief of people in pain.



They have been in the depths of pain themselves, and returned.

Like the tear jar, they can now be with others who grieve and catch their tears.

*Pleasant White, Phd. (SIDS and Kids Queensland, 2007)*

## Give yourself permission to cry

*Time does not always bring relief, but tears always do. To give yourself permission to cry is to bless your body with the benediction of healing. Even when the origin of our tears are sad, crying is good for us, especially the crying that mangles our features and reminds us of how we cried when we were very young, and didn't know how to stop.*

— Sarah Ban Breathnach

***Time engraves our faces with all the tears we have not shed.***

— Natalie Clifford Barney

*Tears are a river that take you somewhere. They lift your boat off the rocks, off dry ground, carrying it downriver to someplace new, someplace better.*

— Clarissa Pinkola Estes



## *Anniversary cards*

If you would like to receive a card of remembrance on the anniversary of the death and/or birthday of your beloved child or grandchild, call SIDS and Kids ACT on 6287 4255 or email [support@sidsandkidsact.org](mailto:support@sidsandkidsact.org)



# Lyndall remembers Jeremy and shares stories

*Lyndall is a member of our Peer Support Program. She is one of a number of mothers and fathers who offer support to our members.*

MY husband David and I never talked about having children. While we were living in a share house in the UK, we found out I was pregnant, we were terrified. We made the decision to stay in England to have our child and as soon as Oliver was born, the world was a different place. I knew that this was what life was about.

We did a bit of travel in Europe with our tiny son and came home via America when he was six months old. We arrived back in Canberra, me to my public service job and David to a new job. We bought a simple house in the suburbs and set about making it into a home for our family. Life was good. The decision to try for another child was easy. Jeremy was born when Oliver was two-and-a-half. We were worried about how we could love another child, but as soon as Jeremy was born, our capacity for love simply doubled.

Life with two young boys was busy. I was lucky to be able to be a stay at home mum, and I loved it. Our family life was much as anyone else's with two

young children. Oliver was growing up and learning to share with his little brother, while Jeremy was trying to keep up with his big brother. Jeremy reached all his milestones at the right times. As a family of four we got on really well, all learning from each other.

Some of my favourite memories from that time include a nappy fight the boys had in Jeremy's cot. Much fun was had with throwing all the nappies into the cot, only to have them all thrown out again. It was just delightful to watch our two boys having such a ball. Jeremy was quite a discerning child, but loved his family. I remember one day walking around Edison Park with my Mum, Oliver on his bike with trainer wheels and Jeremy in the stroller. Jeremy was always picking up sticks and rocks as we walked. We had some lovely times at the beach together.

We have a photo of both boys in their pyjamas under umbrellas while David sprayed them with the hose. They both loved playing on the trampoline and Jeremy, trying to keep up with his big brother, wanted to jump by himself, but really still needed the security of hanging on to a hand. We had two Christmas' together. The last one we bought the boys a Chucky talking truck to share. We had photos of Jeremy done for his second birthday at Target at Tuggeranong. The poor Pixi

Photographer was trying to get a photo of him with a soccer ball, but every time she gave him the ball he threw it straight back to her. Luckily we got some great shots, including some with the soccer ball.

In 2002, Oliver started preschool, which he loved. I often helped out there which I enjoyed and Jeremy loved being part of it all. Jeremy's second birthday was Sunday, August 4, 2002. We had organised a simple gathering of family and friends to celebrate. On Friday, August 2, he woke up with a sore tummy. By lunchtime he was vomiting and we went to the doctor in the afternoon. He died in my arms at lunchtime on Saturday. The autopsy showed he died of a twisted small intestine. We had no warning signs and no time.

The last almost eight years of my life have been the hardest I have ever faced. At times I have been in a very dark and bleak place. But we still had Oliver to look after and, thank God we do. The impact on all our lives of Jeremy's death is immeasurable. Who knows where we would be now if he was still with us. Oliver is now an only child and gets all our attention. That is just the way it is. David and I have grieved together, separately and differently. At times he has been a tower of strength standing beside me and at

## Guests had a ball at *A Night at the Circus* gala fundraiser

LAST year, the SIDS and Kids ACT team began preparations to hold their greatest gala charity ball ever in the Canberra region — *A Night at the Circus*.

And what a night it was. With over 120 guests and a fantastic entertainment line-up, the ball proved to be a huge success.

*A Night at the Circus* could not have happened without the ongoing support of our sponsors and volunteers.

The SIDS and Kids team is, once again, so thankful for the generosity demonstrated by those who donated their time, money and products to ensure the ball ran smoothly and was a

fun-filled evening for all. It was a fantastic effort all round.

The evening line up included guest speaker Lyndall, a SIDS and Kids ACT member, music performances by local band *Hit Parade* and pianist Stuart Warner, raffles and auctions with terrific prizes and a fabulous display of circus acts performed by Highwire Events to entertain all.

The night was a huge success, raising nearly \$20, 000 with all proceeds going to save babies lives and support local families within the ACT and surrounding regions. SIDS and Kids ACT thanks you for a wonderful evening and we look forward to seeing you all again next year.



Ball sponsors Kylie and Jason Maxwell (above) and (below) the SIDS and Kids ACT team Danielle Mackay, Catherine Cotter, Marnie Barton and Janine Brissett.





## of his short life at annual charity ball

times he has had to carry me. I hope at other times he has felt my love and support.

After my son's death I went into shock for I don't know how long. I pushed everyone away. I didn't want anyone intruding on our now family of three. Nobody knew how I was feeling and I didn't want anyone pretending they did. I have lost contact with many people over the years. Luckily my family and a few close friends just waited patiently while my grief softened.

SIDS and Kids ACT have been part of my life in the last seven-and-a-half years. We initially used their counsellor who came to our home. She was a warm and compassionate woman who I could talk to about anything. After about a year, I attended some support groups and two SIDS and Kids weekend residential Bereavement Journey workshops. The first time was just 13 months after Jeremy died. In retrospect that was too early for me, but I did meet a few people there, who were further down the track than me and found them amazing. Just to see them still standing was inspiring. I laughed with them and I cried with them. I did my second bereavement journey workshop three years ago. I am not sure why I wanted to do it again, but maybe it was time for me to revisit it and touch it all again.

A few months after doing the second Bereavement Journey workshop I had the idea of setting up a playgroup for bereaved parents. I work at a wonderful Early Childhood Centre and thought that surely I could bring together my work and its facility, and do something to help bereaved families — two things I feel passionate about. I felt that I could facilitate a playgroup for bereaved families, providing a safe environment where they could come and play with their other children. I spoke to Karen at SIDS and Kids who fully supported the idea. A generous spirited woman I met at the Bereavement Journey workshop agreed to co-facilitate the group with me, and so Puggles started.

We have now been going for more than two years and I feel that it is really valuable to the mums who attend. To be able to talk about our children, issues relating to our grief, or to share common experiences is a great relief.



Lyndall and David are members of the SIDS and Kids ACT family. Lyndall was the guest speaker at the *A Night at the Circus* ball, the annual charity fundraiser of SIDS and Kids ACT.

The loss of a child and all the related issues can be very confronting for people who have not gone through it. Many don't know what to say, or where to look and certainly don't want to make you cry. To be with others who have shared the experience has been very comforting. Some weeks we talk about our losses and some weeks we don't, but its okay if we need to.

Puggles is a SIDS and Kids program and they have been great in both setting up the program, offering it to families and supporting me in my facilitation of it. It is funded by SIDS and Kids and one of their counsellors has responsibility for it. At times, when I have found the going tough, dealing with some very sad stories, they have been there to help me through it. Although facilitating Puggles has been challenging at times, has been a wonderful opportunity for me. I have got so much from meeting the incredible people who come. Running the playgroup and meeting with these people every week has made me much more comfortable talking about my son and my grief. So much can be gained by being open and sharing feelings and experiences.

Being a SIDS and Kids program, I had to undergo training to become a peer supporter. This training was not about my grief, but about learning how best to support other bereaved parents.

At times I found it extremely hard. How could I help these people while maintaining the boundaries SIDS wanted? I decided that it was more important to me to help others than to worry about my issues. I wanted the playgroup to go ahead and I settled it in my mind that I would do it according to SIDS and Kids requirements. I have often been thankful of SIDS and Kids training and support.

SIDS and Kids ACT have provided me with so much support and opportunity I will always be thankful for the wonderful people who have and do work there. Even selling product on Red Nose Day is rewarding. One year, Oliver and I sold red noses at Bruce Stadium in sub zero temperatures and driving rain — an experience we will never forget. They have always welcomed Oliver's involvement which I appreciate. I have always felt welcome at the SIDS office and have often just dropped in for a cuppa and a chat. I feel part of a very special organisation.

These days, most people forget that we are bereaved parents. That is okay, but we never forget and the special people I have met through SIDS never forget either. Today, after much heartache, hard work, help and time, Jeremy's life and death is part of the tapestry of my life.



# Tools to help a child cope with the trauma of death

*“When we have the courage to confront death and dying openly with children, we teach them that death is part of life, that it hurts, but most importantly that the hurt is survivable when we deal with it together.”*

PREPARATION for significant events around death and dying is not really different from the preparation we give children for any important occasion.

In both cases, the important thing is to keep talking to our young children, explaining what will happen next and cuing their responses with our facial and verbal expressions.

Many of us know how to prepare children for significant events involving pleasure, but shy away from doing the same thing around those that are potentially painful.

When we take a young child to a funeral service or visit a memorial garden, a simple and familiar formula such as “This is where we are going, this is how we might feel, and it will be all right because we are together” works.

## How to help a two to four year old

- Providing love, comfort, reassurance and nurture.
- Ensuring that they have a consistent routine.
- Answering questions honestly,

first asking what they understand so that we can build on that understanding.

- Making sure they are included at significant times. Opportunities and encouragement for inclusion should be provided, but never forced.

## How to help a four to seven year old

- Talk about the death.
- Show your own feelings and reassure the child that it is all right to do so. Validate feelings so the child knows that nothing terrible is going to happen as a result of expressing feelings.
- Provide opportunities for them to draw and write stories about the death/dying/separation.
- Do not be alarmed when children play games about death, dying and funerals. These games are important to help them make sense of the experience and gain some feeling of control.
- Encourage them to make a memory box.
- Maintain discipline and routine to provide security.

## How to help a seven to 11 year old

- Show your own feelings openly,

labelling them, and when possible explaining why we feel the way we do.

- Be there to provide love, reassurance and routine.
- Talk about the death, answering questions, no matter how explicit.
- Private ‘space’ is important. Allow the child time alone.
- Provide opportunities for the child to regain a sense of control in his life. This includes opportunities to express feelings or change his mind if arranged activities, outings or sleepovers have been arranged.
- Encourage the child to make an appropriate memorial, but resist any temptation to romanticize life after death.
- Do not be surprised if children use symbolic play stories and art to make sense of their experience.

From *The Grief of Our Children*,  
Dianne McKissock (1998).

**If you have any questions about supporting your child, or would like a SIDS and Kids counsellor to provide support through play and art therapy, please call Janine on 6287 4255.**

## Wine, dine, have a great time and help raise much needed funds

TWO fundraising dinners to support SIDS and Kids ACT are currently being organised by volunteers. The first event is a wine dinner being organised by Canberra Institute of Technology Public Relations student, Bridget Cocker.

Bridget’s dinner will be held on Tuesday, May 18 at The Hermitage. This event will consist of a three-course meal comprised of signature dishes served at The Hermitage. The meals will be accompanied by red, white and dessert wine donated by Canberra district vineyards including McKeller Ridge Wines, Jeir Creek Wines and Affleck Vineyard.

There will be live entertainment by a string trio and a short presentation on Canberra district wineries, in particular McKeller Ridge Wines, by Brian Johnston.

Tickets are \$100 per head and every booking will receive a complimentary book by Brian Johnston, entitled *Wine of the Canberra District – Undiscovered Treasures*. Places are limited. For further information or to make a reservation, send an email to [blisswithoutignorance@gmail.com](mailto:blisswithoutignorance@gmail.com)

### Bright Horizons

The second event – called Bright Horizons – is being organised by bereaved parents Renee Rodda and

Wayne Alger. The Bright Horizons fundraising dinner will be held at Ellacure Restaurant, Bruce, on Monday, June 21. The evening will consist of a degustation meal with matching wines, charity aided auctions and entertainment throughout the night in an intimate and relaxed setting. The meals for the event are to be a mystery until the night. All staff have kindly donated their time, with all funds raised from the event going to support the much valued ongoing efforts of SIDS and Kids ACT.

Tickets for Bright Horizons are \$180 per head. For more information or to book your place please contact [bright.horizons.act@gmail.com](mailto:bright.horizons.act@gmail.com)



# Calling for expressions of interest on courses

AS the counsellors and peers get to know each other, we are discussing both existing services as well as new ideas for support groups.

Please let us know if you are interested in attending either the Bereavement Journey workshop or the new options that have been raised as possibilities for the coming year.

While some of these ideas are likely to suit mums best, dads are also most welcome to attend or offer alternative suggestions.

## Healing Memories: scrap-booking album

Do you enjoy scrap-booking? Are you interested in sharing your skill with others? SIDS and Kids would like to hold a scrap-booking course, and we're looking for expressions of interest from someone willing to help facilitate the course.

It is anticipated that this would be a quiet, reflective group where mums would meet for a couple of hours each week (possibly four to six weeks) to put together any mementos, drawings, photograph or poems that

express the special bond they feel between their baby themselves and/or their family.

For more information, please contact Janine or Mandy on 6287 4255.

## Relaxation/Mediation group

Set aside one hour of your time to come and experience the art of relaxation through meditation and focus purely on needs and your own wellbeing.

We are considering holding the relaxation group on Tuesdays at 10.30am.

Expressions of interest are very welcome. Please contact Fiona on 6287 4255 for more details.

## Multiple Birth and Loss Support Group (MBSAL)

We are looking to re-establish a support group for parents who have experienced the death of one or more children from a multiple pregnancy.

The group will be held on the third Tuesday of every month with the time to be advised.

To register your expression of interest in attending this group please contact Fiona on 6287 4255.

## Bereavement Journey workshop

These workshops are one of the support options we offer to families.

The weekend residential workshops are held locally, are free of charge and are offered once or twice a year, depending on demand.

Participants are given the opportunity to explore loss within a nurturing, professionally facilitated group environment, and are invited to share their experience with others, address their grief issues and focus on their own life journey.

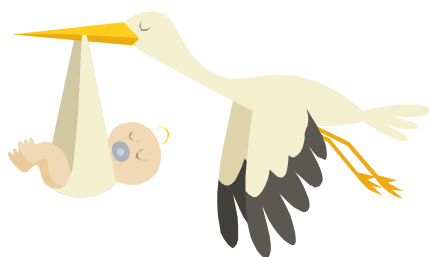
We find that participants tend to gain the most benefit from the workshop when they have been bereaved for more than a year.

Attendance at a Bereavement Journey workshop is also a pre-requisite for those interested in undertaking the Peer Support volunteer training course.

Peer Supporters are parents and grandparents who have experienced the death of a child at any time from conception through to childhood, and who now have a wish and feel ready to offer support to other bereaved parents and grandparents.

Tentative dates have been booked for the next Bereavement Journey workshops on September 11 and 12.

For further information, contact Fiona on 6287 4255.



## Stork news

*A warm welcome to the new arrivals*

**Brydie Kate Beasley,**  
born on October 4, 2009 to  
Stacy and Richard Beasley.

**Polly Sawyers,**  
born on March 31, 2010 to  
Deborah Fiori and Justin Sawyers.

If we have missed the birth of your new baby and you would like us to publish the happy event, please let us know your baby's name and birthday for our next Newsletter.

## New Safe Sleeping educators join the team

SIDS and Kids ACT welcomes Maggie Salmon-Room and Catherine Cotter to the Safe Sleeping Education team.

Maggie and Catherine have been with us now for about six months, and are busy getting out into the community teaching new and expectant parents and healthcare workers the safest way to sleep newborn babies.

Safe Sleeping Education sessions are held from 6pm to 7.30pm on the

first Wednesday of each month at the SIDS and Kids office.

Issues covered include:

- What is SIDS?
- What are the risk factors?
- Ways to reduce the risks.
- Creating a safe sleeping environment.

Sessions are free, but bookings are essential. Phone 6287 4255 for more information.

## STAFF PROFILE

# Finding inspiration in life's challenges



**Mandy Cox,  
Counsellor,  
Bereavement Support Team**

### When you were a child what did you want to be when you grew up?

I was always quite keen on being a postie. I used to drive my mother mad, racing out the back door and knocking on the front door, announcing, "Mrs Walsall (Halsall), I've got a letter for you". It wore pretty thin after the first half a dozen times.

### Now what do you want to be when you grow up?

My husband often refers to me as the "wise old owl", a bit of a family joke in our home. But, actually, I hope that above all I will grow up to be wise — wisdom is such a rare jewel in our society these days and I'd love to taste more of it.

### What is your greatest strength?

Don't you hate that question? I am

told that I am a very objective person which at times is a great strength, but at other times can be problematic. Most strengths are also somehow our weaknesses aren't they?

### What is your idea of a perfect evening out?

Catching the train to Sydney with my husband, going out to a great show, having dinner, staying in a luxurious motel for the night and then catching the train back sometime the next day. One day...

### What is your dream holiday destination?

East Timor is next on the list for a holiday destination — would love to build a guest house there — in my dreams.

### What is your worst habit or vice?

I'm afraid it has something to do with chocolate and coffee.

### What's the best thing about being involved with SIDS and Kids?

The very real privilege of sitting with people who have experienced such a tragic loss, and allowing their honesty and struggle to bring them through to a place of healing and new hope. I love working with people and contrary to how it might be seen, working with those who are confronted by death and dying is not at all morbid or depressing, but rather inspiring and challenging. It challenges the way I view life and death constantly, and it inspires me to continue to live my own life to the fullest potential, because all life is a gift, no matter how short or long.

## Hand in Hand

*Hand in Hand* is SIDS and Kids ACT's Bereavement Support Services newsletter.

It is our hope that through reading the newsletter, bereaved families will feel less isolated and alone as they grieve for and remember their beloved child or children. We believe that the more input we have from families, the more likely this is to happen.

**If you would like to contribute to a future edition of *Hand in Hand* we would love to hear from you. Please contact SIDS and Kids ACT on 6287 4255 or email [newsletter@sidsandkidsact.org](mailto:newsletter@sidsandkidsact.org)**

*And don't forget to let us know if you would like to receive your newsletter by email — you will receive it in colour and we will save postage and trees.*

## Support meetings

If possible please let us know you will be attending  
**Phone:** 6287 4255 or  
**Email:** [support@sidsandkidsact.org](mailto:support@sidsandkidsact.org)

### Parent Support Group (1)

A facilitated group for parents who have experienced the sudden and unexpected death of an infant from 20 weeks of pregnancy. Held on the second Tuesday of each month from 6.30pm to 8pm in the Family Room of SIDS and Kids ACT. **Please note the change of time for this group.**

**Meeting dates:** May 11, June 8, July 13, August 10, September 14, October 12, November 9, December 14.

### Parent Support Group (2)

A facilitated group for parents who have experienced the sudden and unexpected death of a child. Held on the last Thursday of each month from 6.30pm to 8pm in the Family Room of SIDS and Kids ACT.

**Meeting dates:** May 27, June 24, July 29, August 26, September 30, October 28, November 25.

### Early Pregnancy Loss Support Group

A facilitated group for parents who have experienced an early pregnancy loss (up to 20 weeks of pregnancy). Held in the evening on the third Thursday of each month in the Family Room of SIDS and Kids ACT.

**Meeting dates:** May 18, June 15, July 20, August 17, September 21, October 19, November 16, December 21.

### Puggles Playgroup

A free playgroup, held in partnership with Noah's Ark Resource Centre, for bereaved families with children aged 0-5 years. Held for two hours on Mondays from the second to the last week of each school term.

**Contact with SIDS and Kids ACT's counselors prior to attending the group is essential. Phone 6287 4255.**