



Hand in Hand

sids and **kids**[®]
ACT

Edition 2, 2010 —
Father's Day

The newsletter of SIDS and Kids ACT Bereavement Support Services

SIDS and Kids ACT

Grant Cameron
Community Centre
27 Mulley Street
Holder ACT 2611

P: 02 6287 4255

F: 02 6287 4210

E: support@sidsandkidsact.org

PO Box 3118
Weston ACT 2611

www.sidsandkids.org/act

24-HOUR CRISIS LINE

Freecall
1800 138 300

Thinking of you on Father's Day

WHILE our newsletter is produced for all bereaved parents and their families, we dedicate our Spring newsletter each year to our **dads** and grandfathers.

Some of you have shared many Fathers' Days with us over the years, while others may be feeling the numbness or heartache of your first Father's Day since the loss of a child. Whatever your situation this year, our team at SIDS and Kids wish you moments of sweetness amongst the sadness as you remember a child who is no longer with you.

It is a normal reaction to want to avoid painful emotions, so what is a grieving dad to do when reminders of fatherhood are being celebrated and broadcast all around him, in the days and weeks leading up to Father's Day? While keeping busy, working hard and caring for others may all help, the first Sunday in September can be a very difficult day for any man whose baby or child has died

"Who Needs a Heart When a Heart Can be Broken?" is a protest that many a grieving dad can relate to, particularly when his heart had just begun to stir with the first tender feelings of love and protectiveness for a new baby or young child. There is so much that a man can provide for a young family in this wonderful country of ours, that a man's sense of purpose may well have centred around keeping his family safe and happy.

When a baby's life ends, the sudden loss of the profoundly personal experience of



becoming a parent is another loss fathers struggle with.

Mandy's article on Page 6 reminds us, that life in a modern and relatively secure society like Australia can separate us from the intimacy with death that those in earlier times experienced. Other articles will offer suggestions for living with the fear and uncertainty this realisation may create.

As an organisation who works primarily from 9am to 5pm, we do not meet as many fathers as we would like to. We hear a little about the dads from their wives, and know that most of you are carrying on, doing your best to preserve your sense of family as you find new ways of being and living together.

We will be thinking of you this Sunday and trusting that you will find a poem, a story or even a few words that will comfort you and remind you that you are not alone.

Please let me know what you find most helpful in the newsletter and send on anything you have discovered that may be helpful to others. Your feedback and contributions help so much as we work to find new ways to support you and your families.

*With kind regards,
Janine Brissett, Bereavement Support Team*

September 2010

Inside this issue:

- Importance of allowing ourselves to grieve. **3**
- Light a candle on International Pregnancy and Infant Loss Memorial Day **4**
- Inaugural Red Nose Day parents' art exhibition a resounding success **5**
- Normal reactions to an abnormal or traumatic event **7**
- Bree shares her story, helping us to understand the unique nature of loss and grief **10-11**
- Discover the difference between sympathy and compassion **14-15**
- What's new at SIDS and Kids: Relaxation/meditation classes and a twin support group **16**

The struggle: How can I accept something that should never have happened?

FOR years after a precious baby or child has died, most bereaved parents still have times when they struggle with “what ifs” or “if onlys”.

Different scenarios may flash through their minds, in which someone, including themselves had acted differently, and their child had not died, but gone on to live a long and happy life with them. Perhaps one reason for this is our difficulty understanding “acceptance”, which is one of the most misunderstood words in the English language.

When we talk about 'accepting thoughts and feelings', many people think that means liking them, wanting them, or approving of them. Others think of it as a kind of virtue, which means putting up with, tolerating, or resigning ourselves to having them.

But acceptance, in the context of grief, doesn't mean any of these things.

It's not about grinning and bearing what has happened; not about letting thoughts and feeling push us around; not about getting overwhelmed by or bogged down in them; not about resigning ourselves to them; not about gritting our teeth and putting up with them.

It is about learning, over time to react to them in a fundamentally different way.

Imagine a 'struggle switch' at the back of your mind, which determines how much you will struggle with painful feelings.

When the switch is on, you actively battle with your feelings, doing whatever you can to make them go away. When the switch is off, you do not invest the tiniest bit of effort or energy in struggling with your feelings, no matter how painful they are; this is true acceptance.

When the switch is at the halfway point — neither off nor on — that is tolerance, or 'putting up with it'.

When we tolerate, or put up with, our feelings, that's a step in the right



direction. It's better than an all-out battle with them. But it's a long way off true acceptance.

To get the distinction, ask yourself this: would you rather your loved ones accepted you, or would you rather they tolerated you?

When we tolerate someone, we are in state of tension: we grit our teeth and put up with that person, but we are hoping all the while they will go away, give us a break, leave us in peace.

Tolerance keeps us ill-at-ease. And it requires a lot of effort and energy, so that over time, it becomes draining.

Here's a little experiment. Find a heavy book — and imagine that this book is all your painful thoughts and feelings.

Gripping it tightly with both hands, straighten your arms out, and hold the book out in front of you at arm's length. (If you don't have a book handy, just imagine doing it.) Hold the book as far away from you as humanly possible — and keep it there — and notice just how quickly your shoulders and arms get tired.

Imagine walking around like this all day; how exhausting would it be? How difficult would it be to get on with your life and do the things that really matter? This is what it's like to go through life in a full-on struggle with your feelings — trying your utmost to keep them well away from you.

Now, keeping a tight hold of the book with both hands, slowly bend your arms at the elbows, bringing the book closer towards your chest. Stop when the book is around 15 centimetres from your chest. This is much easier, isn't it?

This is like tolerating your feelings. It's considerably less effort than all-out struggle, but there's still quite a bit of effort involved. After a few minutes, you're going to get quite tired of holding the book in this position.

Now let go of the book, and place it gently on your lap.

This is what true acceptance is like. Notice how much easier that is: it requires no physical effort, no expenditure of energy. Now your arms and hands are free to move; now you can use them to do something life-enhancing. Is there a way to move from tolerance to acceptance?

On the next page you will find some suggestions for those wanting to move, over time, to a place where painful feelings are something they are more able to accept, and less something they either struggle with or allow to overwhelm them.

*Janine Brissett from The Happiness Trap: How to Stop Struggling and how to Start Living.
(Dr Russ Harris)*

*There is a sacredness in tears.
They are not the mark of weakness,
but of power. They speak more
eloquently than ten thousand tongues.
They are messengers of overwhelming
grief... and unspeakable love.*

- Washington Irving



Allowing ourselves to feel our intense emotions

GRIEVING parents often say, that the pain of losing a treasured child is not something they could or would even want to put behind them.

Becoming a parent is one of the most intimate and transformative experiences a person can have, regardless of the length of their child's life. As a consequence, the depth of pain a parent feels when that precious life ends is likely to be beyond anything he has ever known.

Self-Compassion

When we're hurting, we often forget to be kind and compassionate towards ourselves.

Try placing your hand on the part of your body where you feel the emotion most intensely. Let your hand rest there, gently.

Imagine it is the hand of somebody very kind, loving and caring. Feel the warmth flowing from your hand into your body. See if you can 'hold the feeling' gently; hold it as if it's a crying baby or a precious butterfly. And try saying some kind words to yourself: whatever you might say to someone that you really care about, if they were feeling what you are feeling right now.

Tears

While tears often flow more easily for a woman than a man as a result of our social conditioning, holding back tears can be exhausting.

Most men sense the need to be strong and in control for their wives and families, but paradoxically, those who allow their tears to flow in a safe place, find they feel stronger as a result.

As bereaved father, P.F. Thomese writes in his book, *The Shadow Child*, "A person who weeps usually has himself under control. A feeling you can express is a feeling you can handle."

Caring versus not caring

In the midst of intense emotional pain, it is sometimes helpful to consider for a moment, what you would have to stop caring about in



order to get rid of the kind of pain you are experiencing. When we do this, we are reminded that our most painful emotions are intimately linked to our ability to care.

In other words, the more we allow ourselves to care about life, ourselves and others, the more we open ourselves to painful feelings.

Next time painful feelings threaten to overwhelm us, remember what your painful emotions are revealing about you. Try reminding yourself, "This feeling tells me how much I care about... X, Y, or Z."

Openness and curiosity

Remaining open and curious about your experience of pain can make all the difference between tolerance and acceptance.

Study this unwanted feeling in your body as if you are a curious scientist that has never encountered anything like this before. Discover something new about it — about where it is, what

it feels like, what it does. Notice the energy, the pulsation, the vibration; notice the different 'layers' within it. Can you identify where it starts and stops, and how deep or shallow, how light or heavy, how hot or cold it is?

Study the way it continually changes and fluctuates, and finally notice what difference it makes when the painful feeling becomes an object of curiosity, as opposed to a problem?

Unfortunately there is no magic wand, for managing the pain of grief, but it may well be worth your while to play around with these strategies, individually or in combination, and see what works best for you and your painful emotions.

Finally, if you do get stuck in 'tolerance mode' rather than 'acceptance mode', then try accepting that's just where you're at right now.

Janine Brissett from *The Happiness Trap*
www.thehappinesstrap.com
(Dr Russ Harris)



Coroners' invitation provides opportunity for change

By Karen Faichney
Chief Executive Officer

IN November last year, I was fortunate to be invited to address the Asia Pacific Coroners Conference and associated Forensic Pathologists meeting. The presentation focussed on two aspects which are often raised by families as being particularly difficult to cope with in the days, weeks and months following a death.

Firstly we discussed classifications and definitions and how these relate to sudden unexpected deaths in both infancy and childhood (SUDI and SUDC). While consensus was achieved in respect to a common definition of SIDS at a meeting hosted by SIDS and Kids in Canberra in 2004, very little has happened since. The impetus for raising this issue is to address the concerns of families who find themselves in the possession of death certificates for their children with cause of death recorded as "undetermined" or "unknown" or "unascertained". The use of this

terminology can be very distressing for families.

The second issue discussed was that of Death Scene Investigation (DSI) protocols, and in particular how they relate to children who die beyond 12 months age.

Most states and territories have well defined DSI protocols (even if a national protocol has not yet been achieved) for the investigation of deaths of infants under the age of 12 months of age. For deaths of children over the age of 12 months there is no formally agreed protocol, however most states and territories would use their existing protocol for infants.

This situation is imperfect and there is significant room for error and/or omission in this process.

We are keen to see a standard approach implemented nationally for all deaths (over and under 12 months age) so that parents can expect a full and thorough investigation regardless of where they live or how old their child was at the time they died.

As a result of all the above, SIDS and Kids have been invited to host a half-day workshop within the program of this year's Asia Pacific Coroners Conference to be held in Auckland in November.

The workshop will further consider the issues outlined above, involving coroners and forensic pathologists from all over the Asia Pacific in a discussion on how to move forward to better meet the needs of affected families.

I have been invited to participate in this workshop as both a presenter and panel member and I have a great sense of optimism that we may be making some significant inroads in addressing areas that have long been neglected. Ultimately I hope that we can eventually see the implementation of national standards for investigation of deaths (regardless of age) and a new classification system that better describes all deaths that sit outside of the SIDS classification. I will keep you posted.

October 15 is International Pregnancy and Infant Loss Memorial Day

ON October 15 at 7pm, (wherever they live), parents from Australia, Canada, Great Britain and the USA or anywhere else in the world where this time and date are known, will light a candle for:

- ♥ Their own own baby, lost during pregnancy or infancy.
- ♥ The baby of a friend or family member lost during pregnancy or infancy.

Whether we light a candle in public or in the privacy of our own homes, the wave of light created by this simple gesture is a reminder that parents who lose a child during

pregnancy, birth or infancy are not alone.

In lighting a candle, you are choosing to:

- ♥ Honour the inherent dignity of each child's life, however short.
- ♥ Honour all parents who love and value their babies.
- ♥ Make a small stand for creating a more compassionate society.

*I don't know how to grieve
How to tell anyone
How to hold on to the memory
of a baby I never got to hold.*





Inaugural art exhibition a resounding success

FOR the first time this year as part of our Red Nose Day activities, SIDS and Kids ACT held an art exhibition to create awareness of the extensive range of services we offer to the wider Canberra community.

Titled *Journeys — An Exhibition of Works by Bereaved Parents*, the exhibition was held at Gallery 12 in the Pialligo Plant Farm in Pialligo, from Thursday June 17 to Sunday, July 4.

The exhibition was opened by Federal Member of Parliament, The Hon. Bronwyn Bishop, who spent hours talking to the artists and our many invited guests before sharing her own experiences of miscarriage when she and her husband were starting their family.

The *Journeys* exhibition displayed the works of six regional artists: Deborah Fiori, Bernadette Maurer, Dionne Bond, Georgina Perri, Debra Boyd-Goggin and Sebastian Perri, all of whom, through their artwork, have journeyed through the grieving process following the death of a child.

The exhibition showcased a range of different artworks portraying the artists' journeys through the use of: ceramics; jewellery; painting and photography.

Each bereavement journey is as individual as the people living through it. Through the support offered by SIDS and Kids ACT, parents are able to learn ways of coping through their



The Hon. Bronwyn Bishop, MP with artist Debra Boyd-Goggin at the opening of SIDS and Kids ACT's *Journeys* art exhibition.

bereavement journey so that they may continue to live full and productive lives.

To help promote the exhibition and highlight the work of SIDS and Kids ACT, ABC Television's Stateline filmed a heart-warming story based around the exhibition. You can see the full story at <http://www.abc.net.au/news/video/2010/07/02/2943783.htm>

SIDS and Kids would like to thank Di Eccles, Julie Shaw, Trish Brodie and

George Abraham who volunteered their time on the weekends to supervise the exhibition; Lachlan from Integrity Signs for donating the banners; Rhondda and Geoff Cleary and their staff from Gallery 12 for donating the gallery space and being so helpful and accommodating before, during and after the exhibition; and especially all the artists, whose amazing artwork really did make the exhibition a success.



Photographer Bernadette Maurer proudly shows some of her artwork to her parents, Mary and Bernie Fanning.



Photographer Dionne Bond with fellow photographer and SIDS and Kids ACT supporter, Jodi Shepherd, of Hotshots Photography.

I wish

I wish you would not be afraid to speak my child's name. They lived and are important and I need to hear their name.

If I cry or get emotional when we talk about my child, I wish you knew it isn't because you have hurt me; the fact that they have died has caused my tears. If you allow me to cry, I thank you. Crying and emotional outbursts are healing.

I will have emotional highs and lows, ups and downs. I wish that you wouldn't think that if I have a good day my grief is over, or that if I have a bad day I need a psychiatrist.

I wish you knew that the death of a child/sibling is different from other losses and must be viewed separately. It is the ultimate tragedy and I wish you wouldn't compare it to other losses.

Being a bereaved parent isn't contagious, so I wish you wouldn't stay away from me.

I wish you knew all these "crazy" grief reactions that I am having are in fact very normal. Depression, anger, frustration, hopelessness and the questioning of values and beliefs are to be expected following a death.

I wish you wouldn't expect my grief to be over in six months. The first few years are going to be exceedingly traumatic for us. I will never be "cured" but for evermore be recovering from my bereavement.

I wish you understood the physical reaction to grief. I may gain weight or lose weight, sleep all the time or not at all, develop a host of illnesses or be accident prone, all of which are related to my grief.

I wish you could tell us that you are thinking of our loved ones on their birthdays or anniversaries. If we get quiet and withdrawn, just know that we are thinking about them and don't try to coerce us into being cheerful.

I wish you understood that to get through this grief I need to experience it. I have to hurt before and I can heal.

I wish you understood that grief changes people and I will never be the same person I was before my loved one died. If you keep waiting for me to "get back to my old self" you will stay frustrated. I am a new creature with new thoughts, dreams, aspirations, values and beliefs. Please try to get to know the new me — maybe you'll still like me.

— Author unknown



Having the courage to talk about death

HOW often have you watched others struggle to "find the right words" to comfort you when someone you have known or anticipated knowing has died?

Australians have many colloquialisms (slang words) to describe death. However, these words are seldom spoken out loud when talking to someone who has experienced a loss, because of how offensive or insensitive they sound.

Words like "croaked it", "kicked the bucket", "carked it" (you get the picture) somehow get stuck in the throat of those trying to find something appropriate to say. At times of loss however, many people don't have a substitute vocabulary to help them express their sympathy and support to someone who has experienced a death.

Bland words like "passed on", "gone", "lost", or "sleeping" can sound more palatable, but they only encourage us to skirt around the reality of what has happened — a person has died.

In an article he wrote for *Grief Matters*, David Ritchie tracks the evolving sanitisation of death in our culture over the past few centuries, and its almost complete exclusion from our mainstream narratives of life.

"In pre-modern culture...", Ritchie reminds us, "... life and death were integrated, part of a continuum of life, with the living ever aware of the frailty of life."

Rather than skirting around the

reality of death and the decomposition of the body, family members created rituals around it, reflecting deeply on the location of a burial, accepting the decomposition of remains, and even leaving representations of the inevitability of death on gravestones and memorials.

Those who research this area of grief and loss suggest that it is "modern" society's unwillingness to integrate death within our culture, that leaves us feeling silenced, isolated and unable to "normalise" our experiences in the same way we could if we lived in a less "progressive" society.

In raising this issue, it is not my intention to minimise the experiences of grief and loss, but to give us the courage to talk more openly about our experiences of loss, in spite of the lack of vocabulary our society has provided us with.

Rather than hiding our experience with death for fear of upsetting ourselves or others, perhaps what we need most is the inner strength to create new vocabulary, rituals and visual symbols that will give expression to our grief.

While this may not be strictly necessary in an age when hospitals and funeral directors do the work that families once did, it is worth considering how much less isolated we may feel, as we learn to talk about death in ways that are more "normal" and natural for us.

— Amanda Cox, quoting David Ritchie from *Grief Matters*.



Normal reactions to an abnormal or traumatic event

BELOW is a list of reactions which may occur in a person who has suffered a sudden and traumatic event.

While very disturbing, each reaction can still be considered a normal response to an event that came as a shock and could not be foreseen, including still-birth or the sudden death of a child.

When a child dies unexpectedly, each parent is likely to grieve differently, with one parent needing more initial support in returning to daily routines, and the other finding familiar activities helpful, at least in the short term.

In either case it is important to remember that these symptoms are unlikely to emerge and recede in an orderly way, and may require professional assistance if they become overwhelming.

- Recurring thoughts or nightmares about the event.
- Having trouble sleeping or changes in appetite.
- Experiencing anxiety and fear, especially when exposed to events



or situations reminiscent of the trauma.

- Being on edge, being easily startled or becoming overly alert.
- Feeling depressed, sad and having low energy.
- Experiencing memory problems including difficulty in remembering aspects of the trauma.
- Feeling “scattered” and unable to focus on work or daily activities. Having difficulty making decisions.
- Feeling irritable, easily agitated, or angry and resentful.
- Feeling emotionally “numb”, withdrawn, disconnected or different from others.
- Spontaneously crying, feeling a sense of despair and hopelessness.

- Feeling extremely protective of, or fearful for, the safety of loved ones.
- Not being able to face certain aspects of the trauma, and avoiding activities, places, or even people that remind you of the event.

Finding support for Post Traumatic Stress

If you have decided to ask a therapist for support, it is important that you feel comfortable with him or her.

A good therapist will listen well and show flexibility about the timing and frequency of support you may need. Feel free to let your counsellor know what has been helpful or unhelpful and ask questions about anything you feel uncertain about.

Since many of the symptoms of post traumatic stress are similar to those of grief, you and your family are the ones most likely to know when your suffering is the natural and unavoidable sorrow associated with loss of a loved one, or whether you feel, it has become something more.

Please support this important online survey: *The Voices of Bereaved Parents*

At the October conference of the International Stillbirth Alliance (ISA) and the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID), Ros Richardson, General Manager of SIDS and Kids, NSW will be giving a presentation on *Parent's Perspective across stillbirth and infant death: The Voices of Bereaved Parents*.

Ros, who is a bereaved parent herself, and has worked with bereaved parents and health professionals in voluntary and paid roles for more than 20 years, is urging the bereaved parents of ACT to contribute to her research, which will be presented to researchers, clinicians, midwives, health and

allied professionals, counsellors, support people and bereaved parents.

For more information about the conference visit the website at www.isaispid2010.com

This survey is for completion by parents who have experienced the death of their child during pregnancy, birth, infancy and childhood.

It is not a formal study, but an informal opportunity for parents to express what they would like those who provide clinical care; research

their losses; and support them at home, and in the community; to know about their experiences.

Participation in the survey is anonymous. It has 21 questions and takes 10-15 minutes to complete.

To discuss the survey or provide further feedback please contact Ros at rosr@sidsandkidsnsw.org or phone 9818 8400 or Margaret McSpedden at margaretm@sidsandkidsnsw.org or phone 9818 8400.

The survey can be accessed at www.surveymonkey.com/s/voicesofbereavedparents



Inspirational quotes

By making us stop for a moment, poetry gives us an opportunity to think about ourselves as human beings on this planet and what we mean to each other.

— Rita Dove



A person who weeps usually has himself under control.

A feeling you can express is a feeling you can handle.

— P.F. Thomese,
Author *The Shadow Child*



The cure for anything is salt
Water — sweat, tears, or the sea.

— Isak Dinesen



*The soul would have no rainbow
had the eyes no tears.*

— John Vance Cheney



Love is never lost.
If not reciprocated, it will flow
back and soften and
purify the heart.

— Washington Irving



How long will it take to get over it?

How long will it take me to get over
the feeling of sorrow?

A lifetime.

How long will I continue to feel guilty?

**As long as it takes you to realise
you did nothing wrong.**

How long will it take me to get
over my anger?

**As long as it will take you to stop
blaming yourself and others, and
realise it was the combination of
unpredictable happenings that
occur in one's lifetime.**

Why do friends give such
horrid advice?

**To cover up their own inability to
handle the situation.**

Will I ever be happy again and be
able to laugh?

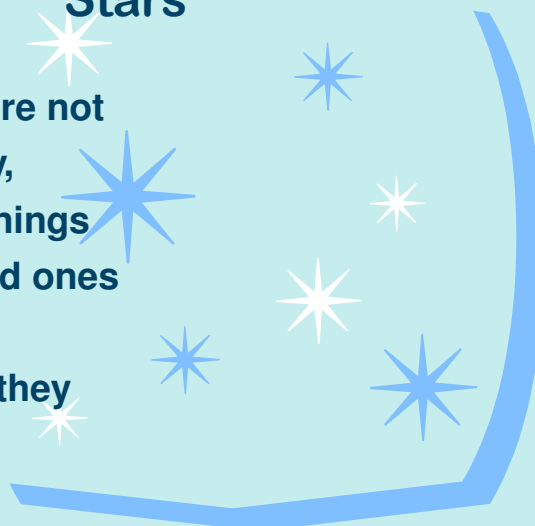
An emphatic yes.

How long is long?

**As long as it takes for you to go
through the process.
Each individual has his or her own
timetable, but it is up to you to
make the decision when to start
healing.**

Stars

Perhaps they are not
stars in the sky,
But rather openings
where our loved ones
shine down
to let us know they
are happy.





Who remembers you?

By S. Ilse, 2009

Dad, supporting mom along the way
Waiting for the time and day
When you can hold your
daughter or son.

And you can finally be the one
To toss your babe above your head
And tuck him in his waiting bed
Make a toy or buy a drum.

Your time was near,
but did not come.
Who knew you would be
standing nigh
And have to prematurely
say goodbye?

This day is yours and yet it's not
The others don't see the many
tears you fought
To hold within and look so strong
As you tried to do nothing wrong.
On this your special Father's Day
Remember your baby who would
want to say,
"I love you Dad. You are the one.
I'll always be your daughter or son.

"Feel my kiss upon your cheek
And know that someday I believe
we'll meet.
Until then, let your tears come,
(or not)
And love my mommy lots and lots."



Memory and love

In every person there is a private
shrine of memory and love,
And in that sanctuary our
loved ones abide.
We sense their presence,
caress their spirits, and
enfold them in our hearts.
They talk to us; they tell tales.

Thus, the pain of separation is
soothed by memory,
the hurt sustained is healed by
love;
and we ourselves become purified
and ennobled through our sorrow.

— Jacob K Shankman,
from the book: *Grief in Our Seasons*.



A butterfly captures our heart
from the moment they appear.
They are vibrant and graceful
as their presence lifts our spirits.
Gone much too soon,
they will never be forgotten.
What the caterpillar perceives
as the end,
To the butterfly is just
the beginning.

Do Not Stand at my Grave

Do not stand at my grave and weep,
I am not there, I do not sleep.
I am in a thousand winds that blow,
I am the softly falling snow.
I am the gentle showers of rain,
I am the fields of ripening grain.
I am in the morning hush,
I am in the graceful rush
Of beautiful birds in circling flight,
I am the starshine of the night.
I am in the flowers that bloom,
I am in a quiet room.
I am in the birds that sing,
I am in each lovely thing.
Do not stand at my grave and cry,
I am not there. I do not die.

— Mary Elizabeth Frye

Celebrating the return of Spring

WE celebrate spring's returning and
the rejuvenation of the natural world.

Let us be moved by this vast and
gentle insistence that goodness
shall return, that warmth and life
shall succeed, and help us to
understand our place within this
miracle.

Let us see that as a bird now

builds its nest, bravely, with bits and
pieces, so we must build human faith.
It is our simple duty; it is the highest
art; it is our natural and vital role
within the miracle of spring; the
creation of faith.

— Leunig





Grief cannot be compared or measured

Bree and her husband Lachlan anticipated the arrival of twin baby girls with great joy and excitement. Their hopes and dreams were shattered, when one of their daughters, Sage, was stillborn. Six months on, Bree shares her story with other grieving parents, helping us to understand the unique nature of each family's loss and grief.

MY journey continues with an intensity I never imagined. As I struggle to bring myself out of the murky depths, I am looking for that life raft that will take me back to my old life, but I can't find it. It has been sunk down to the deep dark hole that her absence has created, along with all my previous perspectives, my identity, my hopes, my dreams and the life I had imagined.

As time goes on, amidst the haze I am beginning to see landmarks. Some days they are clear and easy to spot, but on other days the fog sets in and I am lost again. Six months has hit me hard, I didn't expect it, I am again plunged once more into the darkness, the heavy pain, the struggle for a breath. But I breathe, in and out, in and out, in and out. If I focus on small steps and moments, I can make it through the day and survive. The normality of life continues around us and I step in and out of that normality.

Some days I venture out into different situations that feel "safe", a zone where I feel my raw wounds are acknowledged and understood. The statement that arises constantly is "well look you've got her" (pointing to Yarralea). I want to shake them and say, "Don't you understand? There are no consolations for loss, I want Sage". Usually I just say nothing, but



once or twice I've said "It doesn't quite work like that".

Recently when I told a stranger our story, a look of relief washed over him. When he realised we lost Sage before she was born, "It's better than if you'd got to know her a bit, that would be harder," he said. What I wish for is a just day, a minute or even a second more time with her. I envy those who had the chance to see their baby breathe and open their eyes, but I feel gratitude for having shared almost nine months of her life. There is nothing right about it having our children die before us. There are no consolations for that. It defies the natural order of things.

Anger is an emotion that I have had to confront and the reigning of jealousy arises irrationally. I can't control it. Recently a lovely friend of mine gave birth to her fraternal twin girls. Our pregnancies were very similar, we are similar ages, we both had great first births to sons, we had healthy baby girls on board, we are both midwives, we both went to the same hospital, our birth plans were the same. There is one massive difference, she has two beautiful healthy girls to raise now and I have one. My babies couldn't decide on their position, hers assumed the head down position from early on.

Continued Page 11



Book Review

Hannah's Gift: Lessons from a Life Fully Lived

MARIA Housden's book is the moving and unforgettable account of a mother, who shares memories of her delightful three year old daughter Hannah, and the way she used them to come to terms with her death from cancer. Here are some quotes from its pages, beginning with her first dreaded encounter with LauraJane, the new pastor at her church... and following her reflections as she looks for reasons to go on living.

".....I'm sorry," she said softly, pausing to blow her nose, "but I can't lie to you. I want more than anything to make sense of what is happening to you guys, but I can't even begin to pretend that this is something I understand."LauraJane's humility and

willingness to acknowledge out loud the unfairness and insanity I was feeling came as a profound relief. What I needed most then... wasn't for someone to make me feel better; I needed people like her, who were willing to stand with me in the face of the raw truth..."

".....As I wondered from one room to the next, I saw my life through new eyes. I wondered what had happened to the woman who used to live here; it was hard to believe she had ever been me... Friday morning Mum's group, play dates for children, church on Sunday – was a beautiful life for someone else, but not for me. I had no idea what my life was; I simply knew it wasn't this..."

".....Listening to our laughter, I was filled with relief that our family were together, that we could experience this much love and joy in

such an ordinary moment. I realized, then, that home is not some familiar place you can always return to; it is the rightness you feel, wherever you are, when you know that you are loved...."

".....Truth is fierce and unrelenting. We cannot change it, but we can change the way we live with it. Making mistakes, not being loved, and dying are inescapable experiences of being human; so is our fear of them. By facing those fears, we have a chance to step beyond them. ..."

".....When we are willing to do the best we can with what we know, to be honest with ourselves and others about who we are and what really matters to us, only then are the lives we live and the love we receive truly our own...."

Bree shares her story, helping us to understand the unique nature of loss and grief

From Page 10

This one difference led to two completely different births and outcomes. She will know what it is like to raise twins and the trials, the juggling, the uniqueness of raising, breastfeeding and handling two girls instead of one, I will not. We both went into the game with the same deck of cards, but they have played out so differently. I find this really hard to understand. Why am I in this place? As those uncharitable emotions rise up, I struggle with them. I have been advised not to judge them, just feel them, recognise and observe them. But the feelings are foreign and so awful, they don't sit well.

I know Sage is close by but as time passes, the strong memory of how she felt inside my body is fading. I love her sister Yarralea with a passion I didn't know was possible, but every little thing I do reminds me what it would be like with Sage there. As life moves forward and my living children come into themselves, I have an immense amount of gratitude for their presence in our lives. The bitter side of that gratitude is the yearning we feel for Sage, and the missed opportunity to watch her life unfold.

Grief is so lonely, and nobody is able to lift the pain. I watch my husband grapple with the emotions of loss, and as much as we both want to help each other, we can't. I hate that when I explained to my

son that his friend was having two baby sisters, he says to me "will one die?" and that when he saw a newborn baby for the first time following the birth of his sisters, he takes one look and says "Did it die?" Most people find it very hard to be around people who are in emotional pain and I think many stay away because it's too hard for them or they think we need our space. Even I don't know what I want or need, and it changes moment to moment.

Very few people don't want their spirits dampened, it all ends up becoming very isolating. I regret being that person in the past, putting people in the too hard basket. It's only now in retrospect that I know how lonely and dark that basket becomes. At times I don't want to be around that joy either, I grieve for the complacency and unbridled happiness that I no longer have. Sometimes too, it can be lonely amongst company when I feel my pain is not acknowledged and there is no room for expression.

I appreciate honesty so much these days, someone who will really truly express how they feel. Someone who is honest enough to cry with me and doesn't feel scared to bring up "the elephant in the room" because they'll become uncomfortable. We all know the elephant is there — ignoring only makes it bigger. I love my daughter being acknowledged, it validates her being and shows appreciation of her presence in our lives. I love to hear her name spoken.

Peace feels a long way off but I have glimmers of it, so I know it is possible. I have learnt that tears are not a bad thing, that they cleanse and lighten the load. I have learnt that grief is part of the human journey and that through feeling it brings insight, compassion, gratitude, love, perspective and honesty. I have learnt that this is a journey that has no destination. I know that I am stronger than I ever imagined. I see beauty in people more than I ever had before and I also have a greater appreciation for nature. I feel Sage's spirit in the sunsets, the breeze, the birds, the water and the trees.

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



Aware Parenting: Keeping a sense of connection

ONE of the most difficult things for children whose parents are grieving, is the sense that their parents are less “present” with them than they have been before.

While this is a natural and inevitable consequence of family grief, any effort a parent can make to maintain their connection with their children in the aftermath of their grief, will support them in a way that is deeply nurturing.

Remembering what we prefer ourselves in a support person may also be helpful.

Like adults, children do not need someone to make their pain go away, as much as they need someone who can be fully with them, when they feel shaky or uncertain. Rather than criticising ourselves for lapses of connection with a child, all that is necessary is to notice these times of disconnect, and gently find a way back to re-engagement with your child.

Aware Parenting is about becoming more present and aware ourselves, and then giving that presence to our baby or child, as a gift. We cannot offer to them what we have not first



given to ourselves, so take time to notice what it is you need before reading the suggestions below for keeping connected to your children.

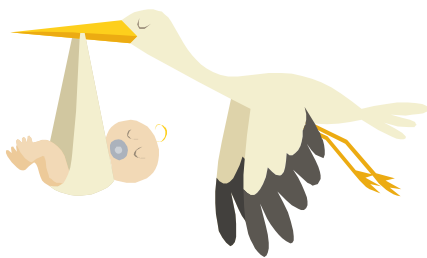
Aware Parenting suggestions

- Fill your children's needs for physical contact (holding, cuddling, etc) and don't worry about “spoiling” them with too much contact.
- Accept the entire range of your child's emotions and listen non-judgmentally to their expressions of feelings. You cannot prevent their sadness, anger or frustration, and validating their feelings is likely to be far more useful to both of you.
- Offer age-appropriate stimulation, and trust your children to learn at their own rate and in their own way. Try not to hurry them on to new stages of development.
- Offer encouragement for learning new skills without judging their performance with either criticism or evaluative praise.
- Spend some time each day giving your children your full attention. During this special,

quality time, observe, listen, respond, and join in with your children's play (if invited to do so). You do not need to direct the children's activities.

- Protect your children from danger, but do not attempt to prevent all of your children's mistakes, problems or conflicts.
- Encourage your children to be autonomous problem-solvers and help only when needed.
- Set reasonable boundaries and limits for your children, gently guiding them towards acceptable behavior and consider everyone's needs when solving conflicts. Don't try to control their behaviour with bribes, rewards, threats or punishments.
- Take care of yourself and be honest about your own needs and feelings. Do not sacrifice yourself to the point of becoming resentful.
- Notice ways in which your own childhood pain interferes with your ability to parent and make a conscious effort to avoid passing on your own hurts to your child.

www.awareparenting.com



Stork news

A warm welcome to the new arrivals

Amelie Jade Squires,

To Liz and Chris, a daughter,
Amelie Jade. Born on July 3,
2010. Little sister for Rochelle,
Douglas and Joshua.

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.



Reconnecting with what we value

FOR parents whose precious child has died, the question, “What is most important to you?” is likely to result in a blank stare or a deep and aching sense of loss.

Their hopes, their dreams, and even the smallest details of their daily lives have revolved around meeting their children’s needs.

Whether at work to provide for their families financially, or at home creating a safe and emotionally happy life for their children, the situation is the same. “Everything I valued has been taken from me!” they may say, particularly in the early days of bereavement.

Reeling to recover from the destabilisation of life, as they knew it, some describe a sense of being faced with a choice.

This choice, they say is not about whether or not to have pain, but whether or not to live a valued and meaningful life in the face of their loss and pain.

When our hopes and dreams have been shattered, the only choice some of us have is to use our values as directions as a beacon in the night when everything is upside down.

After a devastating loss, there are some important things we need to remember about values.

Living by one’s values does not mean our paths are always straight

“Because we are human, we may intend to go in a particular direction, but find ourselves going another for a while. Distractions are a natural part of life, and it is only over time that our underlying values become evident. Like tracks left in the snow, they will show that even though our path was not straight, it was headed in the direction we chose.” (Steve Hayes 2005).



Values are not outcomes

When the thought that life will never hold any joy or meaning again becomes stuck in our heads, life seems to shrink and we lose vitality and contact with those people and things we value.

Rather than judging yourself or the fog you sense within or around yourself, try shining an imaginary torch through your fog of thoughts.

Allow yourself to create a path through the fog, in the direction of those things and people you value.

If possible, imagine yourself taking a step on that path, making the choice to step forward into some new and previously avoided territory.

Values are not in the future

The very instant we choose our values, we are taking a valued path, which may seem to be “about the future”, but is really about the present.

Living a life empowered by our values is like taking a journey down a never-ending path with no finish line;

it is not about our destination, but about the way we travel.

If you have chosen to be a loving person, again, this is not a goal to reach, but a choice of how you have decided to travel.

Choosing to value

Unlike goals, that we can fail or succeed in reaching, making the choice to hold on to what we value allows us to turn back in the direction of what is most important to us, time and time again.

It doesn’t matter how off track we have gone, or where our internal struggles have taken us.

Regardless of how much pain or struggle we are experiencing, we always have a choice about reconnecting to what matters most to us, one minute at a time, one hour at a time, or one day at a time.

— Janine Brissett
(Information from Stephen Hayes,
*Get Out of Your Mind and Into
Your Life*, 2005)



Learning the difference between

Choosing the company of those who are hurting requires courage, because there is nothing that anyone can say to take away pain and fear. While our natural instinct may be to pull away, what we can do is to listen without judging, and offer our time with no expectation that it will make a difference.

This willingness to be genuine and kind is all we have to offer and is the starting point for acting from compassion.

ALTHOUGH sympathy is a form of caring, it implies pity.

We may express concern and ask what we can do, but there is a sense that we are grateful that their problems are not ours.

This perpetuates the fear that we couldn't bear the same situation, and keeps us wanting to avoid the truth of their experience.

While it is natural to feel sympathy when someone is hurting, there is little sense of what to offer as meaningful support.

Compassion is a hard-won state of being. Much more than a feeling, compassion is a choice to view suffering as a universal experience.

This means viewing illness, loss, and even death as human experiences that are bearable with support.

Compassion bridges the distance between people often created by suffering. This is not comfortable to do, as we must acknowledge their problems might reflect our own future.

In the following table, read an item on the left list and breathe. Read the companion statement on the right and breathe again. Notice the differences between how you feel after reading each phrase.

Sympathy	Compassion
Exhausts both giver and receiver	Nourishes and soothes
Defines suffering as helplessness	Recognises suffering as a passage
Wears a fixed mask, tries to mind-read	Is authentic and open-minded
Wears a fixed mask, tries to mind-read	Is authentic and open-minded
Counts the minutes, wants to escape	Is timeless, refuses to be hurried
Asks yes/no and rhetorical questions	Asks open-ended, genuine questions
Holds breath, afraid of being inadequate	Breathes and ignores critical self-talk
Fills the quiet spaces with the "right" words	Knows silence is valid communication
Compels others to hug, and touches in order to stop any crying	Touches with permission, only to connect
Creates a boundary to separate from their pain	Develops heart connection to share the pain



PANDSI

Post & Ante Natal
Depression Support
& Information Inc

Not everyone is blissed out on motherhood

Feeling overwhelmed? Things not how you thought they would be? We can offer you a range of support activities, some with *free childcare

***PANDSI Support Group**
Tuesday 10am—12 noon

***Chillaxing—light exercise, activity and support group**
Wednesday 10am—12.30pm

Pram Walking Group
9.45am—12 noon

Evening Support Group
Thursday 6.30pm—8.30pm

Telephone Support
Monday to Thursday
9.30am—2.30pm

Please contact PANDSI for further information on any of our groups

20 Stokes Street, Griffith ACT
9.30-2.30 Monday to Thursday

6232 6664
info@pandsi.org
www.pandsi.org

Support After Fetal Diagnosis of Abnormality (SAFDA)

This organisation supports parents and families before or after the termination of pregnancy, following the diagnosis of an abnormality in their unborn baby.

If you would like to receive the SAFDA newsletter, please contact Anne Baxendale, Genetic Counsellor, South Australian Clinical Genetics Service at anne.baxendale@health.sa.gov.au

While SAFDA does not currently offer support groups in the ACT, bereaved parents are most welcome to attend either individual or group counselling sessions at our offices here at SIDS and Kids ACT. Phone 6287 4255 for an appointment.



sympathy and compassion

Expressing compassion

Compassion springs from the profound sense of being human and acknowledging the truth of another's experience without pity or fear. Compassion frees us to be courageous and loving, even while sitting with someone who is suffering. When we accept we are not immune from the same fate, we become more skillful and available. Compassion offers a bridge of trust and potential for honesty. The following tools can help us feel more grounded when helping someone with compassion.

Using breath to increase our compassion and reduce stress

Breathing to release our own tension also brings calm to those around us. Try practising conscious breathing by internally counting each exhale as you breathe up to five deliberate breaths, then count your breaths back down to one again.

This process quiets internal chatter and increases our ability to be patient and tolerate silence. You enhance the ability to listen beyond intellect and with your whole being.

Being empty of expectation

It's natural to question our usefulness when meeting with people in pain. It can be helpful to prepare for a visit or telephone call by pausing before we engage with the grieving person. As we prepare to dial their number or while standing in front of their door, it is worth taking time to fill yourself with breath and calm. Empty your thoughts about what you think they need or how they are doing.

Detach from the idea of feeling important or useful and be open to receiving whatever they have to express.

Avoiding thoughts of the bereaved as helpless

Most of us prefer to do things at our own pace rather than being treated as needy. Imagine you are in a similar circumstance; ask yourself how you would want to be perceived.

“Wisdom and compassion are not given to us; they can only be discovered.”

To increase rapport and trust, ask the grieving person or family what they would like more of and need less of during your visits. To receive help is often difficult, especially from a volunteer. Allow for this and avoid sympathizing, which depletes rather than assists.

Moving and talking calmly, without being in a hurry

Each meeting is an opportunity for a heart connection, even while doing a simple task. Increase your patience by slowing your normal energetic pace. Whatever else in your day has come before or will come after this moment with them has no place in this visit.

Adapt to the other person's voice tone and volume. Pace their rhythm for at least three breaths. This is especially important if you want to touch them, offer a massage, or assist them in moving. Ask if there any way you can make this easier or gentler for them. Let them know you want to hear suggestions or requests at any time.

Listening without offering solutions

People in need of medical and volunteer assistance are inundated with suggestions from professionals and well-meaning friends. They may feel incapable of discussion or making decisions about what they will do after the death. Just listening lets them feel the freedom to speak from the heart.

If you are asked your opinion, offer one idea at a time, gently and without ego. Don't try to predict or influence the outcome. If you are asked to assist in making decisions, ask open-ended questions to guide rather than

require instant answers. Allow plenty of silence for them to think over their options.

Allowing others to cry or be silent without interruption

Patting someone who is crying is universally perceived as a signal to stop, and the sadness and hurt are making you uncomfortable. Consciously relax. If you say anything, try, “Don't fight back the tears. It's good to let them out.” If you feel your eyes well up, let the tears roll. You are showing your compassion and shared experience. This is true for professionals and volunteers as well as friends.

Few are comfortable crying in front of others, or expressing strong feelings in front of them. Practice counted breathing, and relax your body. Everyone deserves to have at least one person who allows free expression of fear, tears, and anger without being reminded he or she is supposed to be strong enough to handle what is happening.

Expect to feel upset at times

It's normal to occasionally feel numb or confused. You are connecting with people facing the hardest time of their lives. It's natural to feel guilty at your fortune, or wonder if you could handle their situation with grace.

Compassion means accepting the reality of what is happening in the moment. We all need times of peace and joy. Plan for significant breaks and find places to nurture yourself.

From an article by Cynthia Wall



Staff Profile



**Fiona Vanderhook
Counsellor**

Bereavement Support Team

As a little girl, what did you want to be when you grew up?

I always wanted to be a famous singer. I remember singing into my hairbrush dancing around the lounge room to an imaginary crowd. I loved it!

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

I just want to be the best person I can be and set a good example for my children.

What is your idea of a perfect evening out?

I'm Italian so I love when my whole family gets together and we eat, laugh and enjoy each other's company. The more the merrier and the louder the better.

What is your dream holiday destination?

I'd love to go to Phuket with my husband and children. Fingers

crossed that one day we'll get there.

What is your greatest strength?

As I've grown I realise that my greatest strength is being able to see the positive in everything and also fighting for what is right.

What is your worst habit or vice?

I'm a reformed smoker but I have to admit that I still crave a cigarette on a daily basis. Sadly I've made chocolate my new crutch. Bring on the Caramello Koalas!

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

Being a part of the amazing team of people in the ACT branch and doing what I can to help people and families through unthinkable and tragic loss.

I used to go through my days knowing these sad losses happen but was naively sheltered from it all.

Now my eyes have been opened to the unthinkable tragedies and the raw grief that engulfs bereaved parents. To be part of helping them grow through their grief and move forward though their lives is such an honour. I feel truly blessed to be part of this incredible organisation.

New relaxation/ meditation classes

Take some time out of your busy day and come and enjoy an hour of relaxation using meditation techniques. This is a wonderful way to reduce your stress levels and nurture health and well being.

Classes will be weekly at the SIDS and Kids office on Tuesdays from 10.30–11.30am and are free of charge.

Come along and have a try.

Contact Fiona on 6287 4255 for further information.

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

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

Phone: 6287 4255 or

Email: 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: 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 from any cause. Held on the last Thursday of each month from 6.30pm to 8pm in the Family Room of SIDS and Kids ACT.

Meeting dates: 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: 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.

Multiple Birth Support Groups

A facilitated group for parents who have experienced loss of a baby or babies in a multiple birth pregnancy. Held on the on the third Tuesday of every month. As this is a new group please contact Fiona on 6287 4255 to express your interest in attending.

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