



Reaching Out

September 2010

MESSAGE TO DADS, FRIENDS and SUPPORTERS

This edition presents the theme of Father's Day, a day many of us celebrate in early September. For some, this day is often poignant reminder of our little (or not so little) ones who are no longer with us. Men and dads make up a small yet significant portion of the parents and relatives that use our support services, yet their grief and sadness for the baby or child is no less. To all dads, we hope that this newsletter shows that you are not alone and that there are others there to support you in your journey. You are a father forever.

One of the articles included in this edition profiles a special man who has recently become involved with SIDS and Kids NT. Chris Fairgrieve has just completed our Support Persons training program to enable him to provide support to bereaved families, in particular our dads. Like Chris, we have other wonderful Support Persons and a professional counsellor that can be an avenue for dads, granddads, uncles and all families affected by the loss of a child. If you would like to get in contact with our support services please call 0448 849 234 or 8948 5311.

As this special newsletter goes to print, SIDS and Kids NT embarks on a new direction. Our Annual General Meeting, held on the 24th August farewelled some old faces and welcomed some new. A special mention to Committee members Tracey Scott, Margaret Richards and Naomi Leong, who leave the committee after several years of involvement with SIDS and Kids NT. Their dedication, knowledge and valuable skills will be greatly missed.

SIDS and Kids NT has recently received one-off funding from the NT government for the first time in 25 years. This marks an important recognition by the NT Government of the significant contribution SIDS and Kids NT makes to the NT community through bereavement support and education. SIDS and Kids NT hope that ongoing negotiation and planning with NT Government will lead to ongoing future support.

As this is my last newsletter as the Educator for SIDS and Kids NT, I say thank you to all the families and in particular, the many health and child care professionals who care for these families that I have had the privilege of working with over the last 3 years. I continue my association with SIDS and Kids NT as a volunteer support person and will always hold a passion for education on taking care of our babies.

With that, we welcome Pat King to SIDS and Kids NT as Office Admin/Community Educator and new Committee members, Phil Dempster (Chair), Fiona Peters (Vice Chair), Jenny Djerrkura (Secretary), Arthur Simmons (Treasurer), Chris Paynter, Debbie Gardiner-Munro, Kelly Yates, Cianne Coleman, Peter Kearns, Sarah McNee, Julie Turner, Nicole Whiley and Di Lawrie (currently on leave).

Wishing all our dads peace, love and comfort, especially on Father's Day.

From the team at SIDS and Kids NT.

...dedicated to saving babies lives and assisting anyone affected by the death of a child from conception onwards...

Reaching Out

Stories, thoughts and reflections

Dear friends The following collection includes contributions, stories and poems—some from men who have lost a child or grandchild, others from mothers who have lost their little boys and a poignant few from siblings who have lost a brother. We welcome your contributions to future Reaching Out editions via phone 8948 5311 or email darwin@sidsandkids.org

...the wind in his face, the sun on his shoulders....the exhilaration of the V8 supercars....every little boy's right...working on the Kombi with his dad. He would have loved his big sister...and brother, known as Big Bruz.

**Reflections on 'Kaden the promise of a future denied',
Fiona Peters**

Dear Charlotte

Thank you for being part of my life. I miss you so very much. I am so very proud to call you my daughter. I am so very proud of your strong will that gave us an opportunity to spend that precious time with you. I am sure that you had a very strong personality and an iron will. If you had been born healthy and well, I am sure that it would have been Charlotte's way or no way. I am so very proud of you my beautiful girl and I miss you so very much.

*With all my love always, Daddy.
taken from the book, You Are Not Alone, Nine Months and Nine Days, Andrew Duncan*

*I wonder what colour balloons will be
But as a sister it doesn't matter to me
It can be many colours, I choose red, green and yellow
I think I will pick a colour for a fellow
I will let that yellow one go to the sky
And it will fly very high
Until it reached heaven for a boy
And he will be filled with so much joy
I will keep the other balloons for his brothers and sister
And they will be filled with our little brothers whispers
He did not live for very long and so
Mum and dad had to let him go
He will always be in our hearts
He will forever be our special sweetheart.
So anytime you see a balloon float by
Think of that someone you love in the sky.*

A rainbow makes you think of all the kids in heaven, Sari at age 6.

*Don't cry for me Daddy
Don't cry for me daddy, I am right here
Although you can't see me, I see your tears
I visit you often
Go to work with you each day
And when its time to close your eyes
On your pillow is where I lay
I hold you hard and stroke your hair
And whisper in your ear
If you're sad today daddy, remember I am here
God took me home, this we know is true
But you will always be my daddy
Even though I'm not with you
I am daddy's little boy
We will never be apart
For every time you think of me
Please know I am in your heart.*

*In loving memory of Lucas Christopher Barker
(Taken from Between Friends, Sept 2009)*



NT parents and friends ready to release their balloons in memory of children, May 2010. SIDS and Kids NT inaugural Walk to Remember.

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Males and Grief

The loss of a child is a devastating experience for all family members. The grief that follows has been likened to a wound that needs time to heal while others have likened grief after the death of a child to having an amputation where you now have to learn to live after a part of yourself has been permanently removed. While you know that you will never have that piece of yourself back, you still ache for it and can be overwhelmed by strong waves of grief which can feel insurmountable. It is important to remember that grief and all the feelings and reactions that accompany it, are a normal reaction to loss. This does not mean that the 'normal' isn't painful or difficult to cope with, it just means that experiencing the loss and allowing yourself to feel bereft and in pain is all part of the grief journey that needs to be negotiated.

During the journey of grief couples often find that the ways in which they deal with the loss, while having some similarities, can actually be quite different. There are also expectations placed on grieving parents about how they should behave, feel and cope with the loss. Stereotypically, females are expected to express their emotions openly, to be more accepting of support, and more likely to contact a professional service for assistance. Generally, males are expected to cope on their own, resist offers of outside support, not show or express their emotions, and support their partner by being strong. Often these differences can be wrongly interpreted as the male partner not being as affected or as upset about the loss.

Tom Golden, an experienced grief counsellor who works with male clients in the USA, likens grief to a beast, an enormous, powerful, unfathomable creature which lives in a reality that is so different to our everyday world. Experiencing this beast can be akin to having been drawn out of our familiar world into this reality, where everything is unfamiliar and the landscape is crowded with unknown dangers and instability.

Here is where the beast resides, waiting for your journey to begin, the journey of approaching, sitting with and confronting this beast while navigating through the wilderness of this foreign reality. This foreign reality can be chaotic and while everything on the outside is going on as before, everything on the inside is in turmoil resulting in a sense of helplessness and a loss of control.

The feelings that are experienced when one faces the beast can be powerful, unrelenting and all consuming. These may include anger, sadness, helplessness, guilt and loneliness. Often males will attempt to fight the beast rather than navigate their way through this foreign reality. Navigation through the unfamiliar world of grief can be a difficult and lengthy task that often seems overwhelming. We can feel that we are cut off from our own world, that we are restricted and confined by the beast and that at times that the beast controls our life. When we feel powerless we often try to gain back some of this power by looking for someone or something else to blame or to focus on. However, often there is no one or nothing at fault and we may end up blaming ourselves. It can be even harder to accept that the loss is due to an unpredictable or random event that cannot be controlled nor prevented.

In terms of coping with grief, males tend to connect their grief with their actions. This means that problem focused or more active coping strategies may be more beneficial in order for males to navigate their way through the beast that is grief. For example males may prefer to keep busy after the death and may choose to return to work after a few days. One father who lost a baby at full term commented; "I went to work the day after he died. I know some people thought it strange, but it was good for me. It kept my thoughts away from what had happened. If I had had to stay at home, I would have found some work there. It helps me to use my hands"

**This article was written by Sharon Hillman,
Ph.D. Candidate,
Edith Cowan University**

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After some time has passed some men may seek to become involved in activities that help them to further work through their grief. For example, something might be done in a way that honours the lost child such as volunteering in a community group, where thoughts and feelings could be communicated as a means to advancing the agenda of the group. Others may create memorials to the child, such as planting a fruit tree or building a chest in which to store mementos. Often we see male sporting players dedicating their game to someone they lost by wearing black armbands, while other males may dedicate a scholarship, book, poem or piece of music to their lost child. Each of these kinds of activities gives the father the opportunity to connect his grief with public or useful actions.

Often people do not know how to respond to a man, who is grieving, resulting in them withdrawing from contact with that person. Whilst many men may choose not to discuss their grief, others appreciate being given the opportunity to share their thoughts and feelings. A father reflects after neonatal loss; "I was alone that weekend. Female friends came to visit my wife in the hospital. They hugged her, talked to her, allowed her to cry. Men didn't come to see me, to let me cry and tell them how I felt. How was I to grieve over this loss? Men don't comfort each other during these painful times, but I am sure most men must have feelings similar to those I felt. Later, men told me they had seen me and turned away because they didn't know how to react or what to say". A simple acknowledgment would have been helpful in this situation.

Some ways that may help males navigate the beast of grief involve having some one, such as a close male friend, relative or colleague who;

- Acknowledges the death and tries to understand,
- Expresses genuine concern for the survivors,
- Is accepting and non judgemental,

- Is trustworthy and will hold confidences
- Will share silences and just be with the father,
- Performs incidental acts of compassion such as easing the workload on return to work,
- Asks how they are going, not just assuming only women are hurt by loss, and
- Is honest enough to comment when behaviour is unacceptable (e.g., abusive or inconsiderate to others, unnecessarily risk-taking, substance over-use, over-working, ignoring the living etc).

Holidays and other special days such as Father's day can be a particularly difficult time for men who have lost a child. Often these days are associated with painful memories and exploration of what might have been. However, it is also a good opportunity to celebrate your child and your family relationships. It is important to plan ahead for special occasions. Some tips include;

- Go easy on yourself and your family,
- Begin a new tradition, such as planting a tree, taking a picnic to a special place or visiting the memorial or gravesite,
- Write your thoughts in a journal,
- Plan and hold a memorial service,
- Help others, for example, volunteer with a local community service,
- Acknowledge that you are a father, even though your child is no longer alive,
- Share your favourite stories and music with loved ones over a meal,
- Make a toast or light a candle in remembrance,
- Make a donation in your child's name,
- Spend time with others you care about and who care about you, and

Don't surround yourself with people who are negative or have demonstrated that they do not understand.

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The journey through the foreign world of grief can take years to navigate. Males and females may find different ways to make this journey and sometimes there is no end, just twists and turns along the path. There is no 'correct' way to cope with loss, and differences, while sometimes difficult to deal with, can also provide opportunities for sharing which can enhance couples understanding of each other. It is important to keep the lines of communication open and not to make assumptions or judgements about how your partner is feeling. It can also be helpful to make parts of the journey through grief together, while other parts may need to be explored alone. It is also normal to have good and bad days throughout this time. Eventually you will have more good than bad days, but grieving is one thing in life that cannot be rushed - it will not conform to any schedule. The acute pain will eventually fade, and it can be replaced by a deep acknowledgement that your child was and always will be a part of your life, a part to cherish, to share and to celebrate.

So much more than SIDS....

SIDS & Kids NT offers services to families and friends who have lost a baby or child *through any cause of death*, including miscarriage, stillbirth, accident or illness.

Phone: 0448 849 234

Support Persons Program

Earlier this year, SIDS and Kids NT held a two day training program for people interested in offering emotional and practical support to bereaved families. The program was facilitated by SIDS and Kids NT long term counsellor/psychologist, Margaret Lambert. In addition to the training, post training interview process was undertaken with participants to assess their readiness to take on the role of Support Person.

SIDS and Kids NT welcomes six new support persons to the program: *Fiona Peters, Chris Fairgrieve, Christine Dunleavy, Sonia Fenwick and Rachel Dunne.* *Kelly Yates and Dianne Lawrie*, long term support persons also undertook refresher training and continue in this support role also.

Chris talks of how he came to be involved below:

"I got involved through my wife Christine who works with a few volunteers for SIDS and Kids NT. I had thought about volunteer work for some time however didn't know exactly what to do. This support person role when I read it immediately appealed to me so I signed on for the course. The course opened my eyes to the important role SIDS and Kids NT plays in the community. Prior to this I believed that the organisation only dealt with infant deaths. This new knowledge just cemented my determination to get involved."

If you would like to speak to one of our Support Persons please call **0448 849 234**.

Walk to Remember

SIDS and Kids NT held its inaugural **Walk to Remember** in late May at Sanctuary Lakes, Palmerston. Parents Fiona Peters and Craig Redriff organised the walk as way to honour their child and others who have died. Siblings were treated to face painting and treats, parents shared poems and stories about their little ones and balloons were released into a rainy Darwin sky in memory of loved ones. We hope this walk will become an annual event on the SIDS and Kids NT calendar.

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Red Nose Day wrap

People from all over the Territory donned a red nose to support our campaign during June.

Red Nose enables our organisation to provide grief support to those affected by the loss of a child, from conception up to 18 years of age regardless of cause of death. A proportion of the monies raised is also injected into research aimed at finding ways to save more babies lives. The good news its that more babies are alive today due to the delivery of our Safe Sleeping programs funded by community generosity.

SIDS and Kids NT particularly acknowledge the support from the following:

ABC Moulden North Child Care Centre
Air Liquide
Casuarina Square
Darwin Middle School
Darwin office Technology
Gardens Park Golf Links
Harley Owners Group
Kezia Purick
Kiwanis Club of Casuarina
Mindil Beach Sunset Market
NT Fleet
Palm City Oasis
Palmerston Shopping Centre
Palmerston Shopping Centre Community
Wheel
Toll Express NT
Tracey Village Sport and Social Cub
Variety NT
Tracey Myles
Tracey Scott
Natasha Griggs
Majestic Orchids

Alisha Staines
Chris Fairgrieve
Chris Paynter
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Kerry Huddleston
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Nakita Staines
Natasha Griggs
Nate Rowe
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Peter Chandler
Peter Kearns
Ross Bohlin
Sally Black
Sarah McNee
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Sophia Lam
Taylah Peters
Theresa Jolly
Veronica Edwards



Special dad and tireless volunteer, Craig Redriff, daughter Taylah and volunteer Jasmine.

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to
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Father's Day
newsletter