



NATIONAL TWIN LOSS SUPPORT NEWSLETTER

February 2014 Edition

Editor: Lynne Harford

“Celebrated 21 Years in 2013!”



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Editorial

Welcome to 2014! Much has happened since our last edition in November 2013.

The Bike Run on 29 December 2013 to Two Wells in SA was successful in the fact that it reached out to someone new, and helped spread the word as to what NTLs is all about. However, only having one person join Sean and I for the run was a little disappointing. Never one to waste any opportunity that presents itself, I made a brief video and published it on our Facebook page, as well as on YouTube. If I keep adding these short little clips, someone may eventually take some notice.

Membership through our Facebook page is steadily increasing, and it is wonderful to see members starting to communicate with one another through this medium.

1st March will be our inaugural ‘Fluffy slippers Day’. The aim is to spread the message about twin loss issues, and create a bit of fun with people sending in photos of themselves and their fluffy slippers. The sillier, the better. Laughter is a positive relief during grieving. I’m not asking people for money; just asking members to put on their slippers for a day, and get people talking. Afterall, if people can raise awareness for good causes by running around in their undies, surely we can don a pair of fluffy slippers!?

We continue to publish the findings from our 2008-2010 questionnaires, and in this issue we look at question 5 and how much support people received from friends and family after the loss of their twin/twins.

I have acknowledged that NTLs is too small to be able to provide its own counsellors, so a link to professionals in countries such as Australia, New Zealand, the UK, US and Canada, is now available on our website. Afterall, I’m the person who keeps saying not to duplicate resources and there are already many charities with their own counsellors.

Bit of unfortunate news was recently received. The publisher of “The Survivor”, Winepress Publishing, has closed. We are now looking for another print-on-demand publisher to use. Amazon sadly is a ‘no-goer’ as they will not pay funds into an Australian bank account and it will cost me \$15 a time to cash a US royalty cheque. So watch this space everyone, while we keep searching!

Yours in bereavement care,
Lynne Harford



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“The art of living lies less in eliminating our troubles than in growing with them.”

(Bernard M. Baruch)



Grief is a Thief! By Lynne Harford

Grief is one of the most difficult journeys that each and everyone of us faces during our lifetimes. We don't just experience grief once, but many times over. As a child we may grieve for a grandparent or parent who has died, or a toy we have broken; whilst as a teenager we may grieve for the childhood we have left behind. As a young adult we may grieve for the job we have lost, or the relationship that wasn't to be; whilst in our later years we will grieve for those friends and family members who have died.

People who haven't experienced parental death, or the death of a baby/s, may find it difficult to comprehend the fact that death does not occur in a nice, neat little package at the end of the human life-cycle. It can occur at anytime. The accompanying grief associated with death in particular, when released, is cruel and at times, unrelenting. And for an experience that all of us will endure many times over during our lives, it continues to remain misunderstood, and something that 'polite people do not mention in public'.

I see Grief as a common thief. It robs us of our self-confidence, and strips us of our self-esteem. It dissolves our ability to trust others, or even to trust ourselves. It makes us selfish as we desperately seek the love and support we crave.

Grief erases our ability to make clear and rational decisions, making it almost impossible to function in the workplace, social and home environment. It saps our energy and takes away our independence. Grief traps us in a box, slams down the lid and bolts it down tight, leaving us hunching in a dark corner, clutching our knees, and crying uncontrollably for someone to please listen to us. Finally, grief can rip out the happiness from our souls, and destroy our relationships.

The journey becomes all the more challenging because each journey is personal and individual. It is influenced by religious beliefs, cultural and societal factors, plus our own personality traits.

But grief can do more than just destroy. Grief has another side that we cannot always see on our own; one that is not always gifted to those unwilling to open their hearts and minds.

Grief can rebuild, and allow us to reinvent ourselves, often giving us a new direction in life. It can forge new, more deeper friendships and strengthen old relationships. It can make us more resilient, compassionate, and loving. The grief experience can teach us how to understand, listen and be patient. When grief becomes our master we are blinded; but when we become its master, we become better people.





The Latest News from our good friends at OzMOST!

On behalf of OzMOST, I hope that you all had a meaningful and happy break over the holiday season, and that 2014 is a good year ahead for you and your family.

With 2014 gaining momentum, OzMOST continues to grow. New members continue to join our circle of support and I look forward to journeying together - sharing our grief on the sadder days and also celebrating our surviving twins, for the milestones they reach as the years go by. The beginning of the year often marks significant milestones, such as surviving twins starting school. My surviving twin has just started highschool and I have been reminded once again of the bittersweetness that such moments bring. It seems, as the years go by, life is a series of "firsts" that we watch our surviving twins experience, always with a sense of wondering what might have been.

At OzMOST our surviving children are always thought of as twins, and in honour of that I have launched a series of photographs called "Twin Things".

They can be viewed online at my page, and are available for sale on request:

<https://www.facebook.com/Pict4YouPhotography>

email: pict4You@tpg.com.au

If you would like a more personalised image, I am more than happy to add your twin names to the photograph you wish to order.

Please also feel free to contact me with enquiries about membership for OzMOST (OzMOST@tpg.com.au)

Julie Bryant

Promotion & Marketing with Sean McPherson

Hello folks,
Our small team is growing, and I am very pleased to announce that a very good friend, Linda Castle, is joining our team, offering to be a back-up vehicle driver on our fundraising adventures.

Linda has a long history of volunteering, when she finds time from her nursing career. She has been involved with a scuba diving club, the State Emergency Service, Dog clubs, Yachting, and she was a Torch Bearer in the 2000 Olympic Relay around South Australia! Her current hobby is tracking with her Rhodesian Ridgeback, Tilly, (don't get lost in the bush, because she WILL find you!!)

Linda is not afraid to pitch in and will be a very welcome asset to our ever-growing team. Don't forget to keep talking to people about NTLs as you never know, one day you will talk to the right person, who will take notice of us and help us out.

Cheers, Sean

Note from Linda: "I have another puppy too...her name is Abby and we hope she will become a show dog"





2008-2010: NTLs Research Project

Investigation into the quality and type of care provided by Health care professionals to Multiple Birth Loss Families after the Hospital Stay.

By Lynne Harford

We continue our series regarding our project where 15 participants from countries such as Australia, New Zealand, Canada and the United States, kindly provided their thoughts and experiences regarding their own multiple birth losses. All information has been used with permission.

Responses to the question: “How did you feel that your needs were met, by your family and/or friends?”

Joanne—Canada: “One member of a family was supportive, a couple long distance friends we never met at least sent a card, and one local friend was supportive. We had no support from anyone else. The worst part was none of our sisters, (both sides of the family), had any interest in our loss of our sons. And only two persons showed up at the funeral.”

Elizabeth—Canada: “My family were so supportive as I needed them to be. For the most part they respected our need for privacy in the initial couple of days. There were a couple of clueless idiots who “dropped in” to the hospital and didn’t get that this was the ‘best’ and also the ‘most devastating’ day of our lives, and strangely, we didn’t feel like being social.”

Jane—New Zealand: “.“ Our friends and family were amazing at rallying around us, and helping us speak out against the health system so that other mothers don’t have to go through what we did. Friends through the multiple birth club were also fantastic at supporting us and helping us present our case to the Commissioner.

Kim—Sydney, NSW: “Friends and family avoided the subject, as not knowing what to do and say ... like life as usual, and still do!”

Jenny—Port Pirie, SA: “My immediate family were superb, but friends didn’t know how to handle our situation. We were not like the “normal” family as was expected; Ben dying, Kate so ill.”

Angela—Sydney, NSW: “Some family didn’t even contact me probably because they didn’t know what to say, but I found it so k bizarre that at a most terrible time in my life, they were completely absent. Some close family members kept asking if I was better, which drove me to despair. I wasn’t Ill! No one seemed to know what do do for the best, including me. I realise now that I just needed someone to listen to me, someone who wasn’t going to get uncomfortable with my grief, and who wasn’t going to try and offer solutions. Just someone to listen with compassion, was probably what I needed.

My husband thought by talking about things and talking about Callum specifically would result in me taking a back step. I tried to explain a couple of times that this was not the case; talking and crying eased the weight I was carrying. A close friend who was with me a lot after I lost Callum, after 3 months, stopped asking about things and coming to see me, which has made me feel she thinks I should be over it by now, and I don’t feel I can tell her how things are when they get bad. Another close friend has fortunately, been there for me from the start, and is still sensitive towards my loss now, and will ask how I am, and I feel I can tell her truthfully how I feel.”

Bindi—Bendigo, VIC: “Family hassled me about arranging a funeral the same day I got discharged. Social worker told us home help etc., would come and help—but never did. Friends kept ringing which was annoying as I couldn’t talk properly.”

Anon—Adelaide, SA (lost both twins): “Family and friends met my needs initially by acknowledging our loss, and giving us time and space to ‘recover’. However, they do not understand the impact of losing our babies has had on our lives, and how this will remain with us forever. Some cringe when I



mention the twins, others pretend not to notice, others make silly comments about how they know how I feel. Some family still send cards/emails on the twins' birthdays, but others don't acknowledge them at all. The twins were the first born grandchildren on my husband's side of the family, but this is never acknowledged."

Annette—Sydney, NSW: "I always said you find out who your friends are when you lose a baby. Most family and friends were great. Some however, still to this day, haven't mentioned Chloe. At the time of the loss, I didn't want to talk to anyone, and I think people assumed I still feel that way, but I don't! I want her acknowledged all the time."

Linda—Brisbane, QLD: "My parents were wonderful. My husband's parents were very good, but I felt that they were from the old school of thought. She lost a baby at seven months and was expected just to forget about it and sometimes I felt that she was suggesting we do the same. That hurt. My friends did not want to talk about it really, they were sorry for us, but just couldn't face it themselves."

Narelle—Bunbury, WA "Friends varied. Some were very open to talk about the situation and others avoided it altogether. Some friends just stopped all contact which was very disappointing. Two friends really came through for me, and were with me every step of the way. Since I've returned home, it has continued to vary. Again, some friends have really been there for me, and others just haven't been able to be here at all.

I've also been reluctant to 'burden' my friends so some of this is due to me. Often I felt that I had to be the strong one—sometimes had to comfort them at a time when I really didn't have the energy or means. Family live interstate, but have been good in keeping in regular contact. My mum came over to Perth and stayed here the whole four months from diagnosis of TTTS, until after the boys were born. My dad didn't handle it very well and didn't make much contact throughout that time, which was upsetting and disappointing."

Emily— USA: "A few friends were supportive. My husband's family was awful. They never acknowledged the loss of the twins, and were very unsupportive when we couldn't go to family events where my sister-in-law was as we were pregnant at the same time."

Sylvia—Adelaide, SA: "The majority of our family and friends were very supportive and rang, visited, brought us food, etc. A small number of our close friends weren't as supportive as we had thought they might be. This may have been because they were unsure of how to deal with the situation, or they were very busy."

Sally—Bright, VIC: "Family was fantastic, friends were mixed—some people who I hardly knew were a wonderful support, and many of them have now become close friends; others kept their distance and at the time this was very upsetting."

Rachell—New Zealand: "I just wanted to grieve without anyone else—that included my husband, (I felt I couldn't deal with his grief as well as my own). My children needed me to go on, but I just didn't want to. Some people felt they kept me going but I didn't want to keep going. Yes, I was suicidal at one stage, but when I wasn't, I still wanted to grieve."



" Your mind is what makes everything else work ."
(Kareem Abdul-Jabbar)



STOP PRESS!

We may have found a suitable publisher in Lulu, based in the United States. They pay royalties by cheque or paypal, meaning we can have funds deposited into a paypal account. Lulu publishes in print-on-demand and e-book format, and have distribution avenues through Amazon and several other large overseas bookstores.

So we now just need to find some time to finish updating the manuscript, before handing it over to our manuscript editor for a final look. Hopefully we will be one step closer by the next newsletter!

Why NTLS does not provide counselling services

It is important to be aware that grief is extremely complex. Whilst a bereaved parent or family may have required grief counselling to initially assist them during their early time of loss, parents and couples who experience multiple birth loss need to be aware that they may require other types of counselling to assist them in maintaining their personal relationships.

Often during times of loss, communication misunderstandings between partners can result in the complete breakdown of the relationship, leaving couples feeling bitter towards each other and blaming each other for not providing the emotional support that the other needed. Realistically, it is not always possible for both parties to provide support during times of grief.

It is therefore, not uncommon for bereaved families to not only have to endure the pain of infant death, but to undergo the devastation of divorce as well, simply because the communication channels broke down. In these situations, marriage or relationship counselling may prove useful in helping to ensure that the communication channels between partners remains intact.

NTLS has therefore provided a directory of professional counselling and psychiatric practitioners in several Western countries. We are happy to add any other links that may prove useful to our members.

Contributions

If you would like to make a contribution to our newsletter, please send your photos, information, announcements to:

enquiries@nationaltwinloss.org.au and put the words “**Newsletter Contribution**” in the Subject field of the email.

We will be happy to publish your items relating to multiple birth loss issues.

Please ensure that permission has been obtained from the author if not your own work, and advise if it has been previously published in another bereavement care organisation’s newsletter so an acknowledgement can be printed.



**“If you do not hope,
you will not find
what is beyond your
hopes.”**

(St. Clement of Alexandra)

National Twin Loss Support

ABN: 69 695 149 922

PO Box 3157

Salisbury East SA 5109

Australia

Phone: 0419 039 194

Email: enquiries@nationaltwinloss.org.au

Website: www.nationaltwinloss.org.au

FaceBook Page—NTLS:

<https://www.facebook.com/#!/groups/49624969102/>

FaceBook Page—SAMBS:

<https://www.facebook.com/#!/groups/150126301514/>

