



NATIONAL TWIN LOSS SUPPORT NEWSLETTER

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Editor: Lynne Schulz

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Editorial

It's been great to receive requests for assistance from other organisations. It shows that networking is alive and well!

Recently a couple of groups have asked us for specialised multiple birth loss information to assist bereaved families.

This shows two things. Firstly, there remains an almost desperate need for multiple birth loss resources and secondly, that NTLs is becoming more widely known throughout the bereavement care world.

Let's keep up the good work, and continue to produce valuable and much-needed multiple birth loss resources so that they can be shared with our fellow bereavement care providers.

Yours in bereavement care, Lynne Schulz.

Project '08 Update

The initial interest in this project has definitely dropped during the past few months. At the time of producing this newsletter, 12 questionnaires had been returned. Here is the breakup: Australia: 8, Canada: 2, New Zealand: 1, and United States: 1.

Why persist? If multiple birth loss families are still sharing stories that health care professionals remain unsure of how to look after their unique needs and wants, then surely the need for further resources remains.

When people in the wider community stare blankly at you because they were unaware of the existence of organisations such as National Twin Loss Support, after they have told you that 'they lost a twin at birth' for example, then the communication process is broken somewhere along the line.

Numerous studies have already been done which support the fact that multiple birth loss families and their surviving multiple birth children need specialised care. However, useful and credible resources which build upon these studies, appear to remain few in number, when compared to the resources available for singleton loss families.

Multiple birth loss will not disappear. There are organisations in the world that cater for the needs of the adult multiple birth survivor, and from visiting some of these sites, and reading the stories and information published, they are desperately needed.

However, what about the huge gap in between, from birth to adulthood? "The Survivor" was written to try and fill this void, but unless people know it's available, it's pretty much a wasted resource.

Therefore, when stage 1 of this project closes at the end of June 2009, the number of questionnaires returned will not dictate whether or not the project continues, i.e. working towards creating a work booklet for health care professionals, but will determine as to what type of new resource will be created, e.g. Another book instead of a workbooklet, a new type of support pack, etc.

Remember—nothing is wasted in life. Experience, no matter how insignificant it may seem at the time, will always prove to be a valuable resource at some stage. Just remember to keep it safely filed away.



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New Brochures

There are now brochures available in the members only section of the National Twin Loss Support website. Two of the latest additions have been based upon the books, "The Diary" and "The Survivor".

These resources are for members to print out and distribute as required.



Imagination is
the one weapon
in the war
against
reality.

Jules de Gaultier



Networking

This is a term that has been thrown around quite a bit during past years. So what is 'networking' and what is its purpose?

'Networking' is a collective term where groups or individuals work together to achieve a common goal. It is just like a form of 'teamwork' except that each team player may be in a different location and work for a different organisation.

What does this achieve? Firstly, it avoids the doubling up and wasting of valuable resources and time. Secondly, it allows people to specialise. For example, National Twin Loss Support specialises in creating resources for multiple birth loss families, health care professionals, as well as other community organisations who help care for such families.

When National Twin Loss Support was first formed in 1992 under the name of 'Murraylands Lutheran Stillborn Infant Support Service', the main aim was to 'network' with other bereavement care organisations. This strategy proved successful, and through establishing contacts with each different organisation, families were referred to the group that could best cater for their specific needs.

During recent years, it has been observed that some groups enjoy a greater share of the bereavement care market and are reluctant to lose any of it to another group. In remaining steadfast in wanting to keep their larger share of the market, they inadvertently push other participants aside, often to the detriment of the bereavement care industry overall.

As a result, feelings of frustration may arise between groups that had initially intended to work together. It also creates confusion, not only amongst health care professionals who are swamped with an ever-increasing array of bereavement care organisations, all trying to help, but causes confusion amongst bereaved families themselves, because they don't know which group will best serve their specific needs.

It is interesting to note that when National Twin Loss Support was first established, it was initially viewed as a 'threat' by larger bereavement care counterparts. Thankfully over the years, this fear of new bereavement care providers has decreased and NTLS has slowly been accepted into the bereavement care world as a valuable colleague and team-player.

Teamwork involves good communication, honesty and integrity. Let's continue to work with our bereavement care colleagues in supporting these key elements to improve bereavement care for all. After all, we can't do it alone and it makes so much more sense to work together than against each other.

I think I've discovered the secret of life — you just hang around until you get used to it.
Charles M Schulz

Visit our Gallery

The 'Gallery' is another new addition in the members only section of the National Twin Loss Support website. At the present time there are only a small number of photos from past years but that will change—with your support of course! So, if any members are out and about doing interesting things, please email a photo to 'twinloss@internode.on.net' with some details and we will add it to our collection!



Fundraising Update 2009

ACCU Raffle Tickets: Our application to sell raffle tickets with the Australian Central Credit Union's Community Lottery was successful! Although we have only applied for a small number of books, (5 to begin with, and if available at a later date, another 5), it is still a positive start to the fundraising year.

The Australian Central Credit Union initiated this scheme so participating charities and sporting groups could raise funds without any cash outlay. For more details visit the ACCU website:

www.australiancentral.com.au.

Book Sales: Although not in the league of Harry Potter, our books continue to sell at a steady pace. The main retailers are The Australian Online Bookstore, and Amazon Books. The drop in the Australian dollar means that royalties from The Survivor, (which is produced in the US), are really good value, so keep those book sales happening.



Donation Buckets: We are trialling the use of small plastic donation buckets to encourage people to give their spare change to the NTLS organisation.

The first donation bucket has been placed into a small business in Murray Bridge, South Australia and will be left there for a few months to see how successful the idea is. Donation buckets, tins or boxes on shop counters are not a new concept, but it is the first time we are testing them out for our own organisation.

We need the support of the local business proprietors for this idea as well. If nothing else, it will help with getting our name out into the wider community. So keep your fingers crossed!

Your Say

If you would like to make a contribution to our newsletter, e.g. 'letter to the editor', short story, a picture, we would love to hear from you!.





A MOTHER'S PERSPECTIVE *(Taken from "The Survivor", 2003).*



Mothers are in the unique and special position of being able to bond with their unborn babies during pregnancy. This physical and emotional connection is considered by some as unconsciously occurring almost from the moment of conception. We make plans for our unborn children, create marvellous nurseries, and prepare our homes to welcome our new arrivals. The phrase 'feathering the nest' is thus commonly associated with pregnant women who are preparing their households in readiness for their anticipated new arrivals.

Another interesting part of pregnancy is 'intuition'. A woman's intuition, (or that little voice inside), which was once scoffed at by medical professionals, is now being treated with more dignity and seriousness. It is because of the bond between the mother and child, or children in the case of a multiple pregnancy, that a woman has the distinct advantage of knowing when something is not quite right. In many cases of infant loss, women who felt that there was something wrong during their pregnancies, were more often than not, correct.

When something goes wrong in a pregnancy a mother can feel that she has failed her unborn child or children in a major way. She may feel that she has failed in providing the safe protected haven that should have been there. She can think that she has lost control of what her body does and this can cause endless emotional pain and frustration.

It is indeed a great shock to some, but usually exciting, for most mothers to be told by the doctor that they are going to have twins, triplets, quadruplets, etc. The loss of one or even all babies thus becomes even more traumatic. It can be extremely stressful when a mother who has spent months enduring an uncomfortable multiple pregnancy, finally gives birth, only to have to watch one or more babies struggle in isolettes and on life support systems.

However, many bereaved mothers will state that they would have rather had their children for a short time, than never to have had them at all. It is therefore important for families who have had losses in a multiple pregnancy, to have all of their children, acknowledged and recognised by friends, family and health care professionals. Singleton loss families are afforded this luxury—multiple birth loss families only ask for the same.

A FATHER'S PERSPECTIVE

(Taken from "The Survivor", 2003).

Fathers are often the forgotten ones during infant loss. Everybody, from the medical staff to the grandparents tend to forget that it took two people to initially create the baby, and that males have emotions as well, albeit different ones.

We, as females, must remember that the males are just as lost and lonely, and perhaps just as frightened about the whole deal as we are. So, when it comes to speaking about experiences regarding infant loss, and twin loss issues, men are usually the last ones to be considered as having an opinion on the subject.

Many women will remark, "He just doesn't care!" Men have difficulty in understanding the situation, in expressing their needs. They have had to endure the event of pregnancy from a distance because they are not the ones who had the unique opportunity of bonding early with the unborn child in the same way as we women.

Aside from the obvious biological differences men also have different emotional needs that are almost always forgotten during any form of emotional crisis. Many people in our society still seem extremely shocked to hear that men have emotional needs in the first place!



Communication is the key to successfully coping with infant loss so don't forget to keep talking to each other!

FOUNDER SELECTED FOR AWARD

Founder and Coordinator of National Twin Loss Support, Lynne Schulz, has been selected for one of the categories of the Australian Centre for Leadership in Women for 2009.



Winners will be announced on Sunday 8th March, which is International Women's Day.

Please keep your fingers crossed as we hope for a positive outcome. It is awards such as this that helps to raise awareness of multiple birth loss issues throughout the wider community.

Winners receive prize money starting from \$500 so to win would really be a boost to this year's fundraising goals.

If you're interested in finding out more about the Centre for Leadership for Women, please visit their website: www.leadershipforwomen.com.au





Interesting Behaviour Patterns

“Some of the behavioural patterns displayed by surviving twins, especially those of a particularly young age, appear extremely interesting. The survivor may behave in an angry and inconsolable manner, possibly due to the fact that they simply, miss their deceased twin. The twin unit is no longer a whole, and I truly believe that we will never fully understand the complex relationship that belongs solely to the world of twins.” *(Taken from The Survivor, 2003.)*

Meet our Patron!



University of South Australia Lecturer in nursing, Dr Jane Warland PhD has kindly accepted to be the NTLS patron.

Dr Warland has over 30 years experience in nursing, and is a world-renown author of the books, “Our Baby Died”, “Pregnancy After Loss”, and “The Midwife and the Bereaved

Family”. She has written many research papers on the topics of infant loss, and the effects of grief upon bereaved families.

National Twin Loss Support is honoured to have the support of such a note-worthy health care professional!

We're on Facebook!

Modern technology can be a most useful thing at times. Thanks to cyberspace, and all the trends that evolve from its existence, National Twin Loss Support now has a group listing with Facebook—the craze that seems to be sweeping the entire nation, if not the world!

Our group is listed as ‘closed’ which means it will be secure from the general public and can be found under “Non-Profit Organizations”.

A couple of links have been placed in our members only section; one for New Members to join our facebook group, and the other one for members to access the facebook website.

If you wish to join, or to simply access Facebook in general, please make use of these links.

The plan is to spread the word about NTLS and interestingly enough, within the first 24 hours of the group being formed, there were enquiries from 6 new people.

So, now there is absolutely no excuse why we all can't communicate with each other on a regular basis. Meeting fellow multiple birth loss friends and colleagues has never been easier!

NTLS Resource Packs

During 2002-2006, under the name of “Murraylands Twin Loss”, our organisation worked with Apex Australia to develop and distribute over 200 Twin Loss Kits to maternity hospitals, Universities, Church groups, Government agencies, Kindergartens, Emergency Service Groups, as well as other bereavement care organisations, right around Australia.

Since the project concluded in June 2006, we have received a number of enquiries about them. In response to the community need, we have created the “National Twin Loss Resource Pack”.

This pack contains the books, “The Diary” and “The Survivor”, as well as copies of several of our brochures. Because the packs have not been funded through grants or charitable donations, they will be offered for sale at basically, cost price, i.e. \$60 (Aust.) each, which includes postage within Australia.

Packs will be made-to-order so when an organisation, or an individual wishes to obtain a useful multiple birth loss resource, they will once again have access to

valuable and vital information.

NATIONAL TWIN LOSS SUPPORT



RESOURCE PACK

ABN: 69 695 149 922
Postal: PO Box 1139
Murray Bridge, SA 5252
Phone: 0419 039 194
Email: twinloss@internode.on.net
Website: www.nationaltwinloss.org.au

National Twin Loss Support was established in 1992 under the name of "Murraylands Lutheran Stillborn Infant Support Services" to bridge the gap between rural and city bereavement care services. In 1999 the organisation changed its name to "Murraylands Twin Loss" to better describe the change in direction the organisation had taken in specialising for the needs of multiple birth loss families, as well as the health care professionals and community based organisations dealing with such families. In October 2006 the name was altered to its current format of "National Twin Loss Support" to cater for future expansion of the organisation.

This Resource Pack was inspired by the work done during 2002-2006 during the creation of the "Apex Australia Twin Loss Department" as a national service of their kind in Twin Loss care in Australia. This resource pack will be available where the Twin Loss Kit project finished, by providing up to date multiple birth loss information for use by bereaved families, health care organisations, and other community based groups.

This pack contains the following:
BOOKS: "The Diary", author: Lynne Schulz, published 1998, Clever-Close Independent Publishers, South Australia
"The Survivor", author: Lynne Schulz, published 2003, Pleasant World, United States
BROCHURES: Some of the Reasons for Twin Loss, Starving Twins, Coping with Twin Loss, Questions from Parents, Don't Give Up Hope!, New Membership.
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