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NATIONAL TWIN LOSS SUPPORT NEWSLETTER

Summer Edition Editor: Lynne Harford Vol.5

December 2009

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Editorial

It's been fairly quiet during the past three months, but that's ok. Quiet times don't mean disaster for a charitable organisation. They



simply mean that people are busy attending to their own personal matters.

Membership to the NTLS website is steady and it is great to think that people are making use of our multiple birth loss resource material.

Some major personal adjustments in my own life have kept me pre-occupied during this time, so less commitments to NTLS have allowed me to sort a few things out, refocus and get back on track.

I haven't had many speaking engagements of late, but I'm pleased to say that I will be speaking at Kiwanis Club a meeting, in Brighton, South Australia on February 15, 2010. That will help to widen community awareness about multiple birth loss issues, and I am quietly hoping that the group gives a donation on the night as well.

US Publisher, Pleasant Word is keen to see the 2nd edition of "The Diary" happen, but of course the timing of it will depend entirely upon fundraising.

Christmas can be a time of mixed feelings as we celebrate with our survivors. and experience a permanent and deep sense of loss for our multiple children who have died. However, remember that support is important and if you need someone to chat to, please remember to contact one of our support workers, Julie or Karen, via the NTLS website.

Have a peaceful Christmas and New Year and I'll catch up with everyone again in 2010.

Yours in bereavement care Lynne Harford Founder NTLS



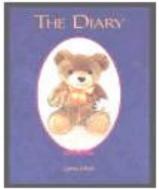


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- A piece from "The Diary"
- A piece from the sequel to The Diary; "The Survivor"
- Grief is an Individual Experience
- Don't forget to use the resources available in the 'Members Only' section of the NTLS website!
- Another piece from the sequel to The Diary; "The Survivor"
- Exciting news with the successful separation of conjoined twins in Melbourne!

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A piece from "The Diary"



The difference that I with maternal noted grief is how others around us react. Babies (whether who die, during the pregnancy or shortly after birth), have had such a short existence compared to the rest of the world's inhabitants. This makes

any tangible piece of evidence that they even existed, worth its weight in gold to the parents. Sometimes all parents have is a memory, and that makes the whole situation all the more sad.

Society seems embarrassed about babies who have died. It is alright to speak openly about an older person; there are photographs, letters, amusing stories to share about them. But mention the name of a baby who has died, who has lived such a short life, and a deafening silence invades the room. Conversation ceases. People look at the floor, the walls, and then within a few moments decide to discuss the weather.

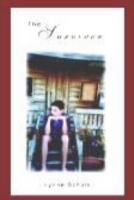
I guess I'm standing up for the rights of these children. They, and their families, are the forgotten ones of our time, and we should be ashamed of ourselves for it! Let's share our stories, our pictures and even our tears with all those around us. I pray that one day, society will mature enough to realise what a silly error it has all been.

(Chapter 9, 'Final Note', p83, "The Diary").



A piece from the sequel to The Diary; "The Survivor".

Sometimes parents may notice that their surviving twins, or higher order multiples, (particularly if a sole survivor), 'disappear' into their own little world within their own minds.



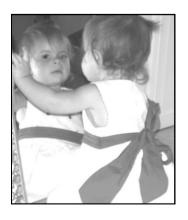
They appear to mentally withdraw from the room

even when they might be right in the middle of a conversation and don't 'reappear' until a few moments later. Although this form of behaviour can be noted on thousands of occasions with singletons, it somehow seems a bit more startling when a survivor is involved.

It also seems to annoy or concern other family members much more than the surviving twin who experiences this behaviour, because they generally don't realise that they do it. This happened on frequent intervals in our own family with Rhys.

A number of parents have mentioned how their surviving twins are absolutely fascinated with images, such as their own reflection in a mirror, or their own shadows. It should be remembered that this is not a behaviour solely associated with surviving twins, and fascination with images is considered a normal part of a child's growing curiosity with life.

(Chapter 5, 'Common Survivor Behaviour', p 54-55, "The Survivor").





Grief is an Individual Experience.

By Lynne Harford, Founder NTLS



Although we can share similar experiences, is it really fair for one person to say to another, "I know exactly how you feel?" We grow up unique. We have varied social and economic backgrounds, different family structures, hold different beliefs, and are individually influenced by our own external experiences. Whilst it is not uncommon for people to share these concepts, I remain convinced that no one truly understands exactly what it is like to live as 'us', in our own unique worlds. It therefore makes sense that if we are all individuals, then our journeys of grief will also reflect that individuality.

Grief, and all its processes, has almost become a commercial commodity in today's society. There are hundreds of books, courses, charitable organisations and experts who are ready to tell us how to experience 'grief'. My observations during the past decade have seen charity groups compete against each other for hard earned funds, and have watched people that should be working together fight like soldiers at war. When does society stop long enough to recognise that Grief is not something to be bought or sold? When do we realise that providing support to another human being, freely and without expectation of financial reward or personal fame should be as natural as taking our next breath?

My aim during the past year has been to produce a small bereavement care newsletter for multiple birth loss families and health care professionals that is also unique. Just like we are. It is easy to 'rehash' articles that have been authored by other people, but it takes greater effort to write something from the heart that hopefully, hasn't been produced before.

This of course is simply my own personal interpretation, but when we stand back and look at Loss and Grief overall, we must admit that the reason we have learnt so much about this topic is the fact that people took the time to observe, record, and report their opinions and ideas. Creativity is just as important as scientific fact. Personal opinion is just as valid as a carefully structured experiment.

Grief is interesting. It is an entity all of its own. It hides from us and reappears when we least expect it. It tricks us into believing that all is well, then jumps out to throw our lives into chaos and turmoil. Grief takes over our lives and shatters our self confidence. But grief has an 'up' side as well.

Grief makes us stronger. Like survivors of a war or natural disaster we can learn from our experiences. Grief creates compassion, empathy, understanding and in turn, can make us better, more loving and caring people. When we can control it, it no longer controls us, and that's a very positive result indeed.

So when you are experiencing grief in your life, don't be frightened to find an avenue that suits you as an individual, through which to travel. Don't let people tell you how you should be feeling and don't let them burden you with unnecessary lectures. Allow people to love you, to support you and in turn share in your pain. Then we will discover the ability to embrace recovery, and move forward.

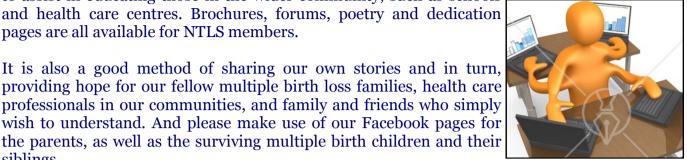


Don't forget to use the resources available in the 'Members Only' section of the NTLS website!

Don't forget there are many resources available to help you personally in your journey of grief, or to assist in educating those in the wider community, such as schools

pages are all available for NTLS members.

It is also a good method of sharing our own stories and in turn, providing hope for our fellow multiple birth loss families, health care professionals in our communities, and family and friends who simply wish to understand. And please make use of our Facebook pages for the parents, as well as the surviving multiple birth children and their siblings.



Remember—education holds the key to providing better outcomes for multiple birth loss families. Ignorance simply holds us back.

Another piece from the sequel to The Diary; "The Survivor".

Some of the world's most famous people were surviving twins. One of the best known was Elvis Presley, whose twin brother Jessie was stillborn on January 1935. Sadly, very little apart from a few lines here and there, is written about Presley's twinship.

The famous American author Samuel Clemens, (better known as Mark Twain), also held an obsession with twins ... He mostly focused his preoccupation upon a set of Conjoined Twins known as the **'Tocci** brothers', who basically inspired Twin to write great and creative literature.

Exciting news with the successful separation of conjoined twins in Melbourne!

After a marathon 30 hour operation at the Melbourne Royal Children's Hospital on November 17, 2009 former conjoined twins Trishna and Krishna are recovering well.

The girls, who are about to celebrate their 3rd birthdays, had been joined at the top of their heads, sharing brain tissue and blood vessels.

This successful operation must surely give hope to those families of conjoined twins. Statistics reveal that most conjoined twins are female and the majority are stillborn. Surgical separation is extremely risky, and success rates depend greatly upon where the babies are joined.

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