



Amanda Young Foundation

Support Program News Spring 2012

The Amanda Young Foundation has provided informal support for survivors of meningococcal disease, their families, and the families of those that did not survive the disease, since the organization was founded in 1997.

In 2010, this support began to be formalised through meetings with survivors and volunteers to plan how the program could work. In 2011, the Program employed its first Case Manager, Tracey Parker. The new Case Manager, Lisa Burnette, started in May 2012, and is herself a meningococcal disease survivor, as well as a nurse.

The Support Program currently offers:

- Advocacy
- Referral and services funding
- Regular support
- Information
- Equipment
- Social Gatherings
- Newsletter

Please feel free to call or email Lisa with any concerns, large or small, or simply to say hello!

Support Mobile: 0433 309 425

Email: support@amandayoungfoundation.org.au

Secret Facebook Group: Please contact Lisa to join

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CASE MANAGER UPDATE

Happy Spring everyone! From talking to many fellow meningococcal disease survivors, frequent illness and depression, especially in the first few years, is an ongoing problem. So I welcome spring wholeheartedly each year.

It is these hidden after-effects that can be the most devastating for many. Recent research (the MOSAIC Study conducted in the UK) shows that up to three quarters of child survivors have psychological sequelae.

This issue contains an article about survivor guilt, another hidden effect. Meningococcal has been around for centuries, but in today's society, information is freely available. This can produce inspiration....or guilt.

I've also included a section answering some FAQ's with our very own Dr. Rob Booy – and would be pleased to have some more questions for future editions.

Look forward to seeing you at our upcoming gathering.....Lisa



AYF SUPPORT SUMMER SOCIAL GATHERINGS

Sat 27th Oct 2013

Amanda's Garden Fete

Southern River

9.30am – 11.30am

Lisa will be at Amanda's Garden for chat – look out for the Support Stall and pop by!



Sat 9th Feb 2013

Burswood Park

9.30am – 11.30am

Come along for a Support Program catch-up and a light morning tea. **I will send more details closer to the time!**

What's happening with Peer Support?

In the early stages of the Support Program, there was consultation regarding what type of meetings participants would like. Several support group meetings were held during 2011.

Feedback from many of the survivors and families has been that the primary request is to simply meet and talk to others who have had a shared experience.

Formal 'trained' peer support programs require frequent referrals to work successfully, and as meningococcal is a rare disease, requests for peer support are infrequent. The best form of peer support is coming along to the social meetings to meet and get to know other survivors in a safe and friendly environment.

The meetings have now been adjusted to have a purely social focus, allowing a chance to catch up and share stories in a relaxed setting.

The first social meeting was a lunch which took place after the AYF Meningococcal Seminar on Fri 3rd August.

15 survivors and their family members attended, met one another and chatted. We heard about the results of the MOSAIC Study into after-effects (please contact Lisa if you would like a copy), and the Support Program library was also available.

If you were not able to attend, we hope you can come next time!

What is survivor guilt?

"No one explains to you how to deal with the guilt of surviving"

Survivor guilt means, in simple terms, that people are grateful to be alive after a traumatic event (such as recovering from meningococcal disease), but feel terribly guilty that others died. In the case of meningococcal disease, it could also be guilt at having no outwardly visible after effects. Their questions can't really be answered: why did I live? Why did the person next to me die? Is there some special reason I survived and they didn't? Survivor guilt can be

part of post-traumatic stress disorder.

Dr. Kathleen Nadar wrote about survivor guilt for the website 'Guilt From Within', for survivors and caregivers of those with PTSD.

She outlines the process of understanding, living and ending survivor's guilt. These include:

- Thank goodness, you survived!
- Know that there is no offense in surviving, that it is good to survive



and okay to delight in being alive

- Feel free to reassess your life
- Recognize the reawakening of old issues
- If guilt persists or disrupts life, seek appropriate therapeutic assistance.

The Support Program can support and assist survivors with counseling.

MENINGOCOCCAL STORIES

Telling your story is a therapeutic process – but it is also your private story. Please remember that receiving any form of support from the AYF Support Program does not obligate you to share the details of your personal story.

No matter whether you want to share your story publicly or privately, Lisa would be more than happy to help you share your story, including writing it up for you. You can share your story in several ways:



- Write or record your story for your own personal benefit
- Share your story in this newsletter and the AYF website
- Share your story for media promotions for awareness raising

SUPPORT PROGRAM LIBRARY

A range of books are now available. These books relate to meningococcal or recovering from a traumatic illness, and include biographies and stories. Feel free to contact Lisa to borrow a book, or to suggest a new title.

Feather – A Child's Death and Life. Robert Peters (Meningitis)
Up and Running. Mark Patikin (Meningococcal Survivor Memoir)
Close to the Bone-Life threatening illness as a soul journey. Jean Shinda Bolen.
Enduring Miracles – Surviving the Effects of Valley Fever. Afton Zapata
Learning to Walk – Recovering from meningococcal septicaemia. Lisa Burnette
It's only a leg! Hugh Drake
Addups and Takeaways. Harry Dumpleton
Never Tell Me Never. Janine Shepard
Lesley's Story. Martha McNey (Meningitis Survivor)
The Woman with a Worm in her Head. Pamela Nagami (p233 Call me spot)

EVENTS CALENDAR

6-7th Oct 2012

Romancing the Stone Garden

27-28th Oct 2012

Amanda's Garden Fete

9th Feb 2013

Support Group Get-Together

See AYF Website for more info.

Tay's Story

Three and a half year old Tay is used to hospitals. At 11 months old, he contracted meningococcal disease – a deadly bacterial infection that can kill within hours. His parents, Kate and Craig, were faced with the devastating possibility of losing their only child, less than 24 hours after his first symptom.

“On the Sunday night he was lethargic and he vomited,” says Kate. “The next morning he slept in and I had to wake him up. He was drowsy with a high temperature, and just seemed floppy and unfocussed. He threw up his milk straight away.”

Concerned, Kate decided to take Tay to hospital, where she noticed Tay's body was very warm whilst his hands and feet were cold. Despite this significant sign of meningococcal septicaemia, Tay was diagnosed with a viral infection and sent home.

After Tay's unusually long afternoon nap he was still feverish, lethargic and unfocussed, and Kate noticed that his hands and feet now felt freezing cold.

That evening, Kate worried about what to do. “I knew something wasn't right. My instinct was to take him back to hospital, but I was worried I was overreacting.”

She then saw something that rang alarm bells. “I noticed a tiny red dot on his tummy. I remembered a rash is bad and I suddenly knew Tay was in serious trouble.”

Kate and Craig flew into action and drove straight to hospital. “In the 13 minutes it took to arrive we watched the rash spread up his chest and neck. It was terrifying.”

Written by Georgia Radinger

Hospital staff immediately treated Tay for meningococcal septicaemia. Kate and Craig were warned to expect the worst. “I was numb,” says Kate. “The previous day he was perfectly healthy. How did he get so sick so quickly?”

Tay survived, but with a long road to recovery ahead of him. “He had to re-learn everything,” says Kate. “Eating, making sounds, crawling. He was as helpless as a newborn.”

Thanks to his parents and support from family and friends, Tay is now thriving. He is an active boy who adores his little sister Charley and enjoys his numerous specialist appointments. However, the disease wrought some serious damage.

“Tay's a survivor. We're just so lucky to have him.”

Tay suffered a brain injury which resulted in mild cerebral palsy, causing language difficulties. The septicaemic blood attacked the growth plates in his right leg meaning it is now unable to grow. Every 2-3 years until adulthood, Tay will need surgery to have his tibia and femur broken, realigned and lengthened.

Tay has just completed his first surgery on his leg. His leg is fixed in a frame and he is in a wheelchair for 6 weeks. Kate worries about how she will keep her bundle of energy still for so long. “He does get frustrated that he can't just run around and play. We try to make it easy for him but it's a lot for a little boy to go through.”

Recovery

If you are or care for a meningococcal meningitis or septicemia survivor, it is recommended to have a full medical check-up six weeks after the illness.

Survivors may feel tired for up to a year after meningococcal, and find you become unwell easily.

Although nobody can definitely confirm this to be the case, many survivors may have health problems ongoing in life relating back to their meningococcal disease.

We are currently producing a brochure with some more extensive information about after effects. We appreciate any input you wish to provide.

SUPPORT PROVIDED

- ❖ Information about after effects
- ❖ Regular phone calls and/or emails
- ❖ One to one meet-ups
- ❖ Counseling referrals and financial assistance – survivors and family members
- ❖ Audiology referrals and financial assistance
- ❖ Equipment (computers, mobility aids)
- ❖ Tutoring/educational support

Feel free to contact the Support Program with any personal support needs you would like to discuss. The service is confidential and free.

FREQUENTLY ASKED QUESTIONS.....WITH DR. ROBERT BOOY

Will my fertility be affected?

Because many organs of the body may be affected by the shock (low blood pressure) that often occurs with meningococcal sepsis, it is possible some people may have reduced fertility. However I am not aware of any studies in the area.

Lisa's comment: We have many meningococcal survivors who have gone on to conceive children.

My memory seems to be worse following my illness. What can I do about it?

There are simple exercises to help with memory like crosswords and keeping a regular diary on your person. If your memory concerns you greatly do see a psychologist. In the meantime get adequate sleep, eat well and be careful with alcohol intake

Do you have a question? Email it to support@amandayoungfoundation.org.au – confidentiality maintained.

Newsletter Sources

Survivor Guilt :<http://www.empowher.com/mental-health/content/why-did-i-get-live-survivor-guilt-and-why-it-happens?page=0.0>
<http://www.mayoclinic.com/health/cancer/>

Disclaimer

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For more information about the events, see www.amandayoungfoundation.org.au or contact the Support Case Manager.