



## *Amanda Young Foundation*

# *Support Program News Autumn 2013*

The Amanda Young Foundation Support Program offers those affected by meningococcal disease and their families:

- 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](mailto:support@amandayoungfoundation.org.au)**

### AYF SUPPORT PROGRAM GET TOGETHER



**Sat 10 August at 2.30pm**  
**Walters River Café, Bicton**

**Come along to meet with  
some fellow survivors!**

**Venue: <http://www.waltersrivercafe.com.au>**

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### CASE MANAGER UPDATE

Greetings fellow survivors and family members.

We've had a great start to the year with a get together at Burswood Park in February.

Recently, I have been hearing about chronic pain. Survivors I have spoken with report 'nerve' pain and headaches, as well as a range of other non-specific pain.

I did some thinking and research and have located some 'tips' on dealing with chronic pain – see Page 2.

Again, we have our section answering some FAQ's with Prof. Rob Booy – and would be pleased to have some more questions for future editions. And don't forget to feedback in our survey!

Best wishes, Lisa



## Living with Chronic Pain

No one chooses to have chronic pain. It is difficult to accept a body that is not functioning as it should.

Despite the frustrations and grieving for the old self, many people eventually learn to lead a new, although different life with persistent pain.<sup>1</sup>

Research shows that acceptance is a key part of living with pain. A study in 2003 shows that just “coping” only was only weakly related to pain adjustment, while if an individual “accepted” the pain, they experienced less pain, disability, depression and pain-related anxiety.<sup>2</sup>

The Australian Pain Management Association agrees. “Many individuals try to fight the pain to make it go away by using “mind over matter.” As a result they aggravate the pain more and end up even more worn out.

Pain is exhausting in itself and willpower won’t make it go away.” Alternatively, some deny the existence of the pain, and do not allow themselves periods of rest.<sup>1</sup>

### Tips for Coping with Pain

- Concentrate on the moment at hand and connecting with people and activities that are uplifting<sup>1</sup>
- Prioritise what is important in your day and then break the task down so that it can be performed in small bites. Try and achieve one thing a day which is important.<sup>1</sup>
- Learn deep breathing or meditation to help with chronic pain.<sup>3</sup>
- Reduce stress in your life. Stress intensifies chronic pain.<sup>3</sup>
- Boost chronic pain relief with the natural endorphins from exercise.<sup>3</sup>

- Cut back on alcohol, which can worsen sleep problems<sup>3</sup>
- Join a support group. Meet others living with chronic pain<sup>3</sup>
- Get a massage for chronic pain relief.<sup>3</sup>
- Eat a healthy diet if you're living with chronic pain.<sup>3</sup>
- Find ways to distract yourself from pain so you enjoy life more.<sup>3</sup>

### Support Services for Pain

In Western Australia, there are medical services at Sir Charles Gardner Hospital, Royal Perth and Fremantle Hospital that assist with chronic pain. These require a referral.

Chronic Pain Australia

<http://www.chronicpinaustralia.org.au>

Australian Pain Management Assoc.

<http://www.painmanagement.org.au/>

## Meningococcal Notifications

Clients often ask whether people who have recently contracted meningococcal know about the program – and they also ask about the statistics.

Hope for a reduction in cases and for increased support to those that do experience the disease is important to those who have been through the experience. You may be aware that meningococcal disease is a ‘notifiable disease’.

This means that each case is reported

to the Communicable Diseases Branch of the Health Department, along with a range of other infectious diseases.

The Communicable Diseases Branch then undertakes contact tracing to ensure anyone recently in contact with the affected person is provided with antibiotics and information as necessary. They then post out a Fact Sheet to the person experiencing the disease, and notify them in a separate letter about our Support Program.

A recent change is that the Department of Health now send out a press release (not containing any identifying

information) to the media when a new case occurs to alert the general public.

You can also find up to date notification data on the Department of Health’s website, which is located at:

[http://www.public.health.wa.gov.au/3/15/20/3/meningococcal\\_infection.pm](http://www.public.health.wa.gov.au/3/15/20/3/meningococcal_infection.pm).



## JOIN OUR SURVEY!

The Support Program is conducting a short online survey to assess the service we are providing to those affected by meningococcal in WA. The survey is open to anyone who lives in WA.

The survey is located at:

[www.surveymonkey.com/s/BNVYSTV](http://www.surveymonkey.com/s/BNVYSTV)

If you are not on the internet, there will be a paper copy of the survey in your newsletter. Contact [support@amandayoungfoundation.org.au](mailto:support@amandayoungfoundation.org.au) if you need any assistance with the survey.

## FREQUENTLY ASKED QUESTIONS WITH PROF. ROBERT BOOY

### Q: Is the hearing loss expected to change over time?

A: YES, some people's degree of deafness noted during hospital admission (or shortly after) does improve over the following months - up to a quarter of cases with early hearing problems can see improvement.

### Q: Can you catch meningococcal disease twice?

A: It is very rare (but possible) to get the disease twice - less than 1 in 100 cases get it again. More likely if the person has an immune disorder like complement deficiency. Even so we recommend 4 Valent meningococcal vaccine for safety.

**Do you have a question? Email:**  
[support@amandayoungfoundation.org.au](mailto:support@amandayoungfoundation.org.au)  
u - Confidentiality maintained.

## Stef's Story

On Sunday night I went to the local pub for dinner, but it hadn't tasted right and I had decided not to eat it. I came home and went to bed early feeling nauseous and unwell.

At 5am on Monday 9<sup>th</sup> January 2012 I woke up sweaty and very distressed. My legs were cramping, my head was pounding and my stomach was churning. I managed to get to the toilet where I continued to vomit for what seemed like forever. At 6am Mum woke up and went into my room to check on me, but it was in the toilet, hugging the bowl, where she finally found me. I couldn't stand due to the shooting pain through my legs, and it took both my Mum and Nana to carry me back to bed where they gathered my things and decided to take me to Armadale Hospital. I was admitted in the hospital, where they gave me some intravenous fluids and a tablet to stop me vomiting, decided it was food poisoning, and sent me back home.

After an hour back at home, my vision blurred, the light was bright, my lips turned blue and I was pale and grey. Just being touched caused intense pain. My Mum called an ambulance and I was taken straight into the emergency ward. As they were putting sticky dots onto my chest for an ECG, my sister said, "Mum, Is that a rash?"

Overhearing Dayle's comment, the nurse inspected the pin prick dots that were showing on my belly and quickly walked out of the room. Seconds later she arrived with at least a dozen doctors who inspected the rash. I was then taken to a separate non-contact room and was put on a penicillin drip. An hour later they

confirmed my diagnosis of Meningococcal Septicaemia Strain B. Mum and Dad were taken into a

room with the doctor and where told to expect the worse as he did not think I was going to pull through. By then I was going in and out of consciousness and the rash was spreading quickly around my whole body.

I was rushed to Royal Perth Hospital ICU where I spent the next three critical nights. I cannot remember much at all from leaving the Armadale Hospital or even being in ICU. I woke up in a ward where I then spent a week and a half on a course of antibiotics. I saw a physiotherapist who helped me to get up walking, which was very hard due to the swelling in all my limbs (thankfully I had not lost any). After being discharged I continued to recover at home. It took a few months before I was able to return to work and carry on with my normal daily tasks.

*For about a year after my illness, I was weak, nauseous and had recurring headaches*

For about a year after my illness, I was weak and nauseous, and not able to eat at times. I had recurring headaches, which eventually went away with a course of medication. I still find, over a year later, that I suffer frequent colds and flu's. My rash has finally started to subside and fade away as bruises, some completely gone and some that are taking their time. I do also find that when I become run down and very tired, my rash will flare up and become noticeable, I guess that's its way of reminding me to slow down.

## Recovery

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

Survivors may feel tired for up to a year after meningococcal, and 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. The after effects vary from person to person, and also whether you had meningitis, septicaemia, or both. The Support Program offers an after effects brochure with some more extensive information about after effects.

Feel free to contact the Case Manager, Lisa, with any personal support needs you would like to discuss on 0433 822 436.

The service is confidential and free.

### AYF Support Group

Join our secret Facebook group!

Search for the AYF Support Program Profile named "Lisa Burnette" on facebook and "friend" this profile so Lisa can add you to the group.

### SUPPORT PROVIDED

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

Contact [support@amandayoungfoundation.org](mailto:support@amandayoungfoundation.org) to discuss your support options

## Foundation Events



Tickets available at [www.amandayoungfoundation.org.au](http://www.amandayoungfoundation.org.au)

### Newsletter Sources

**Chronic Pain:** 1. McCracken, L., Eccleston, C. 2003. Coping or acceptance: what to do about chronic pain? Pain 105 (2003) 197–204;  
2. <http://www.painmanagement.org.au/living-with-chronic-pain>; 3. <http://www.webmd.com/pain-management/guide/>

### Disclaimer

This newsletter is published in Perth, Western Australia for those affected by meningococcal disease. While every effort has been made to ensure accuracy, any advice in the newsletter is intended as a guide only and does not constitute medical advice. Newsletter content does not necessarily represent or reflect the opinions of Amanda Young Foundation. Any feedback or contributions are most welcome. **Unsubscribe? Please email [support@amandayoungfoundation.org.au](mailto:support@amandayoungfoundation.org.au)** For more information about the events, see [www.amandayoungfoundation.org.au](http://www.amandayoungfoundation.org.au) or contact the Support Case Manager.