



Aspiehelp / The Aspire Trust  
**September 2018 Newsletter**  
 Edited by Anna Melling

Roundup - Earlybird prices end soon, In Our Office, Poetry Corner, University Studies,  
 "I'm OK thank you. I hope you are too." - article by Jeanette Purkis

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## Aspie Roundup 2018

**10 days left to get \$50 off for Earlybird Registration!** See [theaspieroundup.co.nz](http://theaspieroundup.co.nz) for more information.

The Roundup will take place on Show Weekend this year—**16 & 17 November in the Rata and Kowhai Lounges at the Cashmere Presbyterian Church, 2 MacMillan Avenue.**

Themes this year are: Aspie Creativity Past and Present, and Designing an Aspie-Friendly Future.



### **Planned presentations** (subject to change):

- Emma Goodall live presentation
- Jeanette Purkis video presentation
- Debbie Ball video on home-schooling
- Sébastien Mathieu presentation on autism treatment in France
- Julie McGeorge "What's good for us is good for NTs also"
- Annie Southern presentation about the brain and aspergers
- Michael Woods will show his latest short horror film
- Building design for disabilities including sensory issues by Richard Cullingworth
- Babbage family on their illustrious ancestor Charles Babbage
- Choi Kwang Do demonstration (on benefit of martial arts)
- Art and photography exhibits

Feel free to email us with any queries—[info@aspiehelp.com](mailto:info@aspiehelp.com)

## Upcoming Fundraising Sausage Sizzles

Here are the dates for the upcoming Sausage Sizzles at Fresh Meats Barrington (Barrington Mall):

**Saturday the 22nd of September**

**Saturday the 13th of October**

**Saturday the 27th of October**

If you're in the area, come and visit, say hello and perhaps buy a sausage!

We are always grateful for volunteers to help out with the sausage sizzles, even 2 hours now and then is very helpful. (contact the office in advance if you want to help out)

## In Our Office

A quieter month has meant we could catch up with admin “stuff” which seems to appear on a regular basis. Those clients we have seen were varied and interesting.

We have continued to add new titles to the library, including four new books by Daniel Tammet.

### Out of the office

It has been particularly busy month for me [Julie] with my singing, which culminated in a concert which was received very well and was very satisfying. I also sang at the funeral of a past choir member, which was an honour.

I managed to walk from Sumner over to Lyttelton on a beautiful Spring day. Try it, you might really enjoy it. I certainly did.

Leith has had a well-deserved break from the office, which we hope will recharge her batteries.



*Our staff from top:  
Leith, Julie, and Anna*

## Social evenings

These are on hold for the foreseeable future.

### Our Patron is Stephen Mark Shore, PhD.

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## Poetry Corner

### The impossible blindfold

*: an autistic adult prepares for a day in the workplace*

Today again I'll strap on my mask for you;  
zip up my ludicrous human suit;

force most of my thoughts into small closed boxes  
so that when I speak, you are not made uncomfortable.

When I am not trapped in a room full of chattering  
sometimes I can pass for one of your kind.

You few who reach for me with well-meaning thoughts:  
even you have no clue how hard this is, nor can you.

If you are sighted and want to try blindness,  
bind your eyes for a day, a week – you might come close.

But there are no easy ways to shut down your empathy,  
lock yourself in my clumsy robot cage

and be. *For my thoughts are not your thoughts, nor are my ways your ways.*  
(c) Melinda Smith 2011

<https://melindasmith.wordpress.com/2011/07/01/the-impossible-blindfold/>



# University Studies

There are two studies being undertaken by a team at Macquarie University in Australia. The first on *current* university students on the autism spectrum, and the second for *previous* university students. Documentation will be attached to the newsletter email.

## **1. Are you a university student with autism spectrum?**

*You could win a \$100 gift voucher!*

*Researchers from Macquarie University Department of Educational Studies are interested in learning about your experiences as a student living with autism spectrum and about your views on the supports or services you may have received while studying at university.*

The survey is completely voluntary and anonymous and will take around 20-25 minutes to complete. Respondents will also have an opportunity to enter a draw to win one of three gift vouchers from JB Hi Fi or Myer worth \$100.

For more information and to take part in this survey, and to also enter the prize draw, please click on the link below or copy and paste it into your browser.

**Survey Link:** [https://mqedu.qualtrics.com/jfe/form/SV\\_9QzjRT5TDrGaHo9](https://mqedu.qualtrics.com/jfe/form/SV_9QzjRT5TDrGaHo9)



**This recruitment notice may be forwarded to other potential participants**

## **2. Research Project: Exploring the experiences of former university students with autism spectrum disorder**

We are seeking participants for a Macquarie University Doctor of Philosophy project.

**The purpose of the research is to explore the experiences of students with ASD from the perspective of former students, including graduates and those who did not complete their course.** We hope to identify the personal features and support practices that may have contributed to their completion or decision to not complete their studies. It is also hoped that the research might generate insights that could both highlight some of the positive aspects of ASD but also lead to improved supports and a better university experience for students with ASD. This information may be helpful to teachers and support staff and may also better inform transition to post-secondary education programs.

The research to be undertaken requires participants to participate in an interview of approximately one hour, and to nominate a significant other (e.g., parent, spouse, partner friend) who can also share their perspective of the university student with ASD experience at an interview. Participants who are interviewed will be given a \$25 gift voucher from JB Hi Fi or Myer.

The registration of interest survey, which includes the participant information sheet, may be viewed at: [https://mqedu.qualtrics.com/jfe/form/SV\\_1HZrBntfUx7rj7](https://mqedu.qualtrics.com/jfe/form/SV_1HZrBntfUx7rj7)



# “I’M OK THANK YOU. I HOPE YOU ARE TOO.” – TALKING ABOUT MENTAL HEALTH, SUICIDE AND AUTISM

**Jeanette Purkis**

Republished with permission from

<https://jeanettepurkis.wordpress.com/2018/09/14/im-ok-thank-you-i-hope-you-are-too-talking-about-mental-health-suicide-and-autism/>



## **Content warning: Discussion of mental health and suicidal thoughts**

On Wednesday I did something I have never done before: I went a morning tea with my team at work and we talked about mental health and suicide prevention. One of my colleagues organised it as part of R U OK day. We had an amazing and very open conversation. It was one of the best things I have been part of at work and I found it really helpful.

The thing that struck me about this meeting was how unusual it was. Most people don’t want to talk about mental health issues or suicide. This silence breeds more silence and tends to make people very reluctant to talk about these topics, even if they really need to.

Up until quite recently the accepted wisdom around talking about suicide and related issues was that you shouldn’t do it because it would somehow encourage people to act on any suicidal thoughts they may have. Also there was – and still is – a lot of stigma around suicide and mental illness, which means most people don’t feel comfortable mentioning they are having issues to those around them. This silence isolates people and makes them feel alone and helpless.

I have had many issues in this space and feel it is really important to let people know they can have these conversations if they need to. In my own life, in addition to my autism, I have a diagnosis of atypical schizophrenia. This means I have had a lot of times in my life struggling with mental health issues and suicidal thoughts. In 2010 I was very unwell but for a variety of reasons I wasn’t seeing a psychiatrist or any other mental health clinicians. I had a GP who was lovely but their knowledge of mental illness was pretty limited. I told the GP I was struggling and she sent me to a psychologist who was not well-suited to me. I remember going in to appointments with a very self-destructive inner monologue and with the psychologist having no idea what I was going through – because I chose not tell her! Despite having been out loud and proud autistic for many years it took me a lot longer to feel able to discuss my mental illness, apparently even to a psychologist. I felt I couldn’t share that I was having suicidal thoughts. I thought to myself “I am a public servant and a homeowner so how would that look?” I worried my work colleagues would somehow find out I was having those thoughts. I was too ashamed to talk about my illness or my thoughts. I imagine that I am far from alone in this experience.

In the years since then I have become a lot more able to talk about my mental health. I think it is essential to have these discussions. If nobody knows what you’re going through then nobody can help. I remember wanting people to figure out how much I was struggling and for them to somehow spring into action to take away the misery and fear but of course that never happened. Nobody could read my mind!

Autistic people can have significant issues in this space for a number of reasons:

- We have far higher rates of something called alexithymia than others do. Alexithymia is also called emotion blindness. It doesn't mean a person has no emotions, rather it means they struggle to be aware of and / or articulate what they are feeling. If we don't know we are having a hard time, how can we know to access assistance?
- Horribly we are still victimised, abused and bullied at very high rates. These things often lead to very low self-esteem and post-traumatic stress disorder, putting us at a far higher risk for mental illness and suicidal thoughts.
- We so often get misdiagnosed and missed by mental health professionals. Clinicians may have a very limited understanding of autism. This means we often miss out on the tailored support we need which can be very frustrating and invalidating. Once again, these are risk factors, particularly if a person is in crisis and feels like nobody can understand or help them.
- The mask. Autistic people often mask ourselves in order to fit in and be socially accepted by others and survive in the wider world. This means that outwardly we are doing great despite what is actually going on. Once again, this can be a big risk factor.
- Many autistic people are socially isolated and disconnected meaning that we don't have that protective factor against suicide that is knowing there are people who love and care for us.

Thankfully there are some useful strategies and protective factors that can be put in place to help address these issues. These include:

- Understanding that suicidal thoughts are something which need addressing and that it is best not to 'go it alone'. Finding someone to talk to is really important. For some people that will be a mental health professional such as a psychologist or counsellor but for others it will be a friend, partner or family member. Know that it is OK – and a very good idea – to discuss your thoughts and concerns with someone else.
- Know that accessing help – whatever that may be – is a good thing to do. I think it is a actually essential to access help in some form if you are having suicidal thoughts.
- There are some crisis services you can access although some are a bit patchy in terms of their effectiveness for autistic people. Lifeline in Australia has a 24 hour crisis phone line and also online real time chat with volunteer counsellors. I have found Lifeline to be very good in the past although they are not for everyone. BeyondBlue also have a phone counselling service. There are also 'official' mental health crisis services. While some people report finding those unhelpful they can be useful to access as they can link you in with other mental health services if you need that. If you are concerned for your safety, emergency services can be contacted as well (ambulance etc).
- If you are in crisis and fearful for your safety, one strategy I find helpful is to remind yourself that the intense period of crisis generally lasts for between 15 minutes to one hour. So you do not need to get through the rest of your life with these intense distressing feelings, just get through a short space of time.
- If you can, it can help to distract yourself when in crisis. This basically means engaging in an activity that will keep your brain occupied so you are not experiencing the height of the crisis. Distractions are different for each person – try one/s that work for you.
- Being around people and / or pets you love and care for when having a crisis and having suicidal thoughts is a very good emergency strategy. Most people will not act on those thoughts when they are around others. It can be difficult asking someone to spend time with you but it even helps some people just going into a public place until the crisis passes and the impact of the thoughts lessens.



### **Where to get help:**

*1737, Need to talk? Free call or text 1737 any time for support from a trained counsellor*

*Lifeline – 0800 543 354 or (09) 5222 999 within Auckland*

*Youthline – 0800 376 633, free text 234 or email [talk@youthline.co.nz](mailto:talk@youthline.co.nz) or [online chat](#)*

*Samaritans – 0800 726 666*

*Suicide Crisis Helpline – 0508 828 865 (0508 TAUTOKO)*

*What's Up – 0800 942 8787 (for 5–18 year olds). Phone counselling is available Monday to Friday, midday–11pm and weekends, 3pm–11pm. Online chat is available 7pm–10pm daily.*

*Kidsline – 0800 54 37 54 (0800 kidsline) for young people up to 18 years of age. Open 24/7.*

*[thelowdown.co.nz](http://thelowdown.co.nz) – or email [team@thelowdown.co.nz](mailto:team@thelowdown.co.nz) or free text 5626*

*Anxiety New Zealand - 0800 ANXIETY (0800 269 4389)*

*If it is an emergency or you, or someone you know, is at risk call 111.*