



Aspiehelp / The Aspire Trust

July 2017 Newsletter

Edited by Anna Melling

In this newsletter: Movie showing, Southern Trust rent grant, 'Aspie Round-Up' information, IHC library info, surveys, Anna's rambling on fidget spinners, and a blog post from Jeanette

Movie showing

Aspiehelp / The Aspire Trust is proud to present
The Parcel

Written and produced by Michael Woods

For the past four months, a teenager has been becoming a recluse as his fear of the outside world increases. One day he receives a parcel at the front door with the wrong address.

After failed attempts at ringing the post office and the police, he decides to travel outside the house and find the rightful owner of the parcel. His travel leads him to a journey of self discovery with a mixture of crazy characters and shocking situations.

Also showing:

Kill the Innocents by Josiah Morgan

2:30pm Sunday 22nd of July at Cashmere Presbyterian Church

Afternoon tea will follow the film

Adults \$15 Students \$5

Please RSVP to info@aspiehelp.com or 337 6337



Southern Trust - grant for rent

The Southern Trust have given us a grant of ~\$3,900 to pay for three months rent! We are very grateful for this, and it will be very helpful!



Upcoming Fundraising Sausage Sizzles

We will be holding more fundraising BBQs over the next few weeks, spread between Mitre 10 Beckenham and Fresh Meats Barrington (Barrington Mall):

Saturday the 12th of August - Mitre 10 Beckenham

Saturday the 19th of August - Fresh Meats Barrington

Saturday the 26th of August - Fresh Meats Barrington

Saturday 9th of September - Mitre 10 Beckenham

If you're in the area, come and visit, say hello and perhaps buy a sausage! We still need someone to organise our sausage sizzles and also more help on the day. Please offer even for 2 hours now and then. We need this income!

In Our Office

What with winter weather and this 'n' that, client numbers have dropped somewhat this month, and we haven't been able to keep up our previous rate of sausage sizzles, so our income stream has dropped as well.

Great news, Leith has now passed all the requirements to be a Registered Social Worker (at great expense) and this will add to our mana as a Resource for Aspies!

The Te Pou standards for qualification for Carers of people on the Autism Spectrum which Leith, Julie and Olivia have been involved with, is almost into its final incarnation, a very pleasing achievement!

On a sadder note, Leith's lovely cat, Molly, has died, suddenly, of a seizure, about two weeks ago. This has left a "Molly-shaped hole" in her life and is proving difficult to accommodate to. (Sniff)

Membership Reminder

We had quite a few people renew their membership at the start of the new financial year, but there are still a lot of membership fees outstanding. These fees are very necessary for us to continue to provide services to our clients. Thank you to those who have paid their membership! We must hold an AGM very soon and only paid members may vote!

Fees are currently \$20 for an individual or \$35 for family membership. If you can't remember whether you've paid your membership or not, feel free to ask!



Our staff, clockwise from top left: Leith, Olivia, Julie, and Anna



Molly

Social evenings

Our regular social evenings are on the first and the third Wednesday of the month, at a venue near Church Corner at 7:30pm. (Please contact Leith for the exact location).

We have board games, hot drinks and biscuits, and a selection of books from the Aspiehelp library available at every meeting. Please bring a \$2 donation.

The next meetings are on the 19th of July and the 2nd of August. You are welcome to attend. (New members should contact Leith or Julie first.)

Conversation group (previously Women's group)

Our Aspiehelp conversation group meets fortnightly on Tuesdays at 2pm.

A get-together for people affected by Asperger's Syndrome.

The next meetings are on the 18th of July and the 1st of August.

Please contact us if you're interested in attending.

Our Patron is Stephen Mark Shore, PhD.

The Aspire Trust, Inc is a registered Charitable Trust. Charities Services registration number is CC46192.

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support us at givealittle.co.nz/org/myaspiehelp
www.aspiehelp.com

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The Aspie Round Up

Friday 17th and Saturday 18th of November

We will be partnering with the University of Canterbury Disability Resources Centre to host workshops. The planned location is the Undercroft Seminar Room, below the Central Library at University of Canterbury.

Workshops covering:

- Life, Education, Employment and Community
- How to empower people on the Autism Spectrum

We will be inviting proposals soon.



Dr Stephen Mark Shore, Clinical Assistant Professor in Special Needs and Autism at Adelphi University USA, will send us a DVD about “Awesome Autism”.

Stephen is himself Autistic. He is also the Patron of Aspiehelp / The Aspire Trust.

To be added to our email list to receive news flashes and notification when submissions open, or to ask any other questions about the round-up, please email olivia@aspiehelp.com

Useful Resources

For those who aren't aware, the IHC's Library actually has a lot of resources about Asperger's and Autism Spectrum. They have ebooks, physical books and DVDs. “Library membership is FREE! We pay for the postage to you – the only cost to you is return postage if you are unable to visit the library.”

You can sign up at <http://ihc.mykoha.co.nz/>



Surveys - Altogether Autism / Specialisterne

Altogether Autism has partnered with Specialisterne to gather information about talented autistic adults ready to work in New Zealand.

Autistic Talent Search

“The purpose of this survey is to get an understanding of how many autistic people are looking for work in New Zealand and to understand the kinds of tasks and roles in which they are interested. This survey allows autistic people to express their interest in a range of areas for which positions may become available in New Zealand in the coming months.”

<http://altogetherautism.org.nz/autistic-talent-search/>



Employment Experiences

“The purpose of this survey is to understand the experiences of autistic people in finding and keeping work.”

<http://altogetherautism.org.nz/experiences-autistic-people-seeking-employment-staying-employment/>



Survey - Autism Research Centre

Autism, life experiences and mental health in adults

The Autism Research Centre would like to invite you to take part in an online questionnaire about vulnerability in the lives of adults with and without autism. You will be asked to complete an anonymous survey which includes questions about autistic traits, mood, life experiences and mental health. The survey will take to 30-40 minutes to complete.



This is the same study that was advertised last month so if you have already taken part please ignore this invitation.

To find out more and take part, please click on the following link: http://cambridge.eu.qualtrics.com/jfe/form/SV_29a9xsrkfscR5S5 [or use the QR code to the right]

If you have any questions, please contact the study team on autism-vulnerability@medschl.cam.ac.uk

Anna's thoughts on Fidget Spinners

There has been a lot of talk about the new fidget spinner craze! If you are unaware of what they are, fidget spinners are a “fidget toy”, which were originally designed as a tool to help people on the autism spectrum and those with ADHD to concentrate on other tasks.



Their intended purpose was quickly forgotten as it became the latest thing that many school children feel they “must have”. They have become so popular that schools are banning them as being disruptive in classrooms. There has been some debate as to whether these and similar devices give any real benefit. I'm personally unwilling to write off all such devices in this way, but as there are smaller and quieter fidget toys that don't require both hands to use, I can see that the Fidget Spinner may not be the best choice for use in the classroom environment.



As far as fidget toys being a modern craze, well I understand we've been using similar items for centuries! More low-tech, but respected as a meditational and relaxation aid (as well as being good physiotherapy for hand muscles). Couldn't the Chinese “Baoding Balls” be considered an ancient fidget toy?

Quote Corner

‘Before diagnosis, many of us were unsuccessfully trying to pursue a neurotypical lifestyle, but if we are not neurotypical, we should not be trying to live in the same way. The neurotypical lifestyle will not suit us, only serving to cause frustration and unhappiness.’



Alis Rowe

Please don't ask me 'How do you feel?' 'Emotion blindness' and Autism

The image accompanying this post is me signing a book at a launch event in 2012. I look very happy don't I? It might surprise you that two days after that image was taken that I was in the psychiatric ward for six weeks with severe depression. Was I putting on a brave face? Actually no. I was unaware that beneath my happiness for signing a new Jeanette book lay a depth of misery which I had simply not noticed. Like many others on the Autism spectrum, I have a condition known as Alexithymia, or emotion blindness. It doesn't mean I don't have emotions but that I cannot articulate them and struggle to notice them. In my case I only feel a few emotions and even then only when they are at a heightened state. It means I don't access what I am feeling unless it is severe and even then I often can't work out what the feeling is, just that it is unpleasant.



In the six week hospital stay after my book signing event, I remember sitting in the hospital psychologist's room and crying. The psychologist told me I was really depressed and I denied it, despite the fact that everyone in the place could tell I was depressed. For a person with alexithymia, being asked by a mental health worker – or anyone for that matter – 'how do you feel?' is about as helpful as being asked what the temperature on Venus is at the moment. It is almost impossible to respond to that question in the way it was intended.

Autistic people experience alexithymia at higher rates than the non-autistic population. It can compound existing difficulties. It can mean:

- Autistic people being unaware that they need to seek help
- People not being able to articulate what they are experiencing because they are unaware of it themselves. This can lead to mental illness conditions or symptoms getting very serious before anyone knows
- Autistic people's level of distress being misjudged and treatment in mental health services not being appropriate for the person. This can include being denied treatment as the person does not seem particularly distressed or speaks about their experience and feelings in an atypical or unexpected way
- Clinicians and support workers having no idea of what their client is going through and treatment being unhelpful as a result
- Making it difficult for Autistic people to understand their own mind and identify when they need to seek help
- Compounding stereotypes of Autistic people being emotionless or 'cold'.
- Many Autistic people are taught small talk type responses to questions. Often they may learn that when someone asks them 'how are you?' or 'How do you feel?' then the answer should be 'good' or 'well, thank you.' This can be an issue when someone has alexithymia and they think the 'right' answer is 'good' even if they have some awareness they are struggling.

Recently I have become aware of my alexithymia and what it means. I do not feel a lot of emotional response to things. The most common emotion I am aware of is stress and from that overload. I can tell a meltdown is coming on when the stress turns into anger. I don't feel much but I observe how I am acting: avoiding other people for fear of yelling at a them, not going online for similar reasons, a tension in my forehead and a sensation of adrenaline in my head. This means that after many years of being at the mercy of overload, I now get more of a chance to leave the situation and take time to de-escalate.

I am also getting better with understanding my mood, not so much by feel but by what I observe myself to be doing. If I am up at 3 am on a work night, talking loudly to myself and Mr Kitty and writing very quickly – and very well, then that is a fair indication I am elevated or getting hypomanic. Once I know this I can physically slow myself down by going to bed and listening to classical music. Conversely, I can tell I am having a depressed mood when my house is messy and I cant imagine being able to clean it. When this happens I know I can take action to help improve my mood – do something productive or energetic like having shower and going to work when I don't really want to or writing. With both the elevated and depressed moods I also rely on friends and family to assist by telling me. If my mum says 'Jeanette your mood is high as a kite!' I thank her because she is a more objective observer than me and her observation is helpful.

If someone asks me 'how do you feel?' I usually can't answer but I can work it out with some strategies. It is important to be aware of alexithymia and Autistic people, especially for parents of younger kids and teens. There are strategies to manage it but often someone isn't aware that they are not aware of their emotions. It is a tricky one and certainly deserving of more information than exists at the moment.

<https://jeanettepurkis.wordpress.com/2017/06/20/please-dont-ask-me-how-do-you-feel-emotion-blindness-and-autism/>

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