

Latest News from Down Syndrome WA

Newsletter 17 April 2020



Unusual times are continuing as we are trying to adapt to our “new normal”. Flattening the curve appears to be happening for us in Western Australia, so hopefully there is good news on our horizon. In our newsletter this week we talk about free membership to DSWA and continue to share updates from the NDIS, good news stories and matters on health and social connection. We feature a blog about personal boundaries from our Counsellor Nicola; so relevant whilst we are confined.

We really value **contributions for our E-news**, so if you have any video footage, photos, stories and ideas on what you are doing on the home front please send them in to jj@downsyndromewa.org.au. We would **love** to share these with our larger Down syndrome community. Your sharing will help others, when we are sometimes struggling to come up with new things from one week to the next!

In this newsletter:

- **Health**
 - **What is happening at the Association?**
 - DSWA Membership is now free
 - A World First: Ask About Down syndrome App
 - Social connection
 - Aim High
 - New parent Connection
 - All things NDIS
 - Emotional Health support
 - **Good news story.**
 - **Light Moments**
-



Health

Coronavirus and Down Syndrome

Sebastien Malinge is a board member for DSWA and works for Telethon Kids. He is a member of T21RS (Trisomy 21 Research Society) and has passed on this advice to our community after receiving an email containing recommendations for people with Down syndrome.



T21RS recommendations to protect individuals with Down syndrome against COVID-19:

Down syndrome is a highly variable condition and everyone is different. However, overall, people with Down syndrome have fewer cells providing active surveillance in the immune system. We also know that people with Down syndrome may mount immune responses more slowly than the general population, and it is possible that this is more pronounced with ageing (as in the general population). Therefore we offer three recommendations for those with Down syndrome, their carers and clinicians:

- 1. Avoid exposure as much as is possible through social distancing. Everyone with Down syndrome with significant additional health issues should be self-isolating if possible.*
- 2. Ensure equitable access to healthcare and treat people with Down syndrome the same as all others*
- 3. If there is any doubt about a change in the health of someone with Down syndrome, seek clinical advice immediately.*

Other resources

Disability Information Helpline – about Covid-19

The new Disability Information Helpline is available Monday to Friday 8am to 8pm (AEST), and Saturday and Sunday 9am to 7pm (AEST) except national public holidays. You can find information about the new Disability Information Helpline, as well as accessible resources on the DSS website - visit www.dss.gov.au/disabilityhelp. This website also includes a number of good Easy Read resources on Covid-19 and support around staying home.

The Disability Information Helpline number is: 1800 643 787

What is happening at the Association?



DSWA Membership is now free



DSWA is pleased to share that we have received a grant from the NDIA, called **Information for Life**. This enables DSWA to now offer **free DSWA membership**. This grant also allows the Association to offer a complimentary copy of the National journal "VOICE". If you would like to subscribe to the VOICE or download electronic copies of articles from the latest issue and other editions please click on the link <https://downsyndromevoice.org.au/>.

Alternatively please email us at emily@downsyndromewa.org.au or call us on 9368 4002 for your copy. "VOICE" is published three times a year and has information and stories which are relevant to our Down syndrome community.

The focus for the April issue are all the ways **technology** can assist the Down syndrome community and challenge it at the same time. There are also great stories of how assistive technology and augmented communication devices can change the lives for people with complex physical and communication needs.... Plus, lots more.

A WORLD FIRST: Ask About Down syndrome App

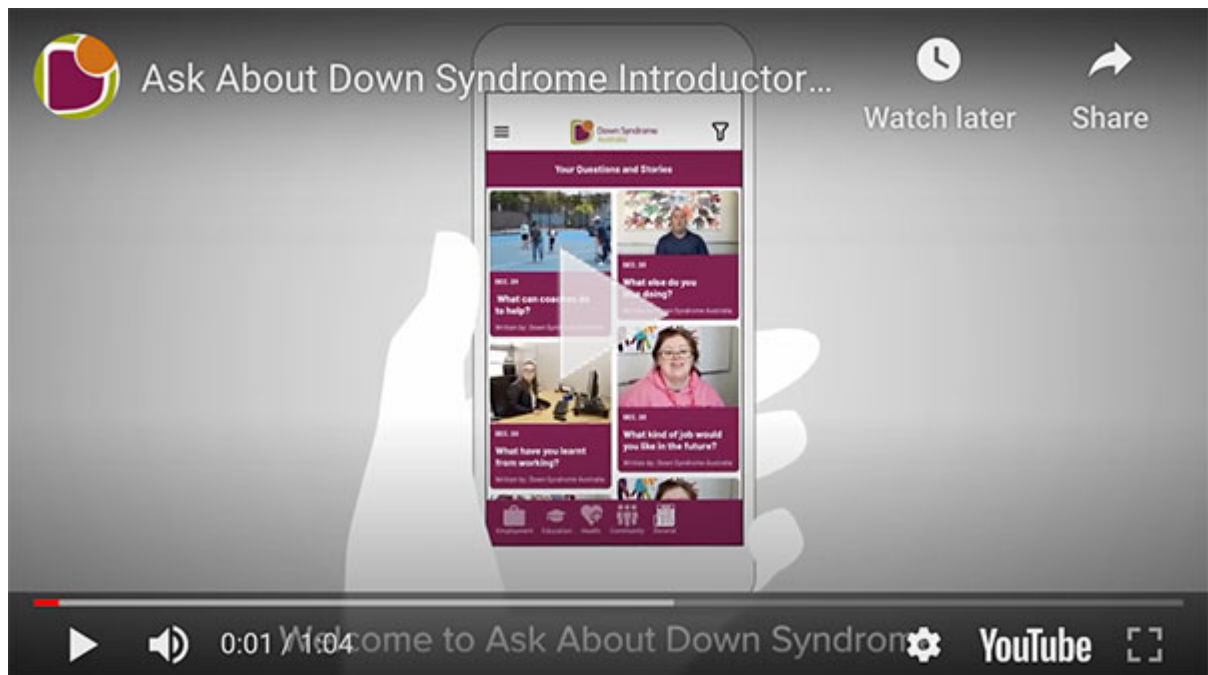
On World Down Syndrome Day there was the launch of the **Ask About Down syndrome App**. This is the world's first app providing information about Down syndrome, which has been co-designed and developed alongside Australians with Down syndrome.

The app features people with Down syndrome from across our country, answering questions and sharing stories about what community inclusion is, what barriers they face, and how these issues can be addressed, amongst many other topics. The app also links to a range of resources that support and promote community inclusion.

Link: <https://www.downsyndrome.org.au/news/AskAboutDownSyndromeApplaunch.html>.

In the App, **Western Australia is represented by some of our young adults**. Awesome job!!

The app is available for free from the App Store and Google Play



Social Connection

Did you know?

Aim High has recently launched regular online meetings via *Zoom*, which have been attracting many adults from our DS community, so much so that we've now introduced two, 60-minute sessions every weekend!

We are in our third week, and **I invite you to join us tomorrow (Saturday 18th April) at 11:00am OR 2:00pm**. The link to join this meeting is below, along with the Meeting ID and Password which you'll be required to enter. I'd also like to highlight that these meetings are open to ALL adults from the DS community, including those who haven't previously attended an Aim High event.

Join Zoom Meeting:

<https://us02web.zoom.us/j/2835414335?pwd=RzNWREVxcW92VW9uVTIsRGR5QnMrZz09>

Meeting ID: 283 541 4335

Password: aimhigh123

At this meeting, we will be exploring creative ways to exercise at home using common household items - something that we could all get used to doing more often, to help take care of our mental and physical health. If you would like further information about these meetings, please email me at aimhigh@downsyndromewa.org.au

Lastly, we will be continuing these sessions over the Anzac Day long weekend joined by Maddie and Acacia from *Let's Yoga Perth*. If you aren't already on the Aim High mailing list, get in touch ASAP so you don't miss out 😊

Suzanna



Zoom social groups

Nikki is having a great response to her social programs via Zoom. Kids club and playgroups via Zoom are underway and Nikki is kick starting Friends for Life on Friday. If you would like more information or want to join one of the Zoom social groups please email Nikki at: Nikki@downsyndromewa.org.au. [See Good news story for more....](#)



New parent Connection

Have you had a new baby in the last 2 years and would like to connect with other parents? Nikki is starting a new parent group, so now is a great opportunity for families throughout the state to connect through these regular Zoom catch ups.

Please contact Nikki at Nikki@downsyndromewa.org.au



All things NDIS



REGISTERED
NDIS
PROVIDER

Latest from NDIS

Thanks to everyone who joined me for the NDIS session on Wednesday: ***Understanding and using your plan in the time of corona virus.*** Please click the link or button to access the PDF of the power point presentation.

[PDF presentation](#)

PDF presentaion

If you haven't yet had your initial NDIS planning meeting or are thinking about your review meeting, please "come along" to the following sessions in the series of NDIS workshops. Please RSVP to elise@downsyndromewa.org.au with the age of your family member with Down syndrome for either of the following two workshops.

1. **Tuesday 21st April 2020, time: 10:30am.**
Your first Planning meeting? How to prepare and what to expect.
2. **Tuesday 28th April 2020, time: 10:30am.**
What happens with the plan review? Considerations.



BIG NEWS and good news around Assistive Technology:

The NDIA has released information where some assistive technology (including ipad/tablets) may be purchased using NDIS funding under the following conditions:

- The item will maintain the provision of other funded NDIS supports, and
- The Participant does not already have the item, another suitable item or access to purchase the item through other means, and
- The item has not been funded by another service system such as education or health.

The Agency will have further information become available in the coming weeks.

Please note that the process of accessing funding from your plan to purchase these devices has not as yet been formalised. Watch this space.....

Emotional Health support

Hi it's Nicola Burton here.

I am a Relationships Therapist, Psychotherapist, Counsellor, Mentor and Empowerment Coach, also a Practitioner in NLP & Hypnotherapy. A teacher of Adult Education, Expressive Art Therapist, a blogger, and a published poet.

I am available on Tuesdays, Wednesdays, Thursdays – 0480 26 3693 Down Syndrome WA to take your calls with any concerns that you may be experiencing, in this current Pandemic and the impact for many of you. Now home schooling, working from



home and having to wear many hats as you juggle so many roles throughout your day “Phew” that’s an awful lot to hold.

I get you, as I am also adapting with my family to some of these changes.

Please reach out to me, if you are a parent having to meet your young or older child and children’s needs – perhaps you are feeling lost, confused, stressed out and overwhelmed?

And maybe a little guidance and support is just what you need right now.

Look forward to speaking with you all soon 😊

Nicola has put together a brilliant 2-part blog around personal boundaries during close confinement.

During this difficult time many families, are having to be ‘All’ things to their children and with each other 24/7 – this is not easy and creates boundary issues.

To find out more, click buttons or links below which will then be downloaded:
Personal Boundaries during close confinement:

[Part A](#) and [Part B](#)

[Part A: Link](#)

[Part B: Link](#)

Good news story



Good news story by Tracy and Elliot Bicker

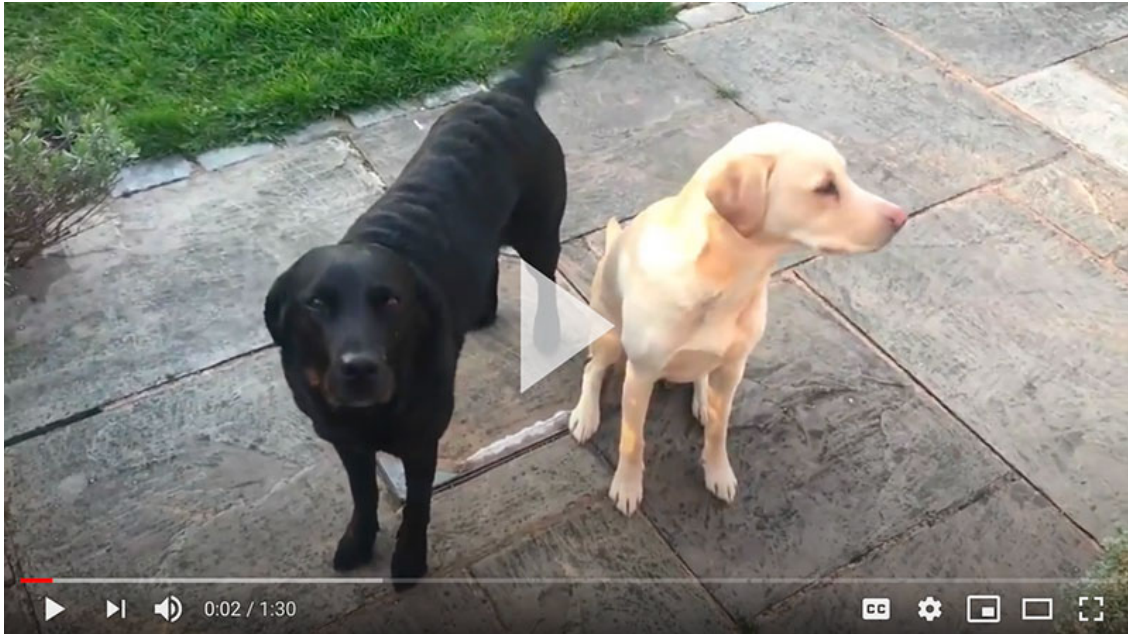
Friday mornings playgroup at Down Syndrome WA may look a little different at the moment but we are still enjoying seeing all our friends faces every week.

Elliot and myself get ourselves set up in the living room with our laptop and a fresh cup of coffee for mummy. We jump onto the zoom session organised by our amazing family coordinator Nikki. It’s wonderful seeing all the familiar faces from playgroup and joining in on a signed song or book.

Keeping a routine during these uncertain times has been very helpful for our mental state and our kids happiness. We thank Down Syndrome WA for adapting their sessions during this time and keeping us all smiling!

Light Moments

If you like dogs, sport, a good laugh or any combination of these, click the link below to listen to “bored” British sports broadcaster commentate on the everyday! **Please be aware that this is a public link being youtube.**



*Stay well everyone and please contact us if you have any questions.
We are here to support, inform and connect our Down syndrome Community.*



**If you know anyone who can benefit from this newsletter,
forward this email and ask them to subscribe. Thank you!**

[Subscribe now](#)

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