

National and international news and views  
Networking Dystonia patients



# News+Views

SPECIAL EDITION ~ APRIL 2020

DYSTONIANS IN LOCKDOWN

**Be strong. Be Kind.  
Unite against COVID-19.**

Welcome to this special edition of 'Dystonians in Lockdown'. Here we are in week 4 – well done team! The last newsletter did not go ahead because of the Covid-19 outbreak, so here is a mini-version to occupy your time. Kia kaha. Jayne Lewington Lovell

## From the Chair – Alison Fitzpatrick



Greetings to you all; what an extraordinary time we find ourselves in at present. We are all worried. What will happen to our loved ones, our jobs, our incomes? What about our non-COVID related medical care? How long before we can access Botox again at the outpatient clinic?

These unprecedented circumstances call for greater self-care than ever before. Make sure you look after yourselves: make time to get out in the fresh air and get some exercise. Yoga and tai chi can work wonders. Physical libraries might be closed, but their digital service is open 24/7. Check out the range on offer – eBooks, eAudio, emagazines, streaming films, genealogy resources and much more. Have you ever listened to a podcast? Well, now's the time - you might just find that you get hooked.

Each one of these activities has a huge community of supporters and participants. Remember that we are all part of the community. We are all in this together – he waka eke noa. Stay strong and take care.



## Botox Clinics deferred until after Lockdown

Adele (Movement Disorder Nurse Specialist) at Auckland City Hospital has confirmed that Botox clinics are deferred until after the lockdown. This could also apply to Level 3 but we will keep you informed of any developments. In her email Adele also told us that Lorraine McDonald has retired and that there is a new nurse on board called Rebecca. Take care Dystonians while we wait for our next shots – lots of self care will be needed!

## Acknowledgement to Roger Terry

The Committee is now missing a team member as Roger Terry had to resign in February due to complex health issues. A stalwart of the NZDPN, Roger will be remembered for his dry humour and well-considered opinions. Your hard work over the years on behalf of the network is greatly appreciated – Go well Roger and;



## Greetings from the National Spasmodic Dysphonia (NSDA) Association

First and foremost, we at the NSDA extend our heartfelt wishes that you and your families are as well as can be expected during this situation surrounding COVID-19. We know these are uncertain times that are impacting all aspects of our daily lives.

Some of our members have reached out to us with questions, so we wanted to respond with the most current information available along with some resources that might be helpful.

❖ *How do you get COVID-19? Does having a voice disorder make the risk the higher?*

Dr. Emily Landon who specializes in infectious disease at the University of Chicago Medicine states that; This virus is really transmissible and can spread easily from person to person even before a person develops symptoms. It's carried on respiratory droplets when we talk, sneeze, and cough and these can land on surfaces or in someone's mouth or nose. When it comes to respiratory droplets, 6 feet (2 metres for us in New Zealand!) is the magic distance. That's how far these tiny, infected droplets can travel. Being within 6 feet of someone who is sick can get you or your personal space contaminated with COVID-19. When droplets land on surfaces, we can pick them up with our hands and transfer them to our eyes, mouth, and nose when we touch our faces. Respiratory secretions (like mucus and sputum) can also be infectious. Two factors that apply to people with laryngeal dystonia in particular are (1) after treatment they have a weakened cough reflex, which may lessen the chance of transmission if they are COVID-19 positive; but (2) with a weaker voice that is difficult to project they tend to approach people they are talking to quite closely – try to avoid that, and instead seek out quiet surroundings. This makes it doubtful that having a voice disorder makes a person more or less at risk than the general population since transmission is the same for anyone that breathes, swallows, or touches their face. However, those over 60 or who are immunocompromised are at higher risk for COVID-19.

❖ *How can the NSDA help you?*

1) Educate. Have you been asked if you were sick because of the sound of your voice? This may increase even more when people are nervous about illness.

The NSDA has cards and buttons that are very helpful explaining what is wrong with your voice.

You can email us at [NSDA@dysphonia.org](mailto:NSDA@dysphonia.org) to order them or [download](#) this [PDF file](#) that can be printed out and used immediately.

2) Learn. You can explore the newly-launched [NSDA website](#). Plan to join us on Saturday, May 2, for the NSDA virtual symposium. This event will be free and open to anyone who wants to join. The presentations will also be recorded and available to view at a later date. You can watch videos from previous symposiums on [NSDA's YouTube channel](#) now.

3) Connect. Go online with the [NSDA bulletin board](#) or [social media](#). We will be exploring additional virtual options over the next few weeks including online support group meetings. Take care of yourself and each other. We are all in this together! <https://dysphonia.org/>



## Living well with Covid-19

The past month has been a time of tremendous disruption; our daily lives look very different now. During these challenging times it is understandable to feel overwhelmed by COVID-19 related events. Below are some tips that will hopefully give your wellbeing a boost;

- **Stick to routines if you can.** Having a routine will help you to cope every day and to adjust when lockdown is lifted.
- **Limit the amount of news you follow.** Pick a trustworthy source like the Ministry of Health's COVID-19 website
- **If you feel you are not coping.** 1737 is a free service for New Zealanders who are a bit overwhelmed or just need to chat to someone. You can call or text 24/7 to talk with a trained counsellor.
- **Take up the Covid-19 Challenge.** Dieter Dvorak is a Clinical Health Psychologist with the WDHB Pain Service. He runs a regular course in 'Coping with Chronic Pain', and, has recently incorporated 'Coping with Covid-19' into the format. His blog is; <https://awakeningtothechallenge.wordpress.com/>



### Online Support Group

Evelyn Watson in Southland runs the Dystonia NZ Support Group on Facebook. You can also contact her by email: [watsayyou@xtra.co.nz](mailto:watsayyou@xtra.co.nz) or phone: 03 208 5120/ 027 308 6305

### New Contact for NZDPN

The Network has a new toll-free phone number. It is advertised at the website, in our Welcome messages, and in other publications. We can now be contacted free of charge from both landlines and mobiles at 0508 397 866. For those with alpha-numeric keypads, this spells 0508 DYSTON.

We can of course still be reached by email, our website <http://www.dystonia.org.nz/> or write to P.O. Box 34 259, Birkenhead, Auckland 0746



### Governance of the NZDPN

The Executive Committee is elected each year at the Annual General Meeting. Like everything else the AGM is on hold because of the C-19 pandemic. Until we are able to have the AGM, the Committee remains as:



President:  
Alison Fitzpatrick



Treasurer:  
David Barton



Secretary:  
Desiree Sargon



Network Manager:  
Dave Mitchell



Newsletter Editor:  
Jayne Lewington Lovell

NZDPN email: [info@dystonia.org.nz](mailto:info@dystonia.org.nz)  
NZDPN Phone: 0508 397 866

Mission Statement: Our 3-fold mission is:

- To support dystonia patients with information, advice and networking opportunities
- To increase awareness about dystonia - both among the medical community and the public
- To encourage and facilitate research, with the aim of seeking better treatments, prevention, a cure

Disclaimer: Nothing in this newsletter is intended to serve as medical advice on dystonia. The NZDPN recommends that you consult your own doctor(s) and other health professional(s) regarding your diagnosis and treatment.