



March Newsletter

Covid-19 and Alert Level 4 Lockdown

We hope you are all safe and well in your bubbles. These are extraordinary times for everyone, but we understand they may be additionally difficult for people with PWS, their families and support workers. We want to assure you that whilst we are unable to arrange visits or training at the moment, we are still available for support via phone call or email.

As maintaining social interaction is important whilst in lockdown, we thought it would be helpful to facilitate some Zoom group video catch ups. More information about this coming soon, but we would be looking to arrange a group for adults with PWS and another for tweens and teens if there was interest. Please [tell us](#) if interested in either group.

Meanwhile, please keep sending us pictures and stories of what you've been doing to pass the time during lockdown - we'd love to share them on our Facebook page!

Please find below some links and resources that may be useful at this time:

As you are already aware, Covid-19 symptoms have the potential to be more severe in individuals with PWS due to underlying health conditions. The information that was emailed to you about this can be found on our website in the event it is needed in the future.

> [Covid-19 and PWS Alert](#)

The disruption of a lockdown will have altered routines and may be causing increased anxiety. Visual schedules are effective ways of managing changes in routine and several resources can be found online to help with this. We think these are particularly good.

> [Visual scheduling images](#)

If you are looking for some easy read resources to help explain about Covid-19 and staying at home, a good collection can be found at the People First New Zealand website.

> [Easy Read resources about Covid-19](#)

TalkLink also have links to social stories and useful resources that support understanding.

> [A staying at home social story](#) and [TalkLink's list of other resources](#)

If you receive Individualised Funding, it has been announced there is more flexibility with how this can be used at this time. Manawanui have a dedicated web page which explains.

> [Individualised Funding flexibility](#) and the [latest IF update](#)

Essential disability services have been defined as any service providing direct support that maintains a person's necessities of life with a focus on keeping them safely in their home. We are told to ask ourselves: if this service was not provided, would the person be at risk of serious harm or hospitalisation. The following resources may answer further questions:

> [Essential health and disability services](#)

> [Information for disability providers](#)

> [Information for people with disabilities and their families](#)

> [FAQs during Covid-19](#)

Family Camp at Lake Taupo, Feb / March 2020



Looking back at happier times, our recent camp at Lake Taupo almost seems to have taken place in another lifetime! However, it wasn't all that long ago that over 90 of us gathered together at MiCamp Taupo and enjoyed a sunny weekend participating in various activities, catching up with old friends and meeting new people. We hope everyone who came had a fantastic time and we would like to thank all our volunteer helpers.

[Read more about the camp weekend and view photos here >](#)

We would like to ask those who attended the camp to please complete a very brief and anonymous feedback form. These are useful in helping us to secure future grant funding for events such as this and also assists with future camp planning. [Camp feedback form >](#)

PWS Training and Support in Christchurch

A training day due to take place in Christchurch earlier this month unfortunately had to be postponed due to Covid-19 regulations. This will be rearranged once we have confirmation that we are no longer at an alert level that does not permit this. If other service providers in Christchurch are also interested in training, we encourage them to get in touch. Whilst facilitating training in Christchurch, Cindy may also be able to visit some of our adults with PWS and could possibly organise a get-together. Please [get in touch](#) if keen.

[Missed our AGM? Request a copy of our annual report](#)



Rare Disease Day 2020

Rare Disease Day took place on February 29th. It was an opportunity for creating more awareness of PWS and living with a rare disorder. Around 300,000 people in New Zealand have a rare condition.

Altogether, there are more than 6000 identified rare diseases, including PWS, which affects approx 1 in 16,000 people. Living with a rare disorder often means not receiving equitable access to diagnosis, treatment, care and opportunities. Information and professional expertise may be limited. To raise awareness of these issues amongst policy makers and others, international Rare Disease Day was started in 2008. Together, Rare is Strong!

On February 28th, Rare Disorders NZ launched the '[Fair for Rare NZ](#)' campaign at parliament outlining 7 strategic priorities for the development of a National Rare Disorder Framework to improve access to diagnosis, treatment and care.

Click here to sign the [parliamentary petition asking for a Rare Disorder Framework >](#)

Other New Zealand Disability Sector News

The roll out of 'I Choose' (the replacement for the inflexible, outdated Carer Support days) has been delayed for over a year. This is due to a lack of funds being made available for the additional cost of families being more able to access the respite they are entitled to. [Read more here >](#).

If you use carer support forms and often have to wait for another form whilst payment is being processed, you can now click here to [download carer support forms](#).

Looking for carers or support workers? Some useful websites are [e-Mploy](#) by Manawanui and [MyCare](#).

[Dates for your Diary](#)

PWS Awareness Day - Friday 29th May 2020

Regional Notices / Events

Regional events and workshops are either cancelled or postponed at the moment, many until at least the end of April at this stage. The following websites can be checked for future dates once our lockdown has been lifted.

[Imagine Better Workshops](#) - i.e. Making Individualised Funding Work, and other workshops for families, service providers or people with disabilities

[Care Matters Workshops](#) - i.e. Explore-Learn-Connect, Transitions

[Parent to Parent Courses and Workshops](#) - i.e. Navigating the System, Renew-Connect-Reflect

[Disability Connect Workshops](#) (Auckland) - i.e. Education Legal Issues, IF, Transition, Planning for Adulthood, Living Options, WINZ, (*\$20 per family*)

[Parent to Parent branches for local support group meetings](#)

[Sibling Support Programmes](#) - SibShops and Camps are advertised on the Care Matters and Parent to Parent calendars.