

# Earning, Learning, Volunteering and Caring – The Many Faces of Work

Scout Barbour-Evans, Kahukura Consultancy  
they/them/ia, Ngāti Kahungunu ki te Wairoa



# Ko Wai Au?

---

Single parent from Ōtepoti

---

Prominent advocate for transgender and rainbow hauora services

---

Work through a lived experience and personal narrative model

---

Small business owner providing consultancy services to institutions and public services

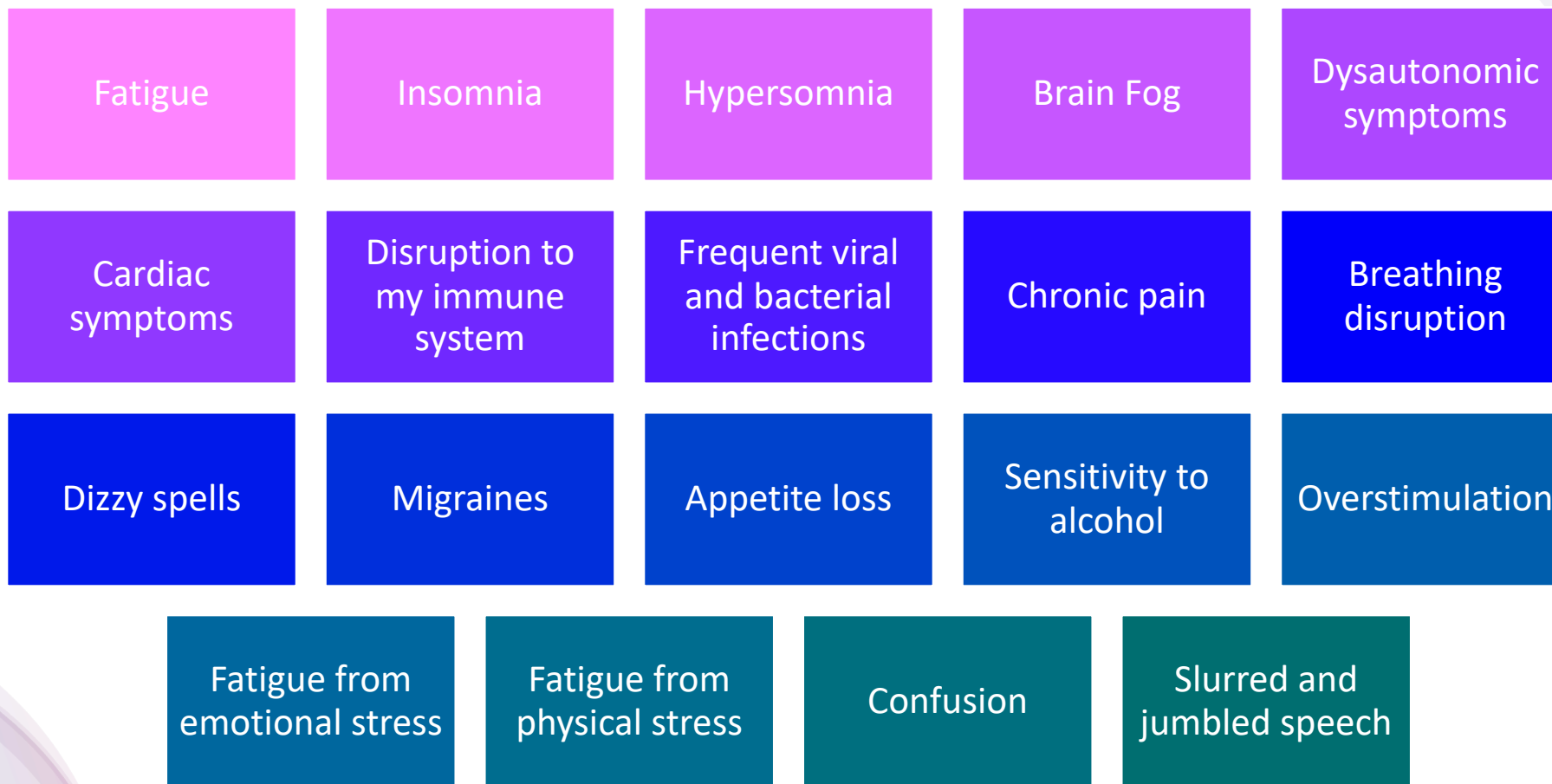
---

Flew a plane before I ever drove a car

---

...and I've had long covid since April 2022

# What does Long Covid look like for me?





## Pre-Covid

Developed Myalgic Encephalomyelitis (ME/CFS) from a bout of Glandular Fever, recovered enough to work

Volunteered for political and humanitarian groups for 6 years, including skilled volunteering in disaster relief roles

Graduated from the Certificate in Mental Health and Addiction Support in 2016 and the Bachelor of Leadership for Change from Otago Polytechnic in 2019

Timed starting a whānau for the final year of my degree, in order to juggle work, study and health needs

Took a break from work to recover from anorexia nervosa, have a hysterectomy and raise a young toddler

Began a business to work part-time while being around for my child

Developed Long Covid and had to seriously reduce my work hours



## Post-Covid

Wrote a literature review while in the acute phase of covid, then slept for about four months

News media and social media advocacy

Participating in every piece of research I can

Writing for the Long Covid Aotearoa website

Chairperson at a local kōhanga reo

Occasionally working in other academic fields and hoping to complete a masters degree in the next year

# Parenting with Long Covid

I've had to foster a lot of independence in my four year old, and she can

- Make her own breakfast
- Wash her own plates
- Vacuum her room
- Collect takeaways from the front doorstep

I've survived this work by adjusting my expectations and accepting a lot of help. Accommodations I need but can't afford due to being unable to find work with the right accommodations include a dishwasher, home help/cleaning services and a one-story house.

# Volunteering with Long Covid

---

My personal experience is that because voluntary organizations are still subject to the Health and Safety at Work Act (2015), it can be considered a strain on their resources to volunteer with chronic health conditions.

---

Without laws to protect disability access rights in Aotearoa it is easier for a voluntary workplace to reject someone with any disability, including Long Covid.

---

I was not able to keep my skilled voluntary roles due to health and safety concerns from the organizations I worked for, so there was no chance to access adaptations.

# Working with Long Covid

---

No one has enough sick leave or annual leave to develop Long Covid. Like ME/CFS, Long Covid can leave you unable to work for anywhere between months-years.

---

MBIE has not been considering Long Covid to be sufficient reason to support small businesses with wage subsidies etc.

---

People with Long Covid are being forced to either go back to work earlier than their health needs, or to quit their jobs and adjust to life on a benefit.

---

People who don't need to leave their jobs may need adaptations like more frequent breaks, half days or short days, the ability to use adaptive equipment or to be seated.