

#longcovid2022

# PEER SUPPORT WITH LONG COVID

*MORE THAN A NICE EXTRA*

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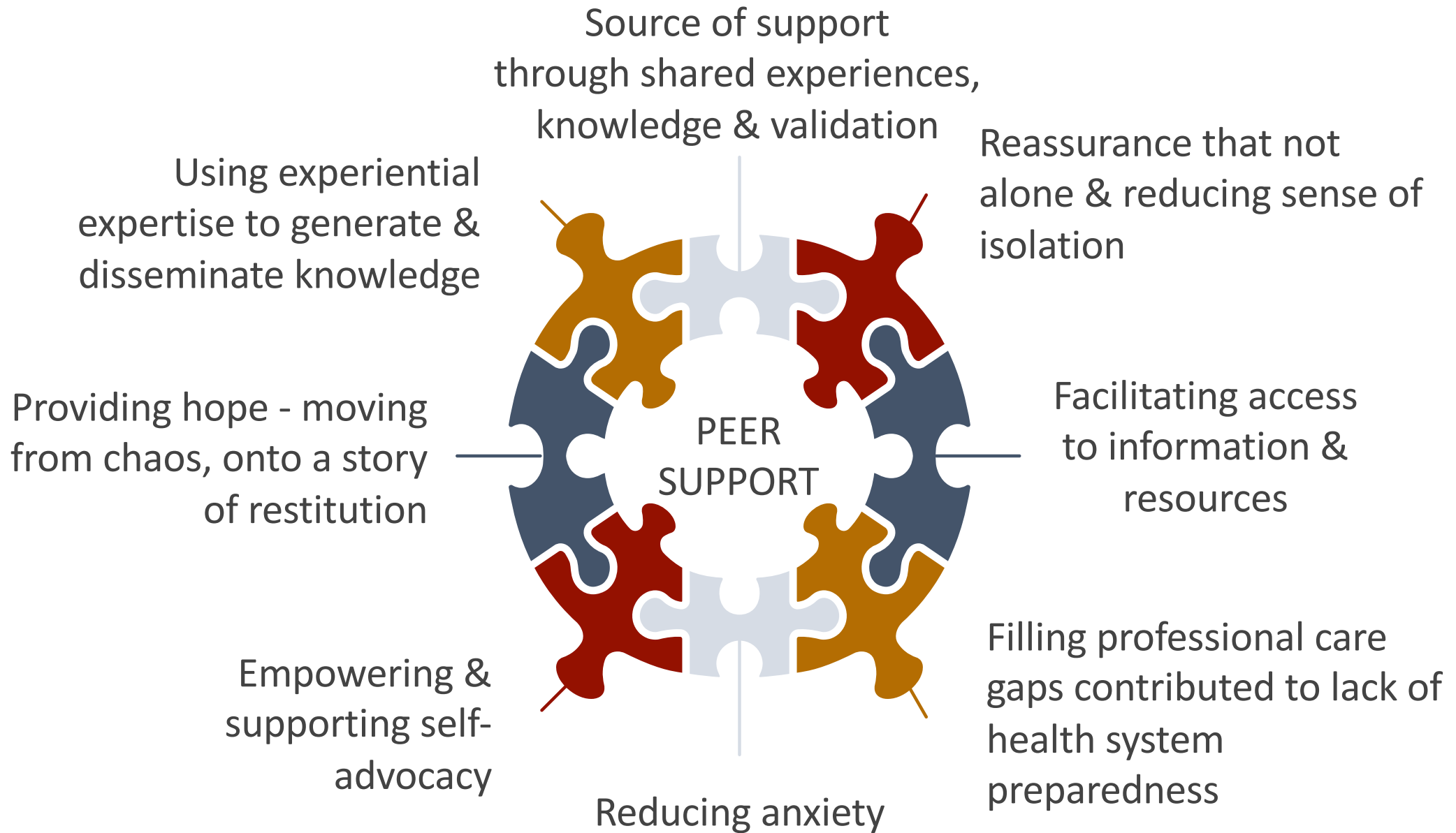


# WHAT IS PEER SUPPORT?

*'It's a relief to me that everything I've gone through in the last eight months is finally being validated by other people now having very similar experiences as mine post-COVID. I've felt very alone in this whole experience to this point.'*

*[Support Group Member]*

Ireson J, Taylor A, Richardson E, Greenfield B, Jones G. **Exploring invisibility and epistemic injustice in Long Covid—A citizen science qualitative analysis of patient stories from an online Covid community.** Health Expectations [Internet]. 2022 May 12; Available from: <https://onlinelibrary.wiley.com/doi/10.1111/hex.13518>



Sources: References [1 – 6] on final slides

# CHALLENGES IN PEER-LED COMMUNITIES

- **Emotional impacts** driven by diversity of long COVID experiences encapsulated in groups
- **Comparison to others** as a means of better conceptualising own situation, however:
  - Fear of prolonged suffering
  - Frustration when seeing those with less severe symptoms express narratives of deep despondence
  - Dismissing varying experiences and/or strategy use
- **‘Taking everything with a pinch of salt’**
  - burden placed on individuals to critically appraise content and suggestions

# WHY IS PEER SUPPORT FOR LONG COVID NEEDED?

- Rapidly **emerging & escalating** situation
- **Lack of clarity** about best way forward in terms of service provision
  - fragmentation of services
  - lack of clear pathways for people to navigate
  - conflicting information
- **Not being listened to & validated**
  - within individual interactions with health providers, colleagues etc
  - within the public space (e.g., media, social media etc)

**Result:** People feel abandoned, stigmatised, isolated, anxious & disempowered



# WHY IS PEER SUPPORT NEEDED MORE GENERALLY?

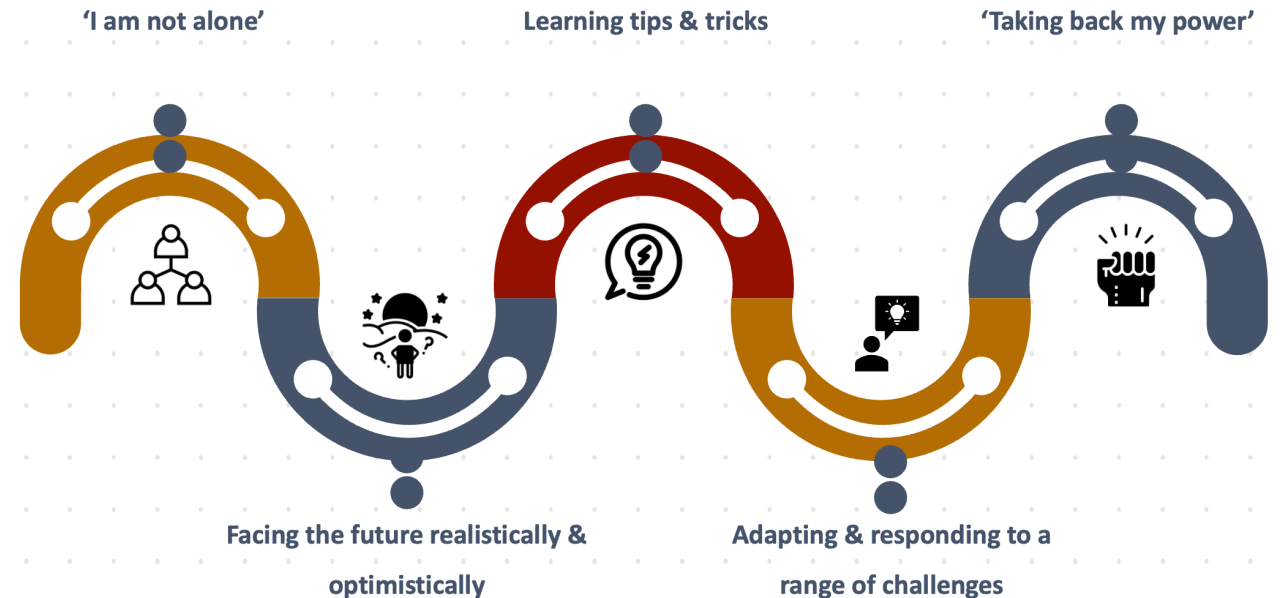
- **Health outcomes are not only achieved by providing discrete interventions**
  - how people are able to engage with resources offered to them really matters
  - E.g., trusted relationships, credible sources, lack of power differential, mana-enhancing interactions
- **Autonomy and agency make significant contributions to positive health outcomes**
  - control over the overall management of symptoms - that by their nature are fluctuating and dynamic
- **People are experts of their own bodies and experiences**
  - the knowledge, hope and self-efficacy that peers can give each other is significant



# PEER SUPPORT IN AOTEAROA NZ

- Peer support is increasingly being used within **holistic health care provision**
- **Examples** from other populations in NZ
  - Spinal cord injury [7,8]
  - Traumatic brain injury [9]
  - Mental health
  - CFS/ME
  - Mana Motuhake [10]

## How does peer support help a person with a new SCI?



# LONG COVID PEER SUPPORT – IT'S ALREADY HAPPENING

But how can we build peer support into the design of services, so that it is more routinely accessed and sustainably resourced?



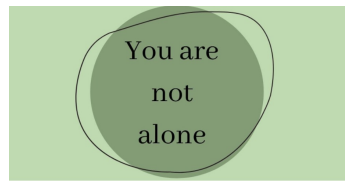
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Private group · 697 members

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*“... new members post about their health journey and the lingering impact of Covid. They are seeking help, solutions, support, guidance.*

*It often comes with an air of desperation, confusion as to what is happening to them and frustration that they are in this position.*

*They are already scared of the unknown, they are anxious about what may lie ahead, and this can be heightened by personal circumstances such as their ability to work, look after their family, pay their bills and pre-existing conditions.”*

*[Long Covid Aotearoa Support Group Member]*

# NEED FOR LONG COVID PEER SUPPORT RESOURCING

*'And the best support I got was from all the Facebook groups, believe it or not. That's where I found a lot of information, because everyone else was on a similar timeline to me. So, we were all going through the same symptoms, so I knew I wasn't going crazy'*

*[Female participant, Burton et al. p.6]*

- Peer relationships are positive for both the supporter and those being supported [11]
- But, also consider the unique needs of people offering peer support
  - training & resourcing
  - supporting psychosocial responses
  - moderating online communities

# TAKE AWAYS: PEER SUPPORT FOR LONG COVID

## Peer support is required for long COVID

- supports equitable access to health services
- enhances the experiences of people navigating health services
- achieves equity of health outcome

## Peer support is effective for long COVID

- often achieving health outcomes that cannot be attained via mainstream health care provision

## Long COVID peer support systems and spaces need to be adequately resourced

- to be sustainable
- to best meet the needs and aspirations of people living with the ongoing impacts of COVID

*“Access to knowledge is the number one question asked of the group “how do I find out what to do”. If we can give them the tools to self manage, gain support, and go armed with intel to approach their GP, employer, or whānau, they’ll be saving time, money, energy and stress.”*

*[Long Covid Aotearoa Support Group Member]*

# REFERENCES

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