Calling in Sick:

Long COVID as an Episodic Disability

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Realize

CAPDA

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realize
FOSTERING
POSITIVE CHANGE
FOR PEOPLE LIVING
WITH HIV AND OTHER
EPISODIC DISABILITIES

réalise
UN MOTEUR
DE CHANGEMENT POUR
LES PERSONNES VIVANT
AVEC LE VIH ET D'AUTRES
INVALIDITÉS ÉPISODIQUES

Acknowledgement of Traditional Land

*The **Realize** office sits on the traditional territory of the Wendat, the Anishnaabeg, Haudenosaunee, Métis, and the Mississaugas of the Credit First Nation.*

Who is *Realize*?

Realize is a national non-profit with the aim of fostering positive change for people living with HIV and other episodic disabilities.

Established in 1998, ***Realize*** emerged as an innovator in bridging the traditionally separate worlds of HIV, disability and rehabilitation.

Our goal is that through our work, the daily lives of people living with episodic disabilities are improved in direct and meaningful ways by research, education, and policy change.

Our Work in Episodic Disability

National Episodic Disability Forum (EDF)

Created and use the IDEAL Framework (Inclusion, Diversity, Equity, Accessibility, Leading to belonging)

Host the annual National Summit on Episodic Disabilities and Employment

Partner on national and provincial research projects

Active policy work with government representatives and advocacy groups

Develop accredited online trainings for HR Professionals

Develop reports, policy briefs, white papers, keynote presentations

What is an Episodic Disability?

"Episodic disabilities are characterized by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and predictability from one person to another."

- Episodic disabilities can be intermittent, invisible, and unpredictable
- Unpredictability has a negative impact on meaningful community participation, employment, income security, social inclusion and access to care
- Many employers struggle with accommodation in the context of intermittent work capacity.

Episodic Disabilities

(this list is ever-changing and expanding)

- Anxiety
- Chronic Pain
- Depression
- Diabetes
- Epilepsy
- Multiple Sclerosis
- Parkinson’s Disease
- Arthritis
- Asthma
- Sickle Cell Disease
- Bi-polar disorder
- Cancer
- Post-traumatic stress disorder (PTSD)
- Schizophrenia
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
- Crohn’s Disease & Ulcerative Colitis
- Hepatitis C
- **HIV/AIDS**
- Lupus
- Cystic Fibrosis
- Meniere’s Disease
- Migraines
- Long-COVID
- Substance use disorder
- Fibromyalgia
- ME/CFS
- Chronic Obstructive Pulmonary Disease (including chronic bronchitis and emphysema)

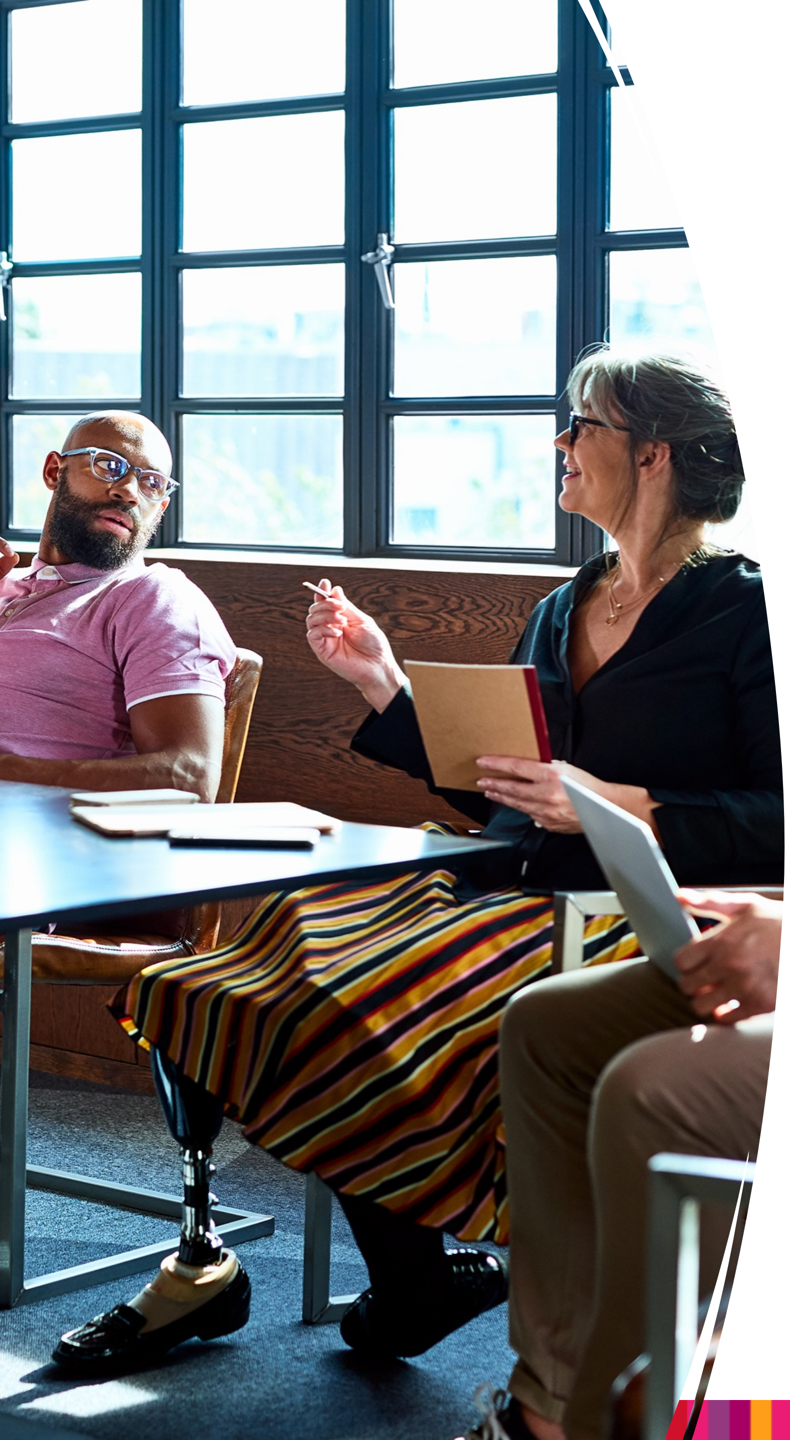
Episodic Disabilities in Canada

Of the 6.2 million people in Canada living with disabilities, 61% experienced some type of episodic disability.

75% of working people in Canada say they would not admit or would be reluctant to admit to their boss or colleagues that they were living with a mental health condition.

It is estimated that:

- 62,050 people in Canada are living with HIV
- 77,000 people in Canada are living with MS
- 2 million people in Canada are living with a recurring or fluctuating disability
- 1.4 million Canadian adults experienced symptoms three months after a COVID infection



National Deliberative Dialogue on Long COVID as an Episodic Disability and Employment

70% of people living with Long COVID have reduced work hours or are not working

Language matters! Using the term “brain fog” under-represents its severity and the impairment caused by cognitive dysfunction

No single accommodation fits all scenarios. Accommodation may look like:

- Employee vaccination & treatment plans
- Duties revised to reduce respiratory impact
- Working from home
- Modified work tasks may not return to pre-COVID levels

Stigma and mistrust of employees are barriers to disclosure and effective accommodation of COVID-19, and thusly Long COVID, has disproportionately impacted people living with disabilities

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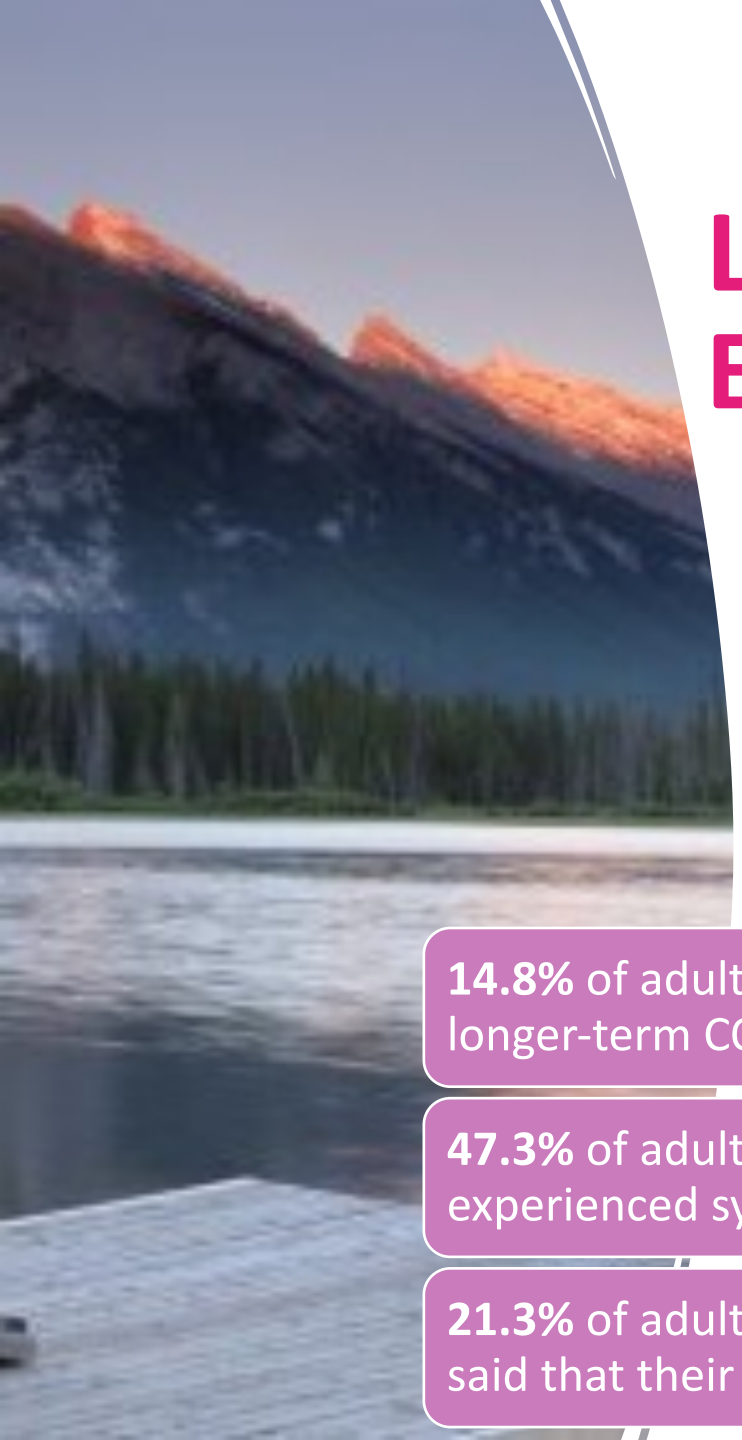
Shari's Story

Shari Ingalls is a former Nurse living with Long COVID.



Long-COVID: Evidence from Canada

The Government of Canada developed the Canadian COVID-19 Antibody and Health Survey (CCAHS), to find out more about people's longer-term symptoms. The survey asked about new or continuing symptoms 3 months or more after a confirmed or suspected case of COVID-19.

14.8% of adults with a confirmed or suspected infection, experienced longer-term COVID-19 symptoms

47.3% of adults that experienced longer-term COVID-19 symptoms, experienced symptoms for a year or longer

21.3% of adults that experienced longer-term COVID-19 symptoms, said that their symptoms often or always limited their daily activities

Long-COVID and Mental Health Practitioners

- Mental Health Practitioners are key to building the knowledge and confidence of the medical community about Long-COVID
- Patients are not at fault and should not be blamed for their illness, limitations, or changes in abilities
- Cognitive dysfunction is part of this medical condition and not psychiatrically caused, it is far more than “brain fog”
- Understanding the complexity of this “multisystem illness” takes patience and Mental Health Practitioners can give people with Long COVID the confidence and tools to navigate and cope with their new illness.

Long-COVID as a Biopsychosocial Condition

Long-COVID can be categorized alongside myalgic encephalomyelitis and chronic fatigue syndrome, biomedical, multisystem, and complex health conditions.

There has been resistance in some medical communities to embrace this categorization despite a growing body of evidence.

Long-COVID symptoms are unpredictable and episodic, and some people can carry out the tasks of daily life one day and then be unable to get out of bed the next.

The invisibility of this episodically disabling condition make it challenging to describe symptoms and limitations to family, employers, friends, and healthcare practitioners.

Mental health practitioners can support those living with Long COVID by validating symptoms, facilitating the management of grief, and supporting adaptation to new life circumstances and abilities.

Eliciting COVID-19 History and Long COVID Symptomatology

- Did you have COVID-19 (or do you think you may have had COVID-19)?
- Did your exhaustion, brain fog, fatigue, sleep disturbance, anxiety/depression exist before your COVID-19 infection or afterwards?
- What fraction of your pre-illness capacity are you functioning at?
- What happens when you engage in normal (previously tolerated) physical or mental exertion?
- How much activity does it take to make you feel ill or to trigger illness worsening?
- How long does it take to recover from this physical or mental effort?
- Do you avoid or change certain activities because of what happens after you do them?

From: Goldberg et. al. (2022) A new clinical challenge: supporting patients coping with the long-term effects of COVID-19

Impact on Employment

- Consultants at the Job Accommodation Network report that a common accommodation across symptoms is restructuring a job or removing unnecessary tasks.
- Telework can also be an accommodation for Long-COVID symptoms
- The episodic and unpredictable nature of Long-COVID requires individualized and creative efforts from a healthcare team and the workplace to facilitate return to work
- Returning to work might be possible for some, but it is often at the expense of participation in other life roles (ie: familial, household, and leisure activities). This should be taken into account when considering employment.

From: *Recommendations for employers, insurers, human resource professionals on return to work for people living with Long COVID. September 23, 2022.*

Impact on People’s Lives

People with Long-COVID often describe their experience as feeling like a ‘shadow’ of themselves with new limitations in energy, movement, and thinking.

They may also experience the loss of family and friends who may not believe in the illness or abandon them because of the influence of an ableist society that still neglects and diminishes chronic illnesses and disability.

We must be empathetic in our approaches, accommodations, and responses when working with people experiencing Long COVID. In the absence of measurement tools, we can listen and believe those who are impacted by this disabling condition.

References

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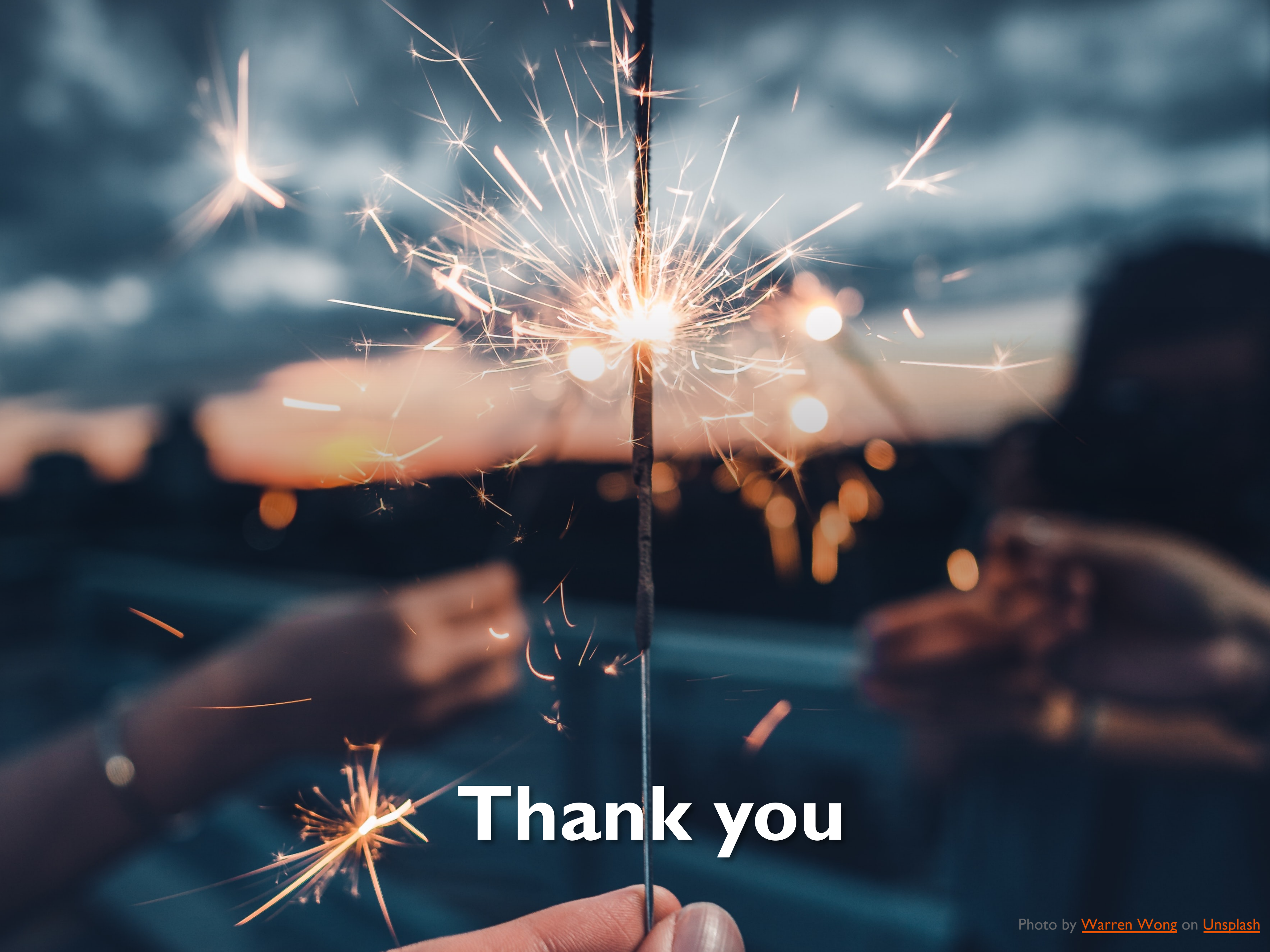
- O'Brien KK, Brown DA, Bergin C, et al. Long COVID and episodic disability: advancing the conceptualisation, measurement and knowledge of episodic disability among people living with Long COVID – protocol for a mixed-methods study. BMJ Open 2022;12:e060826. DOI: http://dx.doi.org/10.1136/bmjopen-2022-060826



Thank you

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