

# Understanding Long COVID and episodic disability to inform rehabilitation approaches

COVID Rehab Network with the Network of Networks

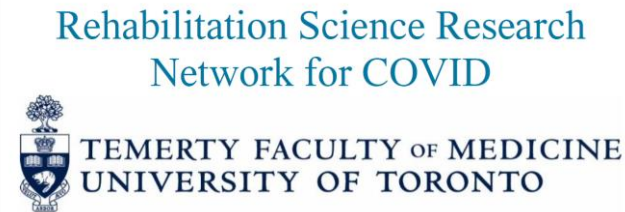
Monday June 5, 2023

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**Funding: Canadian Institutes of Health Research: Emerging COVID-19 Research Gaps and Priorities Funding Opportunity (FRN: GA4-177753)**

# The aims of today's presentation:

- To share updates from a current Long COVID and Episodic Disability study
- To share experiential advice for physiotherapists and rehabilitation providers working with people with Long COVID

# Long COVID & Episodic Disability Team

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LONG COVID IRELAND



[www.longcovidireland.org](http://www.longcovidireland.org)

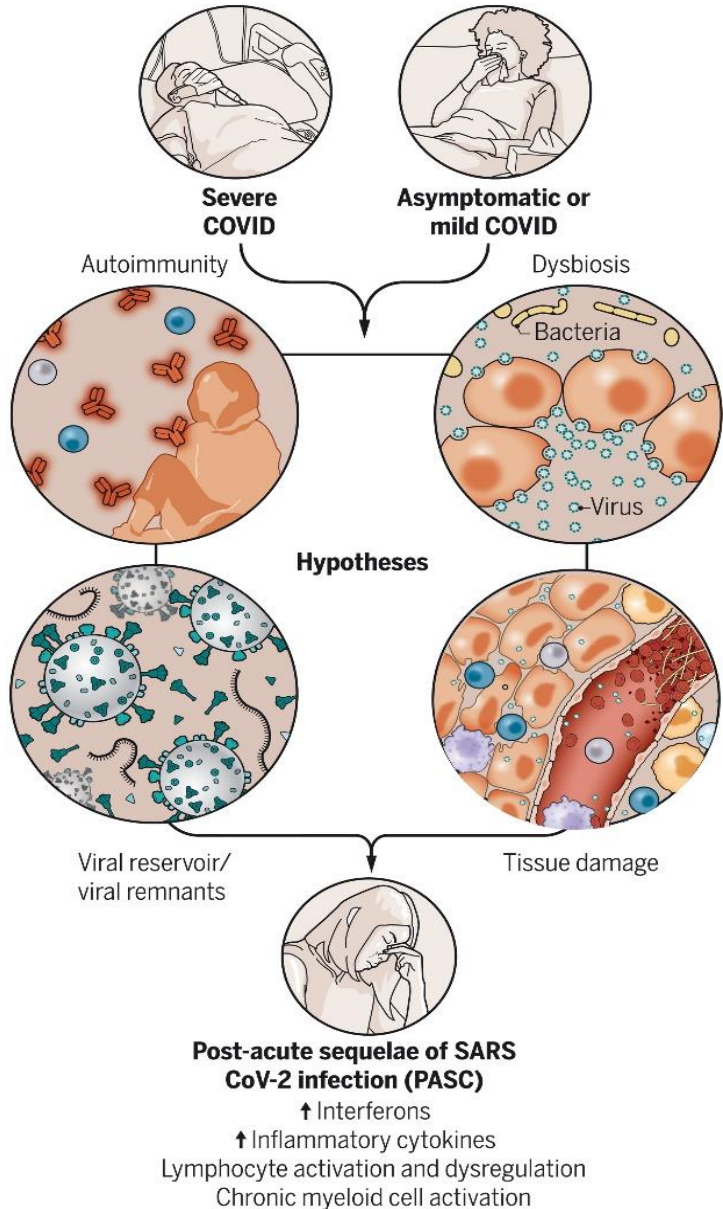
# Some Background – Long COVID

# What is Long COVID?

“Post COVID-19 condition occurs in individuals with a history of probable or confirmed SARSCoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis...

- Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. = **Multidimensional**
- Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. = **Concurrent comorbidity**
- Symptoms may also fluctuate or relapse over time.” = **Episodic nature**

# Pathophysiology and Mechanism of Long COVID

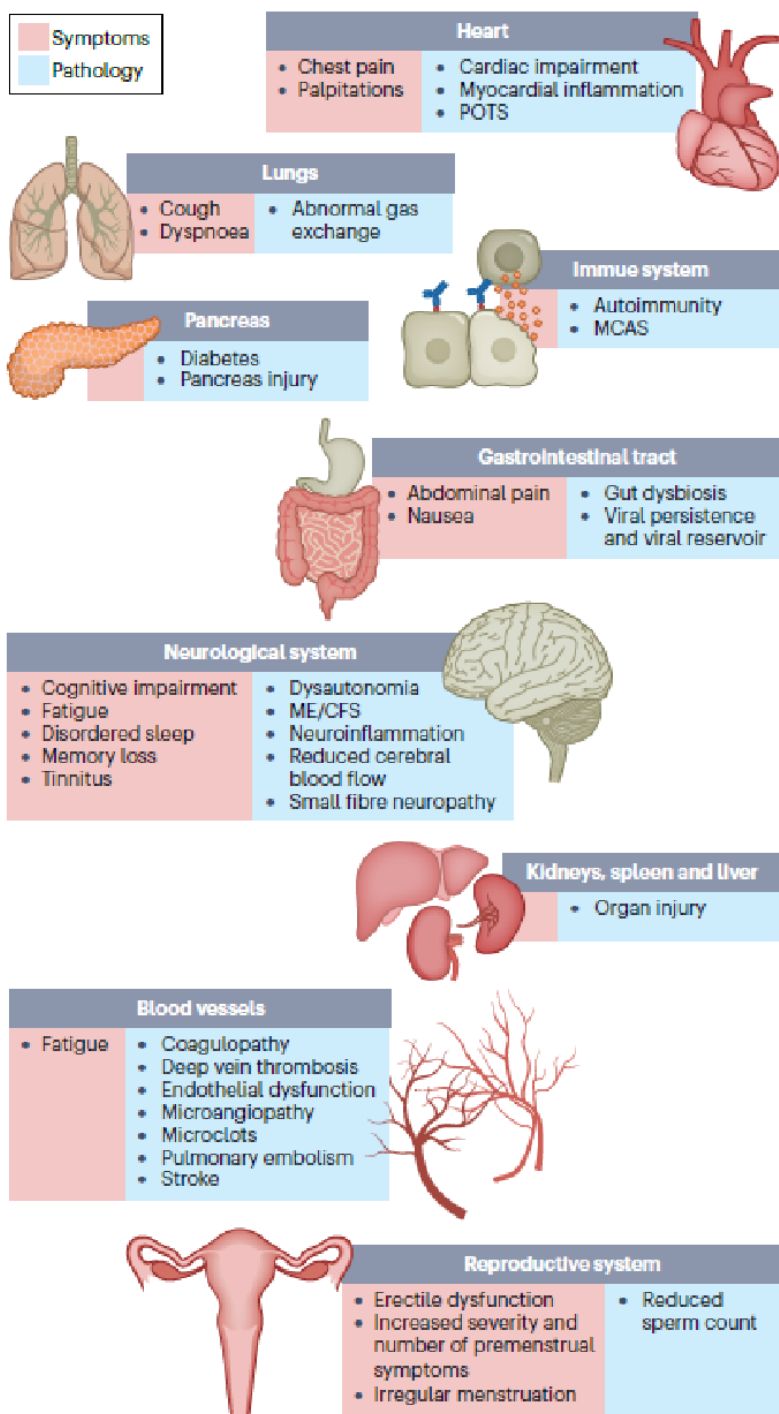


- Long-term organ and tissue damage due to acute infection
- Viral persistence in tissues driving chronic inflammation
- Immune dysregulation
- Triggering of autoimmunity after acute viral infection
- Endothelial cell dysfunction

## Clinical Manifestations

- Systemic
- Respiratory
- Neurological
- Musculoskeletal
- Cardiac
- Vascular
- GI
- Endocrine
- Dermatological
- Cognitive

(Castanares-Zapatero et al., 2022; Mehandru et al., 2022; Merad et al., 2022)



# Multi-Systemic and Multi-Dimensional

nature reviews microbiology

<https://doi.org/10.1038/s41579-022-00846-2>

Review article

Check for updates

## Long COVID: major findings, mechanisms and recommendations

Hannah E. Davis<sup>1</sup>, Lisa McCorkell<sup>2</sup>, Julia Moore Vogel<sup>3</sup> & Eric J. Topol<sup>3</sup>✉

Davis et al., 2023 - <https://www.nature.com/articles/s41579-022-00846-2>

# Symptom Burden & Trajectory

Community-led online survey of people with suspected or confirmed COVID-19 with illness lasting over 28 days and onset prior to June 2020. Data collected from Sept - Nov 2020 across 56 countries.

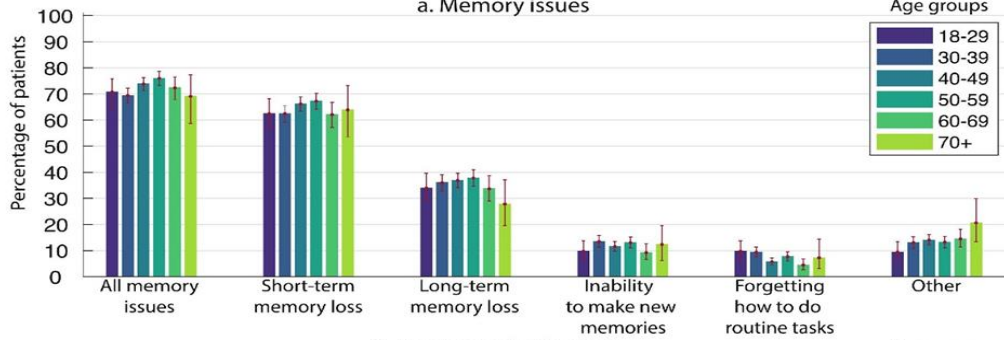
- > 200 symptoms were identified
- Average of 56 symptoms across 9 organ systems
  - Fatigue
  - Post exertional malaise (PEM)
  - Cognitive dysfunction
- 86% experienced relapses
  - Triggers: exercise; physical or mental activity; stress.

Among unrecovered

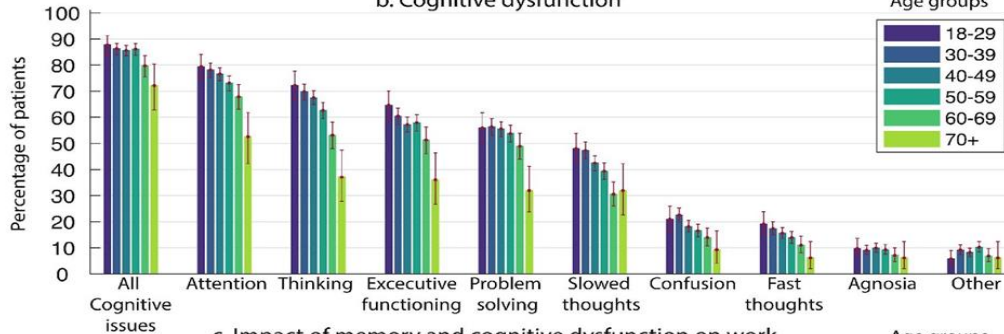
- 45% working reduced hours at the time of the survey compared to pre-illness
- 22% not working at the time of the survey as a direct result of their illness.

Davis et al, Characterizing long COVID in an international cohort: 7 months of symptoms and their impact; 2021. eClin Med; [https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(21\)00299-6/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext)

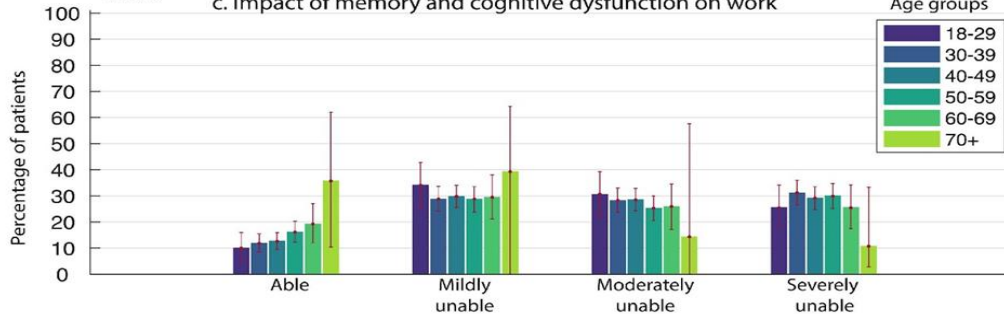
a. Memory issues



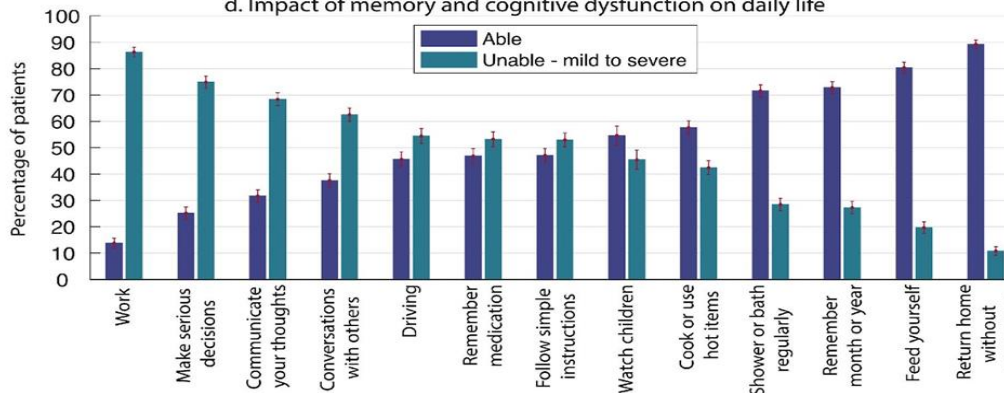
b. Cognitive dysfunction



c. Impact of memory and cognitive dysfunction on work



d. Impact of memory and cognitive dysfunction on daily life





# Prevalence of Long COVID in Canada

- Canadian COVID Antibody and Health Survey (CCAHS)
- Random sample of Canadians between April 1 - Aug 31, 2022
- Asked about new or continuing symptoms 3 months or more after confirmed or suspected case of COVID-19

**14.8%**  
experienced symptoms for 3  
months or more

**47.3%**  
of those experienced symptoms  
for a year or longer

**21.3%**  
experienced symptoms that  
limited their daily activities

**74%**  
among those employed missed  
some work or school due to  
symptoms

**With increasing disability there is a role for rehabilitation**

# Episodic Disability – Informing COVID-19 Rehabilitation

## Six Lessons for COVID-19 Rehabilitation From HIV Rehabilitation <https://pubmed.ncbi.nlm.nih.gov/32737967/>

Darren A. Brown, Kelly K. O'Brien, Jo Josh, Stephanie A. Nixon, Jill Hanass-Hancock, MaryLou Galantino, Hellen Myezwa, Soula Fillipas, Colm Bergin, Larry Baxter, Mark Binette, Verusia Chetty, Saul Cobbing, Colin Corbett, Francisco Ibanez-Carrasco, David Kietrys, Ronel Roos, Patricia Solomon, Richard Harding

- Anticipate disability and recognize its potentially **episodic nature**
- Understand that disability dimension '**uncertainty** or worrying about the future' may play a role
- Consider stigma, health inequities, social consequences
- Build on existing research networks
- Develop disability and rehabilitation-focused responses
- Including and focus on people living with and affected by the pandemic.

# What is Episodic Disability?

Defined as....

Any physical, cognitive, mental or emotional health challenge, difficulty carrying out day to day activities, challenges to social inclusion or uncertainty or worrying about the future that may be experienced by an individual that **may fluctuate** over a daily basis, within the day, or over the longer term.

O'Brien, K.K., Bayoumi, A.M., Strike, C. et al. Exploring disability from the perspective of adults living with HIV/AIDS: Development of a conceptual framework. *Health Qual Life Outcomes* 6, 76 (2008). <https://doi.org/10.1186/1477-7525-6-76>

O'Brien, K.K., Davis, A.M., Strike, C. et al. Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. *JIAS* 12, 30 (2009). <https://doi.org/10.1186/1758-2652-12-30>

# Long COVID and Episodic Disability Study

Aim: To describe episodic nature of disability among adults living with Long COVID.



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Original research

BMJ Global Health

## Conceptualising the episodic nature of disability among adults living with Long COVID: a qualitative study

Kelly K O'Brien <sup>1,2,3,4</sup> Darren A Brown <sup>5,6</sup> Kiera McDuff,<sup>1</sup>  
Natalie St. Clair-Sullivan <sup>7,8</sup> Patricia Solomon <sup>9</sup> Soo Chan Carusone <sup>10</sup>  
Lisa McCorkell <sup>11</sup> Hannah Wei <sup>12</sup> Susie Goulding,<sup>13</sup> Margaret O'Hara <sup>14</sup>  
Catherine Thomson,<sup>6</sup> Niamh Roche,<sup>15</sup> Ruth Stokes,<sup>15</sup> Jaime H Vera <sup>7,8</sup>  
Kristine M Erlandson <sup>16</sup> Colm Bergin <sup>17,18</sup> Larry Robinson <sup>19</sup>,  
Angela M Cheung <sup>2,20,21</sup> Brittany Torres,<sup>1</sup> Lisa Avery <sup>22,23</sup>,  
Ciaran Bannan <sup>17,18</sup> Richard Harding <sup>24</sup>



**CIHR IRSC**

Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

<https://gh.bmj.com/content/8/3/e011276>

**Funding: Canadian Institutes of Health Research: Emerging COVID-19 Research Gaps and Priorities Funding Opportunity (FRN: GA4-177753)**



Physical Therapy  
**UNIVERSITY OF TORONTO**

# Methods

**Study Design:** Community-engaged qualitative descriptive study

## Methods

- Online semi-structured interviews
- 40 adults living with Long COVID
  - Canada
  - United Kingdom
  - United States
  - Ireland
- Interview, demographic questionnaire, visual illustrations
  - Episodic Disability Framework - scaffold for interview guide
- Analysis: Group-based content analytical techniques
  - Discussed the participant drawings illustrations in conjunction with their corresponding interview data

Open access

Protocol

**BMJ Open 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**

Kelly K O'Brien <sup>1,2,3,4</sup> Darren A Brown <sup>5,6</sup> Colm Bergin <sup>7,8</sup>  
Kristine M Erlandson <sup>9</sup> Jaime H Vera <sup>10,11</sup> Lisa Avery <sup>12,13</sup>  
Soo Chan Carusone <sup>14</sup> Angela M Cheung <sup>2,12,15</sup> Susie Goulding,<sup>16</sup>  
Richard Harding <sup>17</sup> Lisa McCorkell,<sup>18</sup> Margaret O'Hara,<sup>19</sup> Larry Robinson,<sup>20</sup>  
Catherine Thomson,<sup>6</sup> Hannah Wei,<sup>21</sup> Natalie St Clair-Sullivan,<sup>11</sup> Brittany Torres,<sup>1</sup>  
Ciaran Bannan,<sup>7,8</sup> Niamh Roche,<sup>22</sup> Ruth Stokes,<sup>22</sup> Patric Gayle,<sup>23</sup>  
Patricia Solomon <sup>24</sup>

<https://bmjopen.bmj.com/content/12/3/e060826.full>



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# Characterizing the Episodic Nature of Long COVID

## Descriptors of Episodic Nature of Disability Living with Long COVID



### Participants (n=40)

Median age: 39 years

- 63% female
- 83% living with Long COVID  $\geq 1$  year
- 93% experienced relapse in symptoms
- 50% unable to work due to Long COVID

# Experiences of Disability Living with Long COVID

Episodic characterized by a range of health-related challenges, resulting in short- and long-term fluctuations in health, some of which may be unpredictable in nature, impacting ability to plan for the future.

**Not an all or nothing concept** of complete wellness and complete illness - a continual state of health challenges with changing presence, severity and duration of episodes over time.

## Episodic Disability as a Continuum

Spanning over the long term; fluctuating on a weekly or daily basis, or within the course of a day.

## Multidimensional Nature of Disability

Physical, cognitive, mental and emotional health challenges, resulting in difficulties with daily function, and social participation.

## Permanent or Stable Episodic Disability Over time

Constant state of disability, reflected by the loss of function compared with their baseline level of health. Stable features of disability may co-exist with episodic disability with Long COVID.

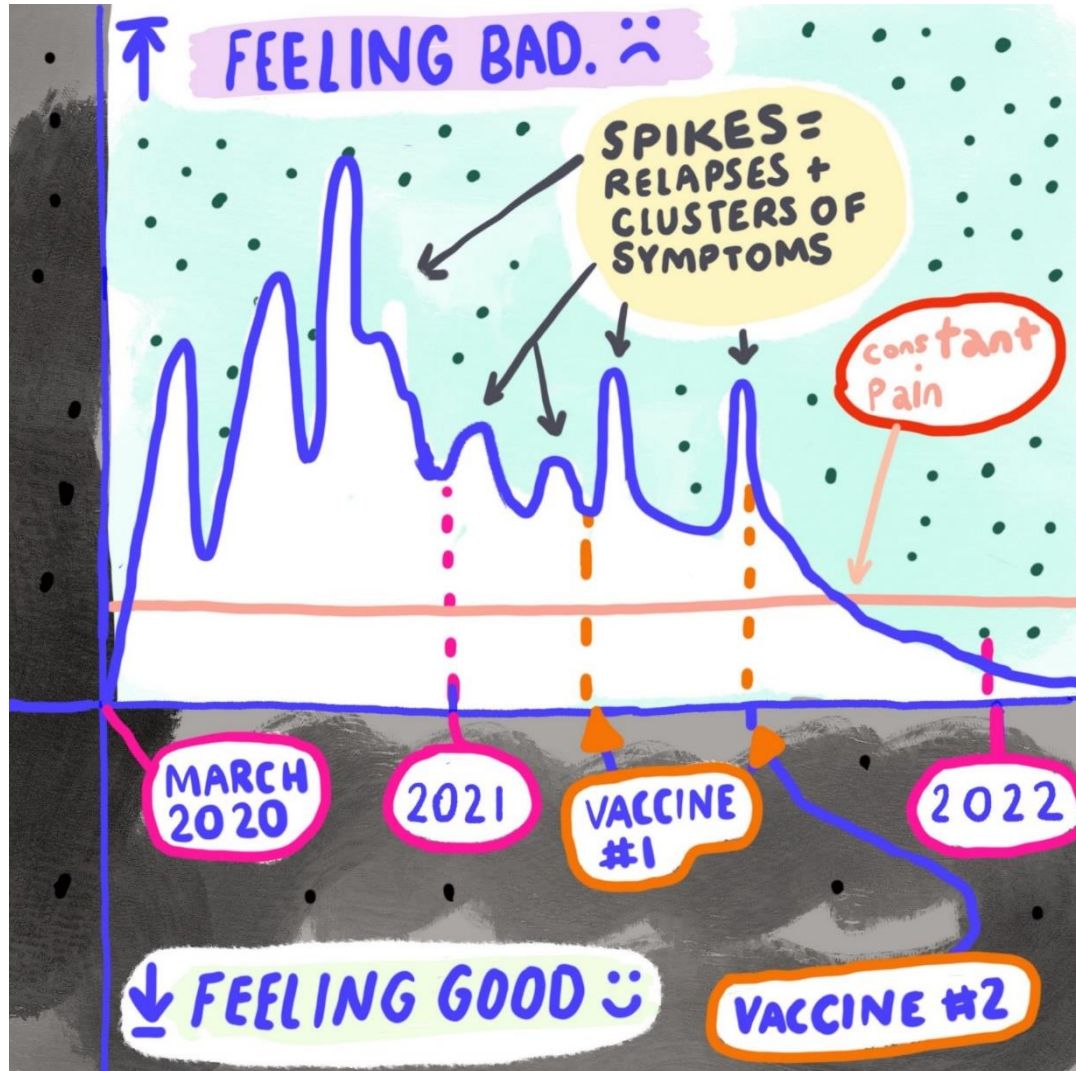
## Visibility and Invisibility of Disability

Fatigue, headaches, cognitive dysfunction, and emotional health challenges were not visible or constant, which sometimes made it difficult for participants to articulate and have their health challenges recognized as a disability.

**“It’s a moving target. I’m still trying to figure out two years later what I’m capable of, although I am getting better or I feel like I am. But sometimes I feel like I plateau and how much is also getting better versus just better at pacing.” P38**

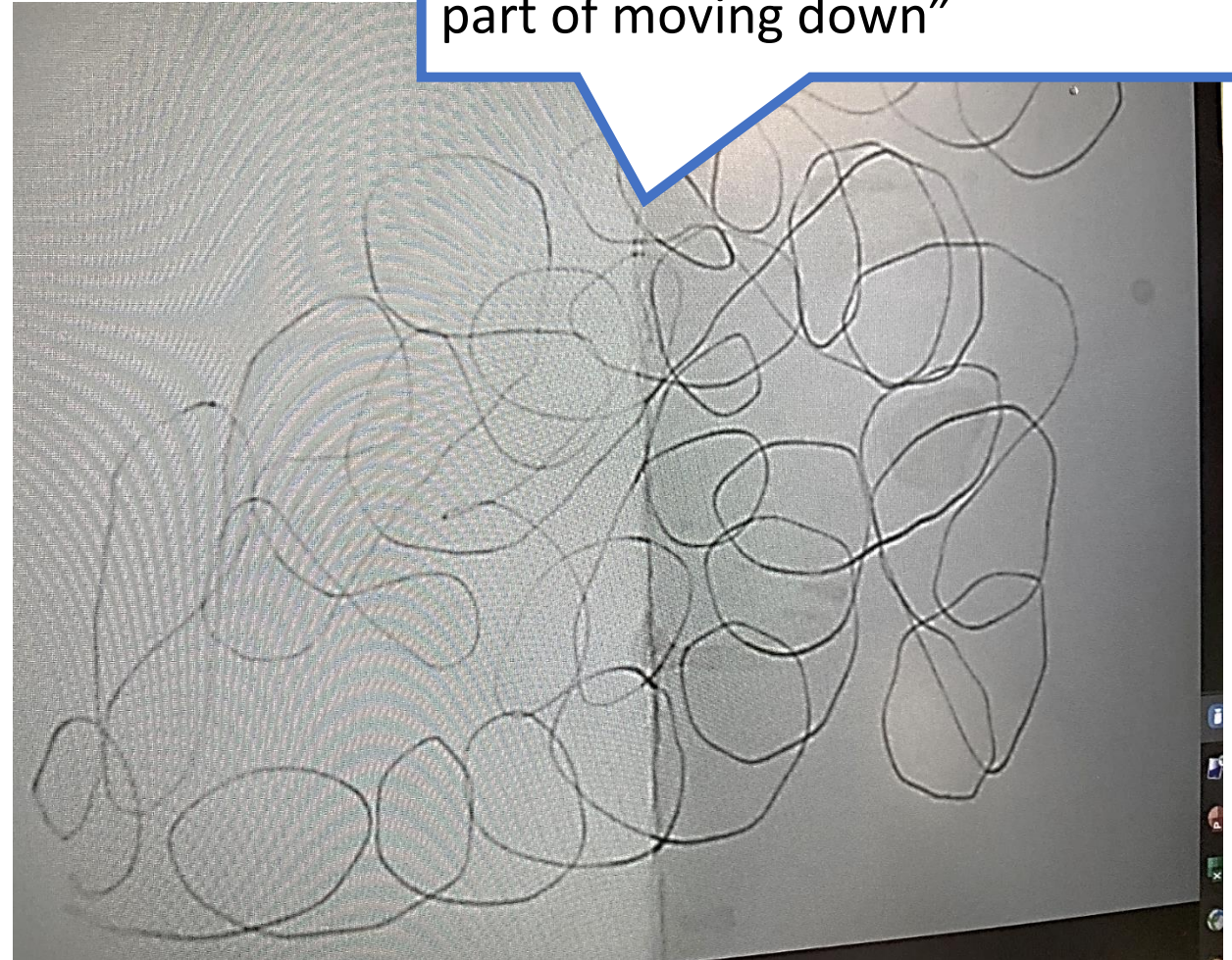
# Timeframe of Episodic Disability

Episodic Disability – the trajectory of illness longer term



## Unpredictability

“There might be a part of moving forward but there’s also a part of moving back. There might be a part of moving up but there’s invariably a part of moving down”





# Dimension – Physical Symptoms and Impairments

**\*\*Note:** Participants often experiences multiple physical challenges at one time / breadth of challenges.

- Fatigue
- Pain
- Migraines
- Weakness
- Shortness of Breath; reduced lung function
- Dizziness
- Nausea
- Post-exertional malaise / PESE
- Altered taste and smell
- Weight loss or gain
- Hair loss
- Difficulty swallowing
- Decreased appetite
- Unexplained bruising
- Eye impairments
- Voice impairments
- Hearing impairment/tinnitus
- Altered sensation
- Sensory / Internal vibrations
- Persistent cough
- Persistent sore throat
- Light sensitivity
- Excessive thirst
- Fevers
- Circulation issues
- Cramping
- Temperature dysregulation
- Tremors
- Sleep issues
- Lymphedema
- Restless leg syndrome
- Rashes
- GI issues
- Cardiac issues
- POTS
- Decreased bone density
- Menstruation changes
- Frequent Urination
- Restless leg syndrome
- Hemi-paresis
- Skin sensitivity
- Infections (skin, ear, pulmonary)
- Allergies
- Liver Disease

# Dimension - Physical Symptoms and Impairments (n=1 patient)

- Fatigue
  - Pain
  - Migraine
  - Weakness
  - Shortness of breath; reduced lung function
  - Dizziness
  - Nausea
  - Post-exertional malaise / PESE
  - Altered taste and smell
  - Weight loss or gain
  - Hair loss
  - Difficulty swallowing
  - Decreased appetite
  - Unexplained bruising
  - Eye impairments
  - Voice impairments
  - Hearing impairment/tinnitus
  - Altered sensation
  - Sensory / Internal vibrations
  - Persistent cough
  - Persistent sore throat
  - Light sensitivity
  - Excessive thirst
  - Fevers
  - Circulation issues (e.g. Raynaud's)
  - Cramping (different body parts)
  - Temperature dysregulation (e.g. excessive sweating; hot/cold flashes; hands turning blue; persistent low grade fevers)
  - Tremors
  - Sleep issues (insomnia; excessive sleep)
  - Lymphedema
  - Restless leg syndrome
  - Rashes
  - GI issues
  - Cardiac issues
  - POTS
  - Decreased bone density
  - Menstruation changes
  - Frequent Urination
  - Restless leg syndrome
  - Hemi-paresis
  - Skin sensitivity
  - Allergies
  - Infections (skin, ear, pulmonary)
  - Liver Disease
- PLUS:**
- Anemia and depleted copper/zinc
  - Microvascular angina
  - Beau's lines and brittle nails
  - Vomiting
  - Hypo/hypertension
  - Syncope/fainting

# Dimension - Physical Symptoms and Impairments (n=1 patient)

- Fatigue
  - Pain
  - Migraine
  - Weakness
  - Shortness of breath; reduced lung function
  - Dizziness
  - Nausea
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- PLUS:**
- Anemia and depleted copper/zinc
  - Beau's lines and brittle nails
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  - Hypo/hypertension
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# Dimension – Cognitive Symptoms and Impairments

- Participants describe either an inability to complete certain cognitive tasks, or describe that the process of completing cognitive tasks has become laborious, energy-intensive, and draining.
- Challenges with...
  - **Executive function**
    - Working memory
    - Losing train of thought
    - Concentration
    - Multi-tasking
  - **Word finding**
  - **Communication**
    - Written
    - Verbal
  - **Memory**
    - Short-term; long-term
  - **Information processing**
    - Reading
  - **Cognitive endurance / stamina**
  - **Fatigue**

**Note on terminology – Brain Fog** - one participant took issue with this terminology, saying that 'brain fog' doesn't sound like a real/legitimate thing and therefore may be more easily dismissed or minimized by others.

# Dimension – Cognitive Symptoms and Impairments

- Increasingly strong evidence of physiological impacts to the brain and nervous system, even after mild infection.
- Brain scan studies show loss of grey matter, tissue abnormalities, and shrinkage, with impacts comparable to aging 10-20 years, indicators of systemic inflammation in cerebrospinal fluid, and hypoxia.
- Other studies have found reduced oxygen in the brain during cognitive tasks, inflammatory markers in the brain stem, myelin dysregulation, and a damaged blood-brain barrier.
- It's been likened by researchers to traumatic brain injury, chemo brain fog, or Alzheimer's in impairment-level.
- Can manifest as akin to OCD (e.g., rumination, obsession, agitation); ADHD and impaired exec function (e.g., inhibition, task ordering, and logic); post-viral psychosis (hallucinations, delusions); or neurodegenerative illness (e.g., working memory, muscle control, etc).

# Dimensions of Disability – Mental and Emotional

- Wide array of mental and emotional health often experienced **as a consequence** of Long COVID (not pre-existing). Severity may vary depending on circumstances and severity of other symptoms. Many described that the mental/emotional symptoms came in response to the other health-related challenges that they had begun to experience with Long COVID.
- **Fear**
  - Of relapse, crowds, re-infection
- **Grief, devastation, loss**
  - Loss of function, health, relationships,
  - Loss of employment / career, housing, finances,
  - Loss of family members, partners or friends to COVID.
- **Guilt**
- **Anger**
  - COVID rage
- **Stress**
  - Including specific stress of dealing with health providers / system
- **Anxiety or depression**
- **Hopelessness**
- **Mood swings; irritability**
- **Suicide ideation**
- **Fatigue**

Inter-connectedness of mental and emotional with social inclusion

Realizing that I couldn't work... was really **devastating** because I liked my job and I worked really hard to get that job and I still have a lot of, student loans... just the **financial implications** of that. My **partner** and I really prioritized my career as the income we were mostly relying on. So that was just practically speaking very **stressful** but then also ... it was **emotionally sad**... I put a lot into my career. But I think... after I stopped working I was able to rest a lot and also kind of came to the kind of trying to come to more of like an **acceptance** of like alright well these are the things that I can't do and these are the things that I can do and trying to work within my limitations.

# Dimension – Mental and Emotional

- Some mental and emotional symptoms are a response to the circumstances of illness (isolation, trauma, uncertainty, life stressors, capacity limitations, medical neglect, etc). However, it can also have a pathophysiological cause similar to cognitive symptoms.
- Emerging evidence suggests some emotional or cognitive changes may be a result of neuro-inflammation; damage or ongoing impaired blood oxygenation in key centres in the brain impairing emotional processing/regulation, memory, and executive function; dysautonomia-related impairment to the autonomic nervous system, HRV, and stress response/recovery; physiological overwhelm from other symptoms, etc.
- Patients' existing psychotropic medication may not work the same post-infection, or they may provoke new or exacerbated side effects or impact other comorbidities.

# Dimensions of Disability – Day-to-Day Activities

Multiple participants spoke about doing ‘the bare minimum’ in order to stay within their energy capacity or avoid triggering physical symptoms

- Mobility
  - Ambulation; stairs
  - Sitting upright
- Bathing
  - Shower; bath
- Brushing teeth
- Dressing
- Cleaning
- Meal preparation
- Shopping (e.g. groceries)
- Going to appointments



# Dimensions of Disability – Challenges to Social Inclusion

- Many challenges attributed to physical, cognitive health challenges which impacted on day-to-day activities (and social inclusion).
  - **Social isolation**
  - Difficulty engaging / participating in **recreation; leisure and other social activities**
  - Inability or difficulty to **work**
  - Loss of **retirement goals / planning**
  - Challenges fulfilling **caregiving roles**
  - **Financial challenges**, instability, insecurity; financial burden of Long COVID
  - **Challenges or strain on maintaining or initiating personal relationships** (including romantic)
  - **Housing insecurity**

# Dimensions of Disability – Challenges to Social Inclusion

**Employment:** What people don't get about people with disabilities is that yes, we're not working or some people for... like I guess I'm speaking for those who can't work or can't work very much right, is like some people might think it's like handouts and stuff like that. But honestly if we could work, we would work. We need some support and we need support that actually gives ability to afford everything that we need. Like again, I'm not looking for handouts but I do know that I need help. If I had capacity to work, then I would. So like I just don't want people to think that I have like some sort of entitlement thing just because I have a disability.

**Retirement:** It's certainly not what I anticipated my retirement being. I had just completed... my retirement was going to include that mix of consulting. I had completed a yoga teacher training program. I was looking at different ski instructor programs, actually more assisted skiing, helping the disabled ski, being the guide for disabled skiers. So those are the things I was looking at. Those are gone you know, boom.

**Social Engagement:** So it's like these things that I used to just take for granted like going for walks, going skiing, you know sitting at a desk. If I go to a restaurant I have to find a place where I can... you know a booth where I can sit sideways and lean so I'm mostly reclined. So all those social things just are out. If we have friends over I can engage for half an hour, 45 minutes or maybe a little longer. But I've come to a point where I just say no, I've got to go upstairs, I've got to go lie down. So all of those things basically are just dramatically different.

**Financial and Housing Insecurity:** ODSP is like six months to a year to get approved for. ....even if suddenly and miraculously I were approved for ODSP tomorrow, which is not going to happen, I don't know how anybody lives on it. The idea with ODSP is that you get \$1,169 [CAD] a month for rent, food, clothes and whatever you need. There's actually nowhere to live anywhere in Canada with that kind of money. And then they're like 'you can get a part time job' and I'm incapable of getting any kind of meaningful...I can probably work an hour and a half every three days if I really tried hard and that job doesn't exist. So would still eventually become homeless and then they take away your shelter portion. So then ... you have \$600 a month to live on the street if you can imagine. So I don't have any financial uncertainty. What I have is a terrible fear of homelessness.

# Uncertainty

Unpredictability of fluctuating health challenges, worrying about the future, lack of knowledge on the causes of and treatments for Long COVID, and the impact on overall health and future life decisions.

## Uncertainty among the individual living with Long COVID

- Overall Long COVID trajectory
- Sources of symptoms; causes of Long COVID
  - Triggers of disability
  - Uncertainty on employment,
    - Financial uncertainty
    - Housing uncertainty
      - Family planning
- Broader implications on future health and life decisions.

## Uncertainty among health providers, employers, insurers

How to treat; how to accommodate safe and supportive return to work

“I couldn’t really commit to even social plans... there were some days where I would have to cancel last minute because it just wasn’t a good day... there’s just not a lot of predictability despite me trying to track everything and log all of the triggers and symptoms and durations, it’s still hard to predict.” P2

# Contextual Factors – also episodic; sometimes uncertain

## Intrinsic Factors

### Living Strategies

- **Attitudes; Belief; Mindset; Outlook**

Including: Acceptance; adjustment; hope and optimism; adaptability; patience; shifting mindset; enhanced awareness of self and health; resiliency; getting on with it; taking everyday as it comes; viewing as an opportunity for growth; goal setting

- **Maintaining Control over Health & Life**

Including: Moving forward; finding balance; planning and preparing ahead; **pacing\*\*most common**; lifestyle changes; practical strategies; journaling / tracking health; finding new roles / purpose; seeking information / resources / services

- **Seeking interaction and support from others** / avoiding interactions with others

- **Blocking out of Mind:** Diverting or Distracting

### Personal Attributes

- Past Health Conditions; Concurrent Health Conditions
- Age
- Sex; Gender
- Race
- COVID Characteristics

## Extrinsic Factors

### Social Support

- Health and rehabilitation providers
- Practical and emotional support from friends, family, partner
- Support from Long COVID Community
- Financial; economic; income supports
- Accessibility of environment
- Support from employers; insurers
- Public health policies

### Stigma; Gas Lighting

- Invisibility of Long COVID disability;
- Gas lighting by Health providers

### Mobility Aids and Technology Devices

- Mobility aids
- Access to internet
- Technology

# Contextual Factors – Pacing

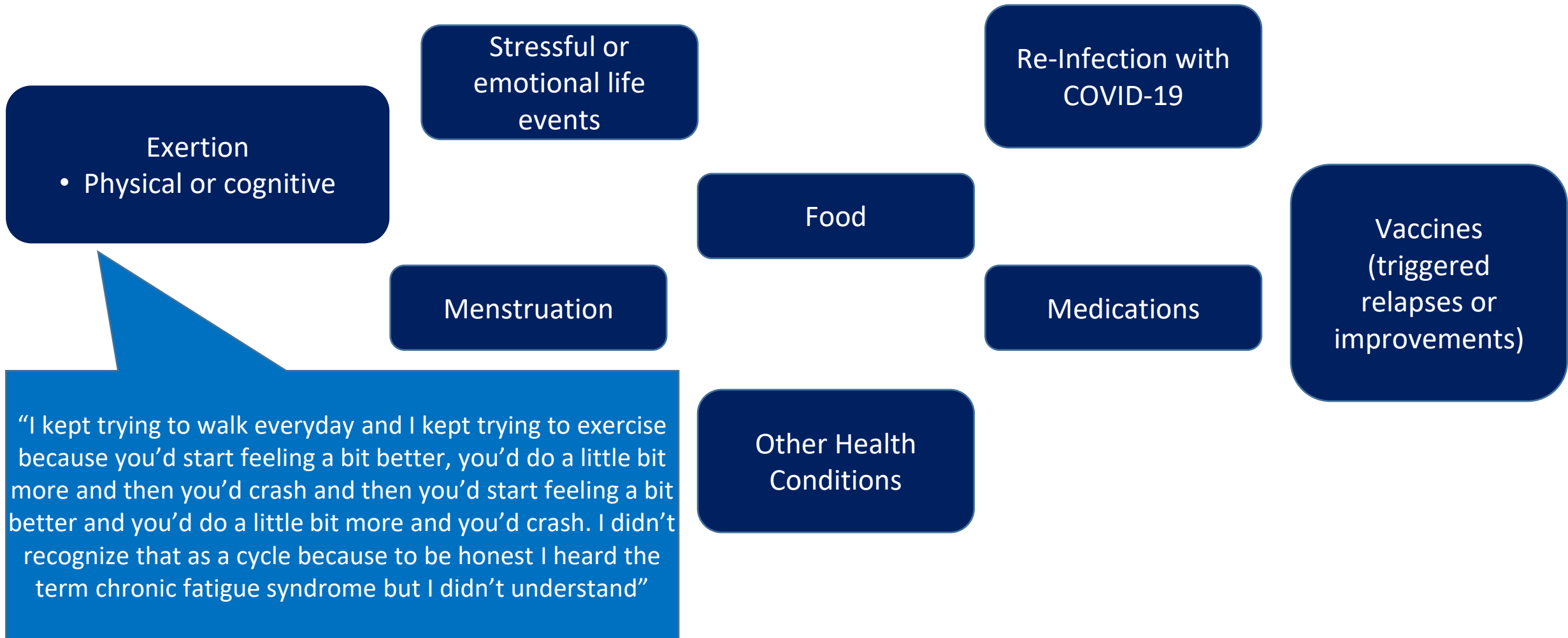
- Most participants identified pacing as the most important and helpful living strategy.
- Pacing requires careful planning and scheduling; establishing a routine.
- Pacing requires awareness and mindfulness over one's activities.
- Strategy to reduce the boom/bust cycle (Post-Exertional Malaise).
- Pacing helps to maintain control.

*“So I have a lot of like some energy saving ways... **There's one day a week where all the cooking gets done... the next day, portion, everything goes in the freezer.** So everything goes into the washing machine so that the day it's laundry day it's just turning the machine and I don't have to do much. Then I have to take everything from there, put it in the dryer and then the next day things come out of the dryer because **I'm not going to try and do all of the steps at once. So everything is like divided out**”*

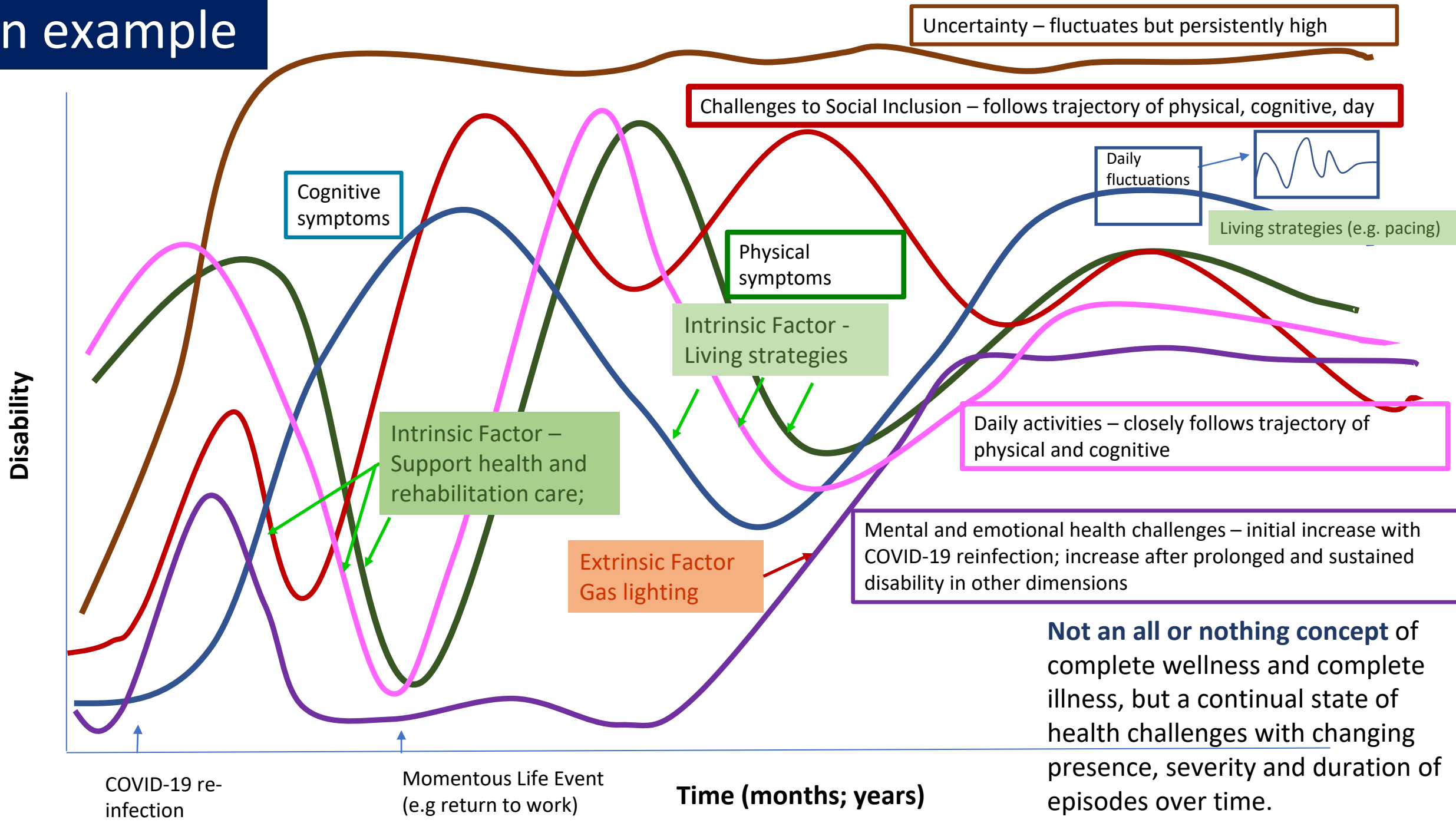
*“**[My parents] were saying like ‘You are getting better’ and I was like I am but I'm sacrificing... but like this time 12 months ago I was kind of still going for a daily walk for like even just five or ten minutes around the block gentle walk. I was starting to bath myself. I was still trying to do all those things that were leaving me so exhausted. Then over the last kind of 12 months... I don't do those things. In some ways I have got better... So like yes there are improvements but then some of it's kind of just learning to manage it better.**”*

# Triggers

- Moments, stimuli, or life events that initiated major or momentous episodes of disability,
- Not always able to identify triggers or anticipate (unpredictability); with knowledge came better understanding of potential triggers and how to prevent or anticipate and plan



# An example



**Not an all or nothing concept** of complete wellness and complete illness, but a continual state of health challenges with changing presence, severity and duration of episodes over time.

# Summary

**Disability:** episodic and multi-dimensional - characterized by fluctuating health challenges which may be unpredictable in nature.

## Implications

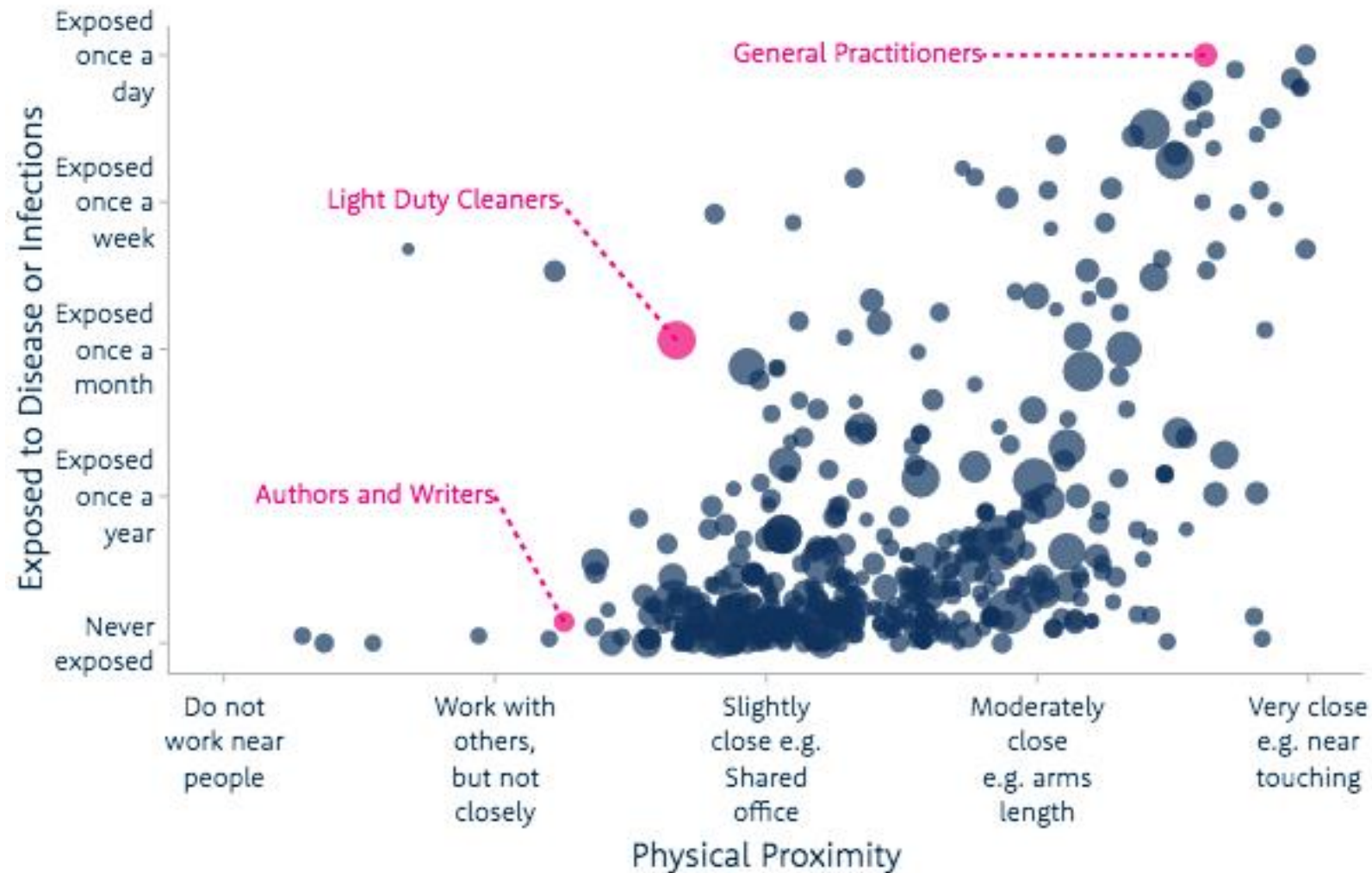
Clear recognition and diagnostic criteria of **episodic disability** associated with Long COVID will help to recognize the health challenges experienced with Long COVID to access timely clinical assessments and treatments, safe rehabilitation services, models of care, disability justice, employment rights, and income support.

**Uncertainty should be recognized as an integral component of disability** experienced among individuals living with Long COVID so health providers can better understand and support those living with uncertainty in the context of chronic illness.



# Impact of Long COVID Episodic Disability on Work and the Workforce

# Applying an Occupational Lens: Exposure



# Workforce Impacts: A Data Snapshot

- The [2022 Household Pulse Survey](#) found that 16M (8.3%) working age Americans have Long COVID and 2-4M of these are out of work. The annual cost of lost wages is as high as \$230B.
- A [CIBC report](#) using StatsCan data found that absentee hours due to illness in 2022 significantly increased compared to 2021 and 2020.
- A 2022 [UK Trade Union Congress survey of members](#) found that, for those who reported Long COVID, 92% reported day-to-day fluctuations in symptoms:
  - 23% were on sick leave, 16% were working reduced hours, 25% had not told their employer they were sick
  - 49% requested changes to their work activities or accommodations (e.g., phased return, breaks, hours, amended duties, and occupational health support)
  - 21% of requests were ignored/declined, 31% of requests were partially approved

# Applying an Occupational Lens: Long COVID

- [In the UK, self-reported Long COVID](#) was highest among those working in social care, teaching, education, and health care, professions with high #s of women and where in-person work was the norm through much of the pandemic.
- Access to paid sick days, disability insurance, remote work, workplace accommodations, etc varies wildly across occupations. At the start of the pandemic, only [51% of working Canadians had paid sick leave](#).
- Some Long COVID symptoms may make an individual ineligible for their previous jobs due to health requirements or may otherwise impact their ability to perform their previous duties.
- Patients may be making trade-offs between seeking treatment and work.

# Approving Workplace Accommodations

- Processes that require medical proof of disability put the clinician in the role of gatekeeper for medical accommodations that are not just necessary for patients to remain working but for the stability of their condition and hopeful recovery.
- “Clinicians’ documentation of patients’ experiences can validate patients’ conditions and increase the likelihood that their employers will recognize their symptoms as debilitating” ([Dorfman et al, New England Journal of Medicine](#)).

# Office of the Chief Science Advisor's Task Force Report

“As PCC affects working-age Canadians, an increase in short- and long-term disability claims related to PCC is already happening and expected to increase....Barriers to disability support include the lack of uniform PCC clinical guidance and diagnostic criteria, a low awareness of PCC among clinicians, and a lack of access to a primary health care provider, which could lead to a missed or delayed diagnosis. Some health care providers may feel uncomfortable submitting claim forms for “uncertain” diagnoses, and others may charge a fee for completing these forms, creating additional barriers to accessing disability benefits.

Whether or not people living with PCC will be eligible for social assistance or employment insurance is uncertain and depends on multiple factors such as the duration and severity of symptoms. A flexible approach that recognizes and accommodates the fluctuating nature of PCC will need to be considered.”

# What Does This Mean for Employment & Return to Work?

## Clinical management of COVID-19

LIVING GUIDELINE

13 JANUARY 2023



### Considerations

- Energy conservation techniques.
  - Energy / activity management.
  - Pacing.
  - Planned activity + planned rest.
  - Environmental modifications.
- \*Need to be able to self-manage energy at home prior start to work.

Conditional recommendation for

New

Interventions for rehabilitation for a return to everyday activities in post COVID-19 condition could include education and skills training on energy conservation techniques, and the provision and training in the use of assistive products to those who need further assistance with activity management and mobility. For a return to work we suggest using a return to work action plan with a prolonged and flexible phased return. Environmental modifications at work may be needed based on an individualized workplace risk assessment of personal capabilities matched to work requirements.

<https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.1>

# Recommendations on Return to Work

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

DECEMBER 3, 2022

Recommendations for Employers, Insurers, Human Resource  
Personnel and Rehabilitation Professionals on

## Return to Work for People Living with Long COVID



### Recommendations include<sup>20-25</sup>:



Recognizing  
the episodic and  
unpredictable nature  
of Long COVID



Prolonged  
phased return



Suitable workplace  
accommodations



Remote  
work



Flexible  
work hours



Reduced physical and  
cognitive workload



Altered tasks,  
longer time to  
complete tasks



Rest-time  
accommodations

<https://www.realizecanada.org/wp-content/uploads/Recommendations-for-RtW-doc-final-4-3.pdf>



# Some Additional Resources

- **World Health Organization** - [Clinical management of COVID-19: Living guideline](#)
- **Long COVID Physio** – Videos Series - <https://longcovid.physio/long-covid-video-series>
- **Patient-Led Research Collaborative** – [Resources for Researchers](#)
- **Safe Rehabilitation** - World Physiotherapy COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy, 2021. <https://world.physio/sites/default/files/2021-06/Briefing-Paper-9-Long-Covid-FINAL-2021.pdf>
- **Canadian Cardiovascular Society** - [Position Paper on POTS and Orthostatic Intolerance](#)
- [Chief Science Officer of Canada's 2023 report](#)



[https://youtu.be/4pWZg\\_epDkg](https://youtu.be/4pWZg_epDkg)



[www.longcovid.physio](http://www.longcovid.physio)  
[www.physiosforme.com](http://www.physiosforme.com)  
[www.workwellfoundation.org](http://www.workwellfoundation.org)  
[www.dysautonomiainternational.org](http://www.dysautonomiainternational.org)  
[www.potsuk.org](http://www.potsuk.org)



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Rehabilitation Science Research  
Network for COVID



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**LONG  
COVID  
PHYSIO**



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