

Where are we at? Highlighting the Current Landscape of Rehabilitation in Long COVID



LONG COVID WEB

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LONG
COVID
PHYSIO

longcovid.physio

Long COVID Web Webinar
Tuesday September 17, 2024



TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO

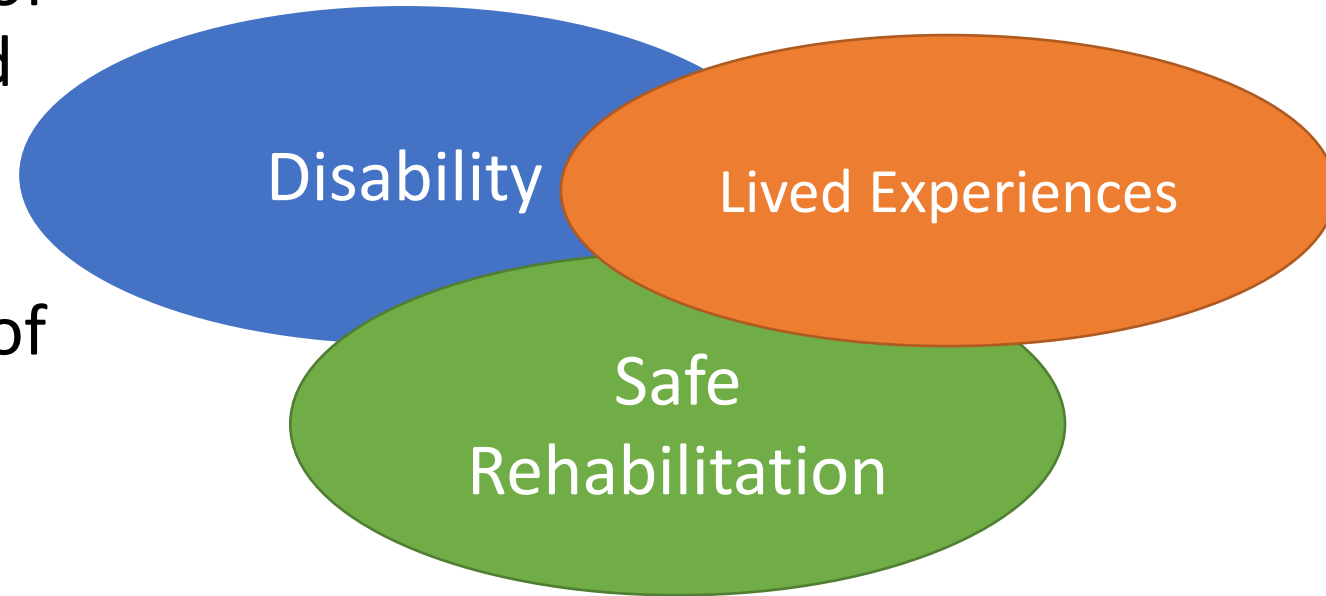
Rehabilitation Science
Research Network
for COVID



Physical Therapy
UNIVERSITY OF TORONTO

Today's webinar

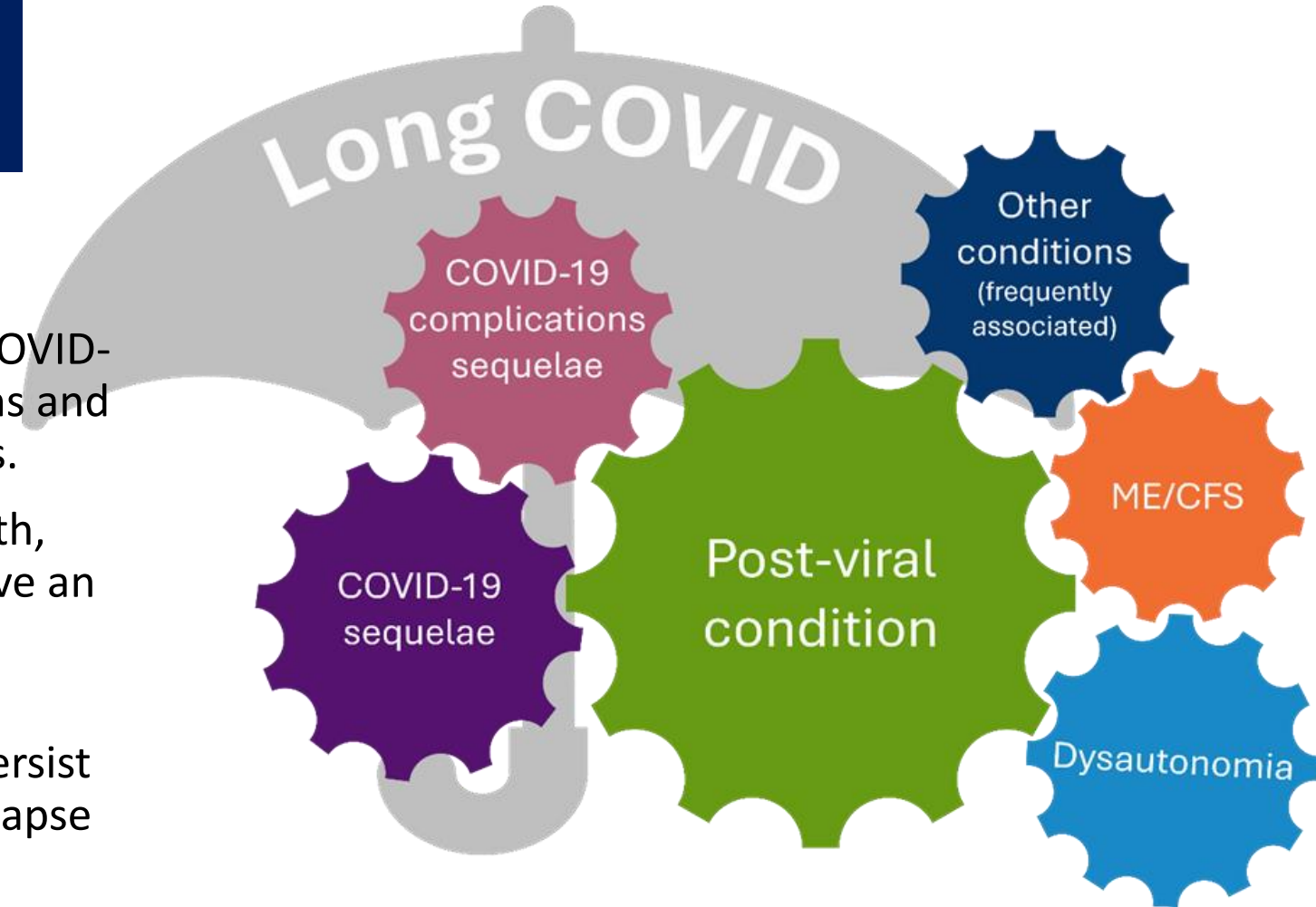
- Conceptual framework to think about **disability** experienced in the context of Long COVID with exemplar embedded in lived experiences
- Role and evidence for **safe rehabilitation** (PT, OT) in the context of Long COVID embedding lived experiences throughout.
- Provide **practical resources** for use in clinical practice and research, and feature priorities for future research, practice and policy moving forward in the field.



Definitions of Long COVID

World Health Organization (2021)

- 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: fatigue, shortness of breath, cognitive dysfunction with others; generally have an impact on everyday functioning.
- Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. May also fluctuate or relapse over time.



Anne Bhéreur, Long COVID Web, 2024

NASEM (2024)

- Infection-associated chronic condition (IACC) that occurs after SARS-CoV-2 infection
- Present for at least 3 months as a continuous, *relapsing and re* systems.....”
- accompanied by more details to describe different aspects

Multidimensional
Episodic nature

Prevalence of Long COVID in Canada – Spring 2023 Report

- Canadian COVID Antibody and Health Survey (CCAHS), Kuang et al, 2023

As of June 2023

19% (3.5 million)
who had COVID-19 experienced
symptoms for 3 months or more

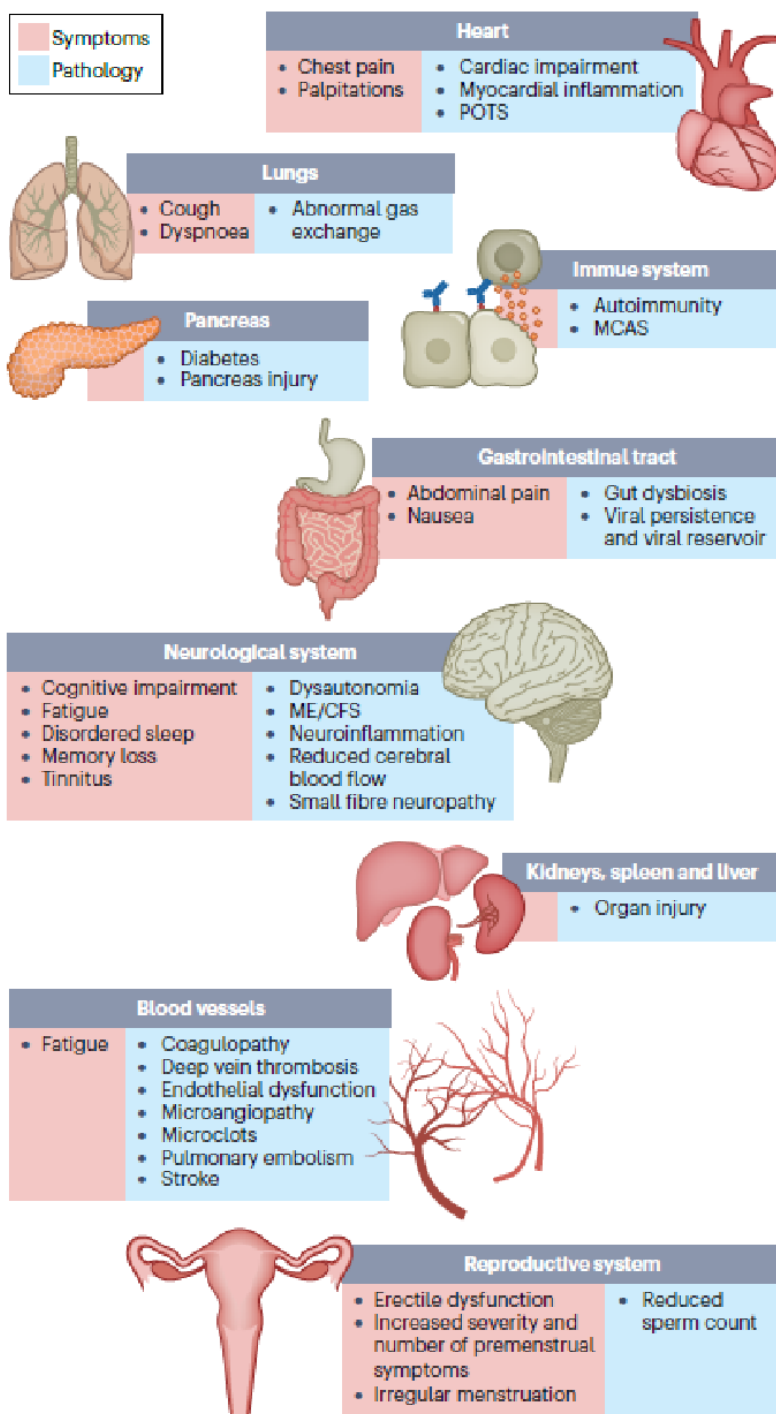
2.1 million
still continue to experience
long-term symptoms

42.2%
of those experienced
symptoms for a year or
longer

21.7%
experienced symptoms that limited their
daily activities

22.3%
among those employed missed some work or
school due to symptoms

**100,000 Canadian
adults have been unable to return
to work or school because of their symptoms**



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. Davis¹, Lisa McCorkell², Julia Moore Vogel³ & Eric J. Topol³✉

Davis et al., 2023

Over 200 symptoms (health challenges)

Long COVID: a clinical update Lancet 2024; 404: 707–24

Trisha Greenhalgh, Manoj Sivan, Alice Perlowski, Janko Ž Nikolich

- Heterogeneous, multisystemic, multi-faceted, can change over time.
- Multiple discrete pathological processes with overlapping phenotypes

What is episodic disability?

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.

What is episodic disability in the context of Long COVID?

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>

Study Aim

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



**PATIENT-LED
RESEARCH
COLLABORATIVE**



Original research

BMJ Global Health

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

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Lisa McCorkell ¹¹ Hannah Wei ¹² Susie Goulding,¹³ Margaret O'Hara ¹⁴
Catherine Thomson,⁶ Niamh Roche,¹⁵ Ruth Stokes,¹⁵ Jaime H Vera ^{7,8}
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CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

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

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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 ≥ 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

Episodic Disability Framework

Components of the Framework

1) Dimensions of Disability

- health challenges as a consequence of Long COVID and other concurrent conditions.

2) Contextual Factors

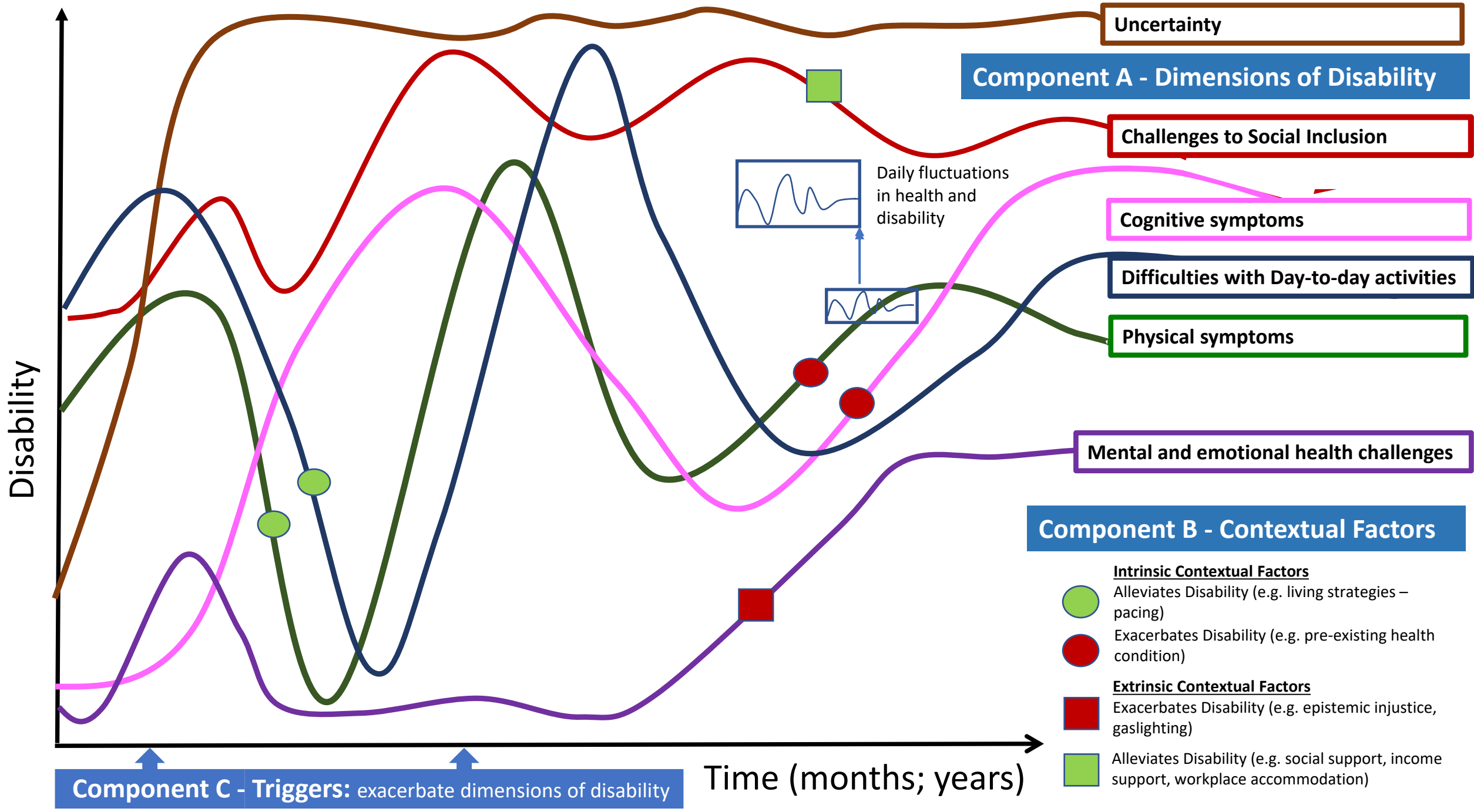
- factors (intrinsic and extrinsic) that can exacerbate or alleviate dimensions of disability

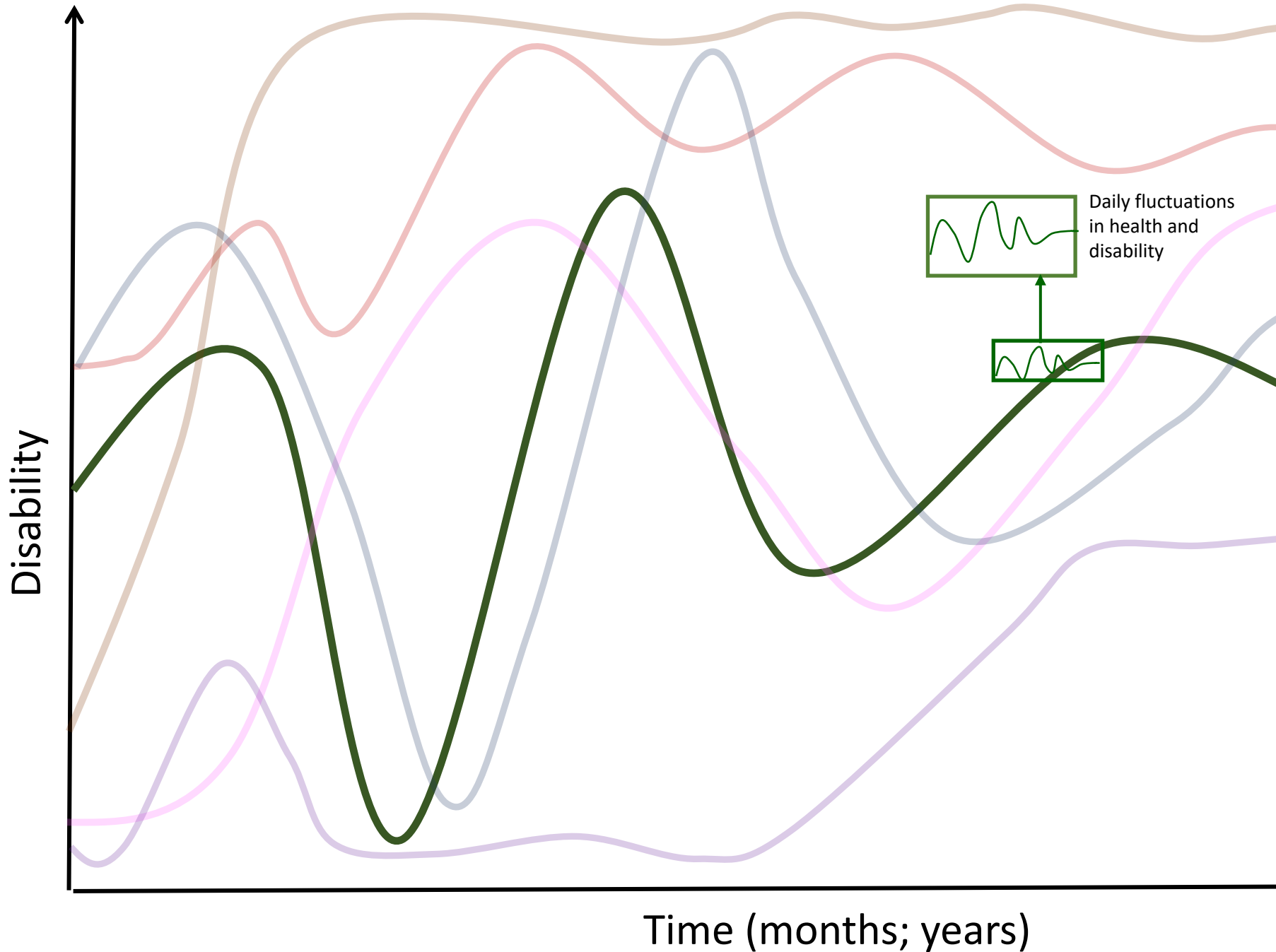
3) Triggers

- momentous events that can spark an episode of disability

Click here to access
the preprint article
in MedRxiv (2024)

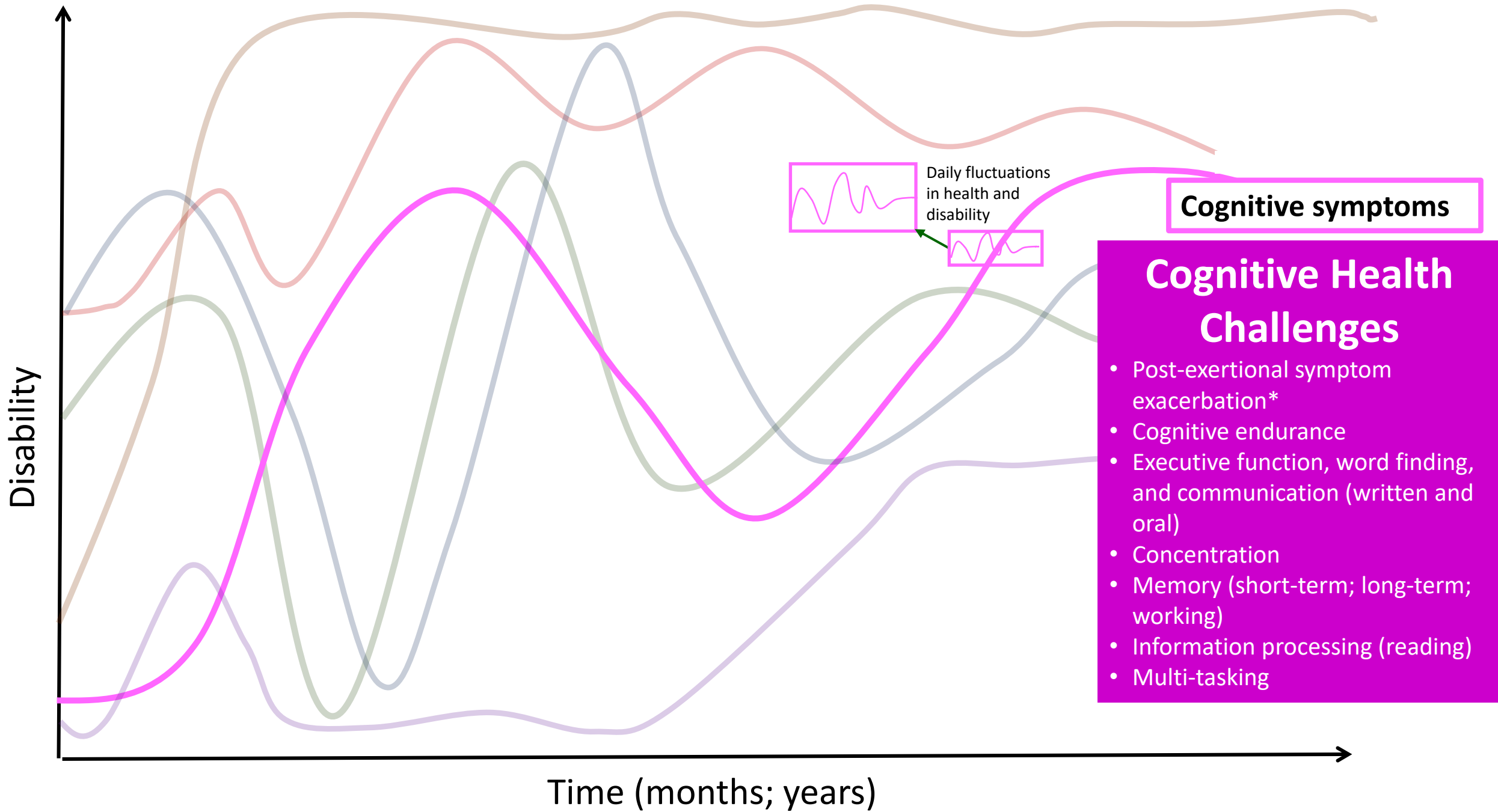
<https://www.medrxiv.org/content/10.1101/2024.05.28.24308048v2.full>

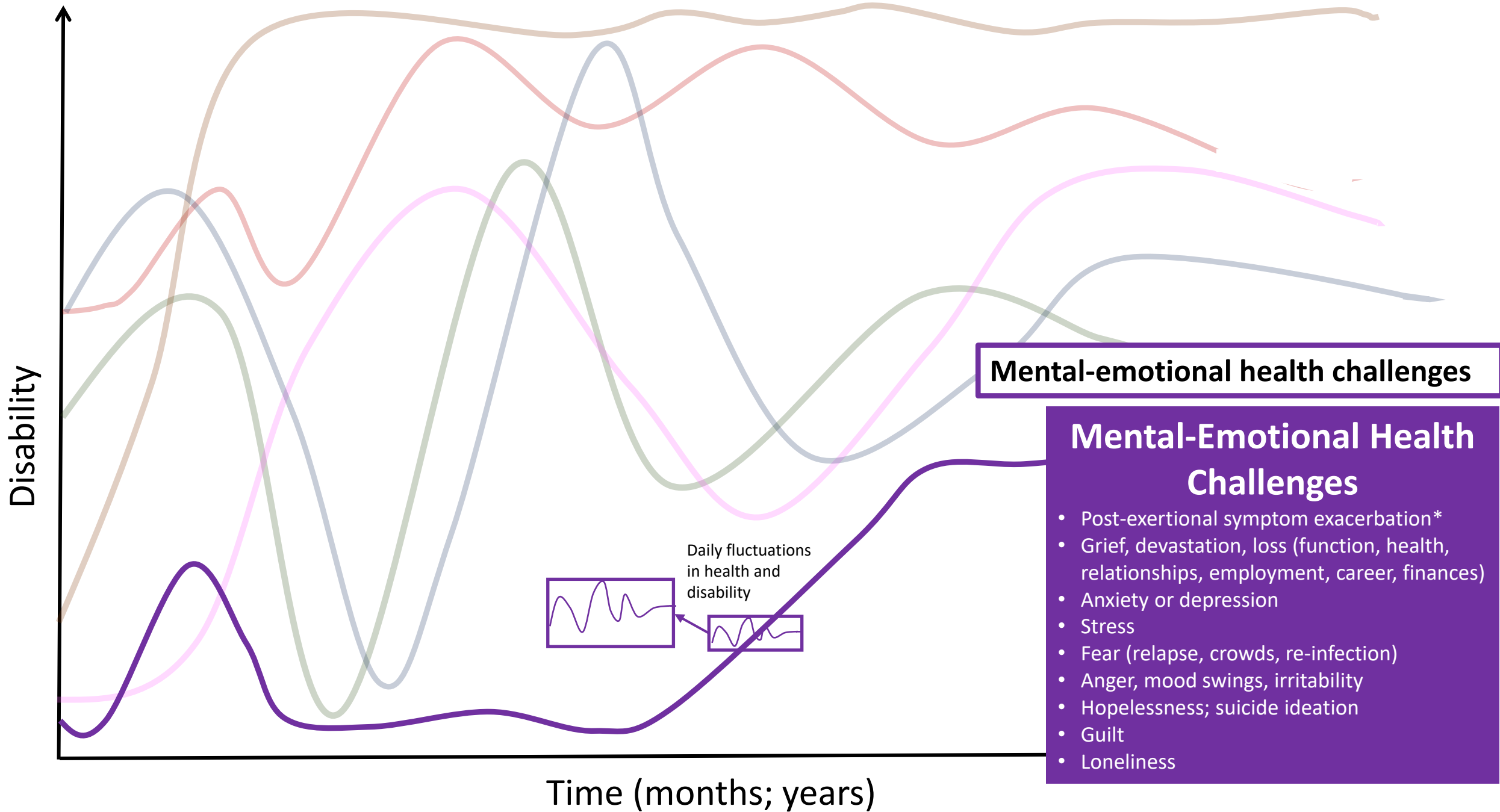




Physical symptoms

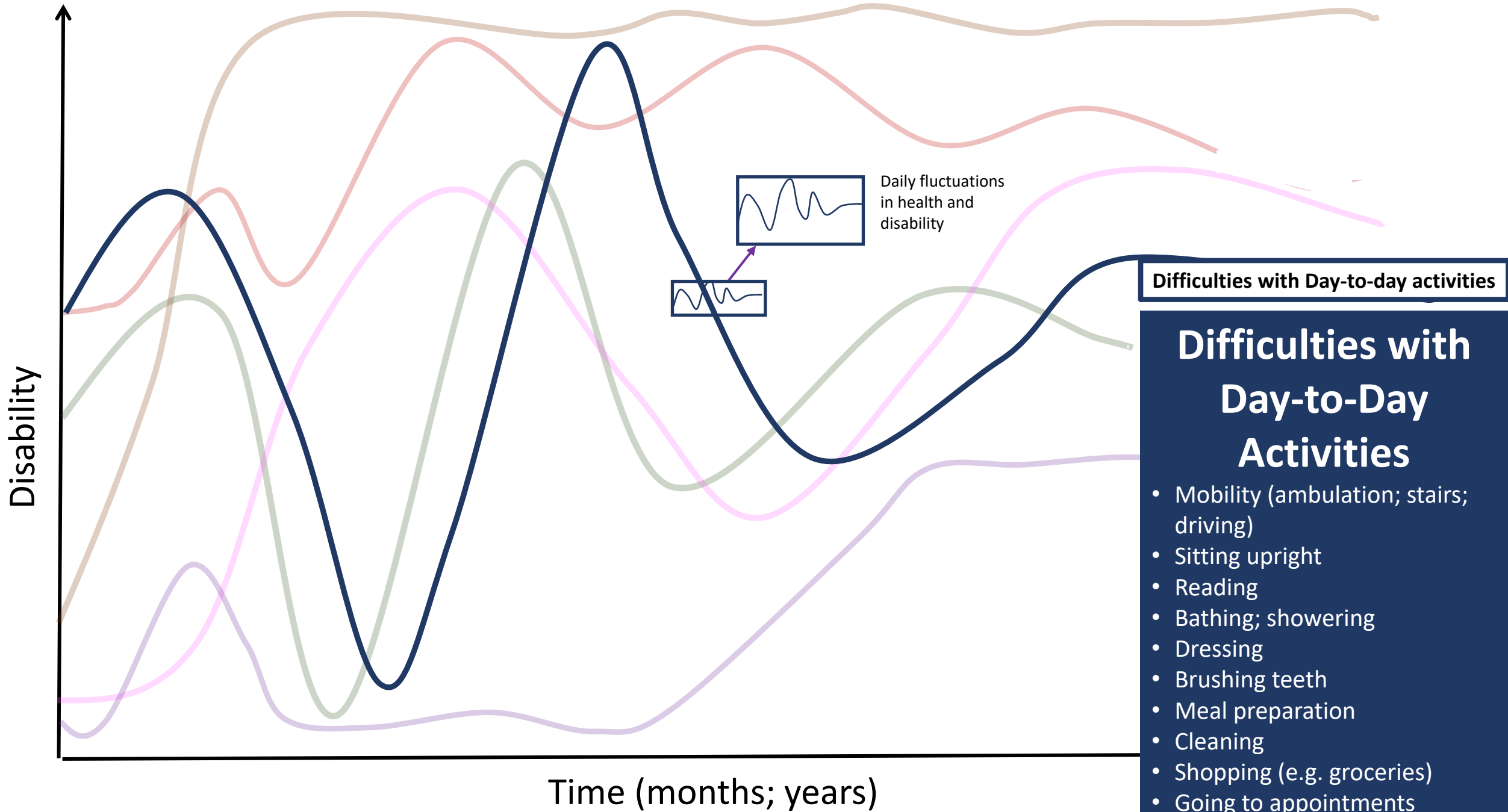
- ### Physical Health Challenges
- Post-exertional symptom exacerbation*
 - Fatigue
 - Weakness
 - Dizziness
 - Nausea
 - Pain
 - Skin sensitivity
 - Hearing; vision; voice
 - Sensory impairment
 - Shortness of breath
 - Swallowing; altered taste and smell
 - Weight loss or gain
 - Hair loss
 - Persistent cough, sore throat; fevers
 - GI issues
 - Cardiac issues
 - Menstruation changes
 - Etc...

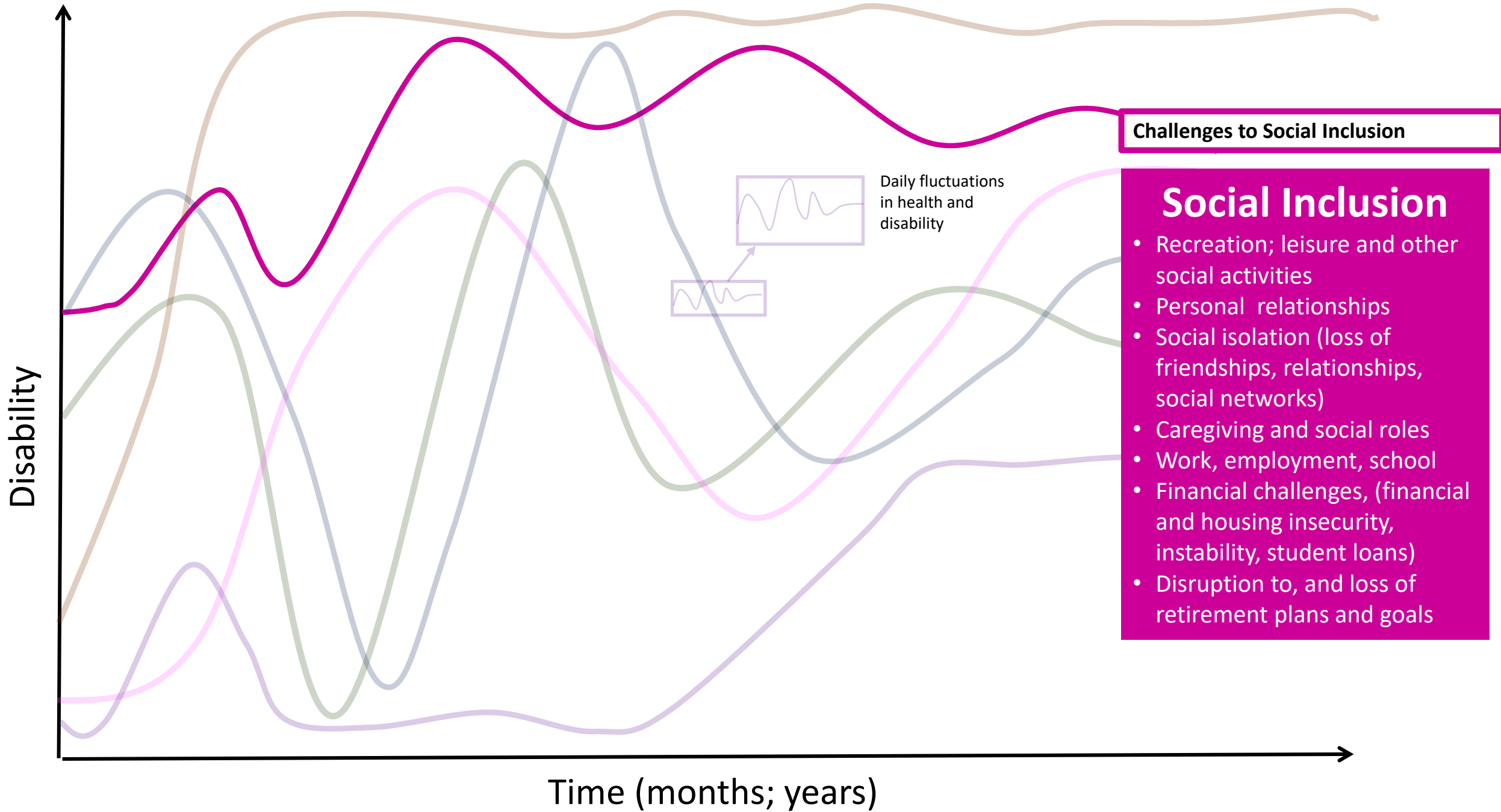




Mental-emotional health challenges

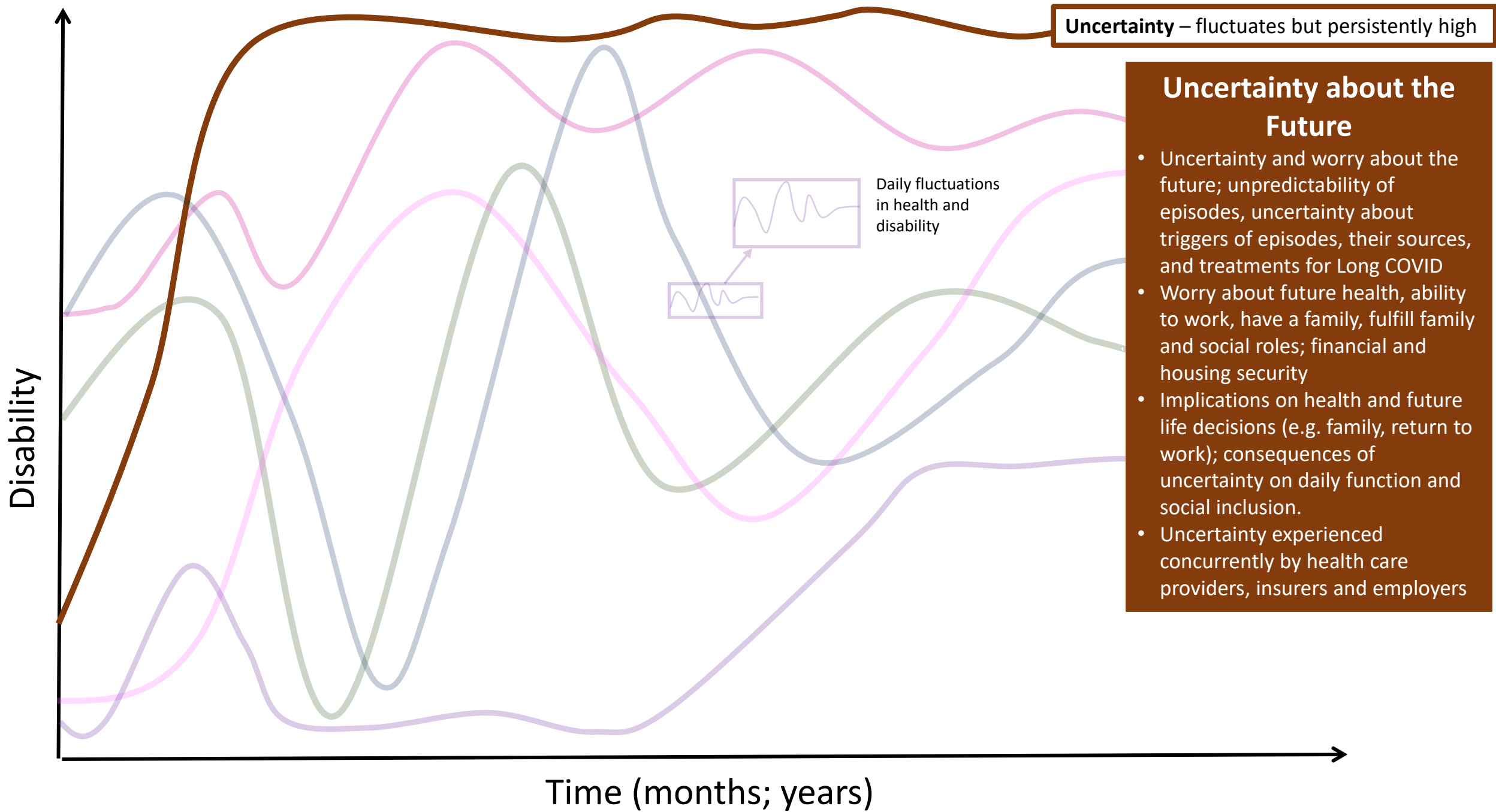
- Mental-Emotional Health Challenges**
- Post-exertional symptom exacerbation*
 - Grief, devastation, loss (function, health, relationships, employment, career, finances)
 - Anxiety or depression
 - Stress
 - Fear (relapse, crowds, re-infection)
 - Anger, mood swings, irritability
 - Hopelessness; suicide ideation
 - Guilt
 - Loneliness





Challenges to Social Inclusion

- Social Inclusion**
- Recreation; leisure and other social activities
 - Personal relationships
 - Social isolation (loss of friendships, relationships, social networks)
 - Caregiving and social roles
 - Work, employment, school
 - Financial challenges, (financial and housing insecurity, instability, student loans)
 - Disruption to, and loss of retirement plans and goals



Uncertainty – fluctuates but persistently high

Uncertainty about the Future

- Uncertainty and worry about the future; unpredictability of episodes, uncertainty about triggers of episodes, their sources, and treatments for Long COVID
- Worry about future health, ability to work, have a family, fulfill family and social roles; financial and housing security
- Implications on health and future life decisions (e.g. family, return to work); consequences of uncertainty on daily function and social inclusion.
- Uncertainty experienced concurrently by health care providers, insurers and employers

Contextual Factors

Interact with and influence dimensions of disability

Extrinsic Factors

Support

- Practical, emotional and social support from:
 - Friends, family, partners
 - Long COVID Community (including other disability and post viral condition groups and communities)
- Health and rehabilitation services and providers
- Employers; insurers, human resource professionals, work colleagues
- Program, policy, income (financial) support (public health policies /mandates)
- Mobility aids, technology

Accessibility of Environment & Health Services

- Access to health services and providers

Stigma, Epistemic Injustice

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

Intrinsic Factors

Living Strategies

Maintaining Control over Health & Life

- Pacing - anticipating, planning and Preparing Ahead; finding balance between activity and rest; prioritizing; establishing structure and routine;
- Lifestyle strategies;
- Practical Strategies (task modification tracking health; wearables, journaling)

Seeking out social and practical support, knowledge, health services and supports

Versus avoiding interactions with others; isolating self

Attitudes; Beliefs; Mindset; Outlook

- Acceptance,
- Adapting or adjusting mindset (shifting, adapting, and managing goals and expectations; patience; self-awareness; redefining success; resiliency, taking every day as it comes)
- Hope and optimism; positive and growth mindset (opportunity for growth) versus despair
- Adopting new roles and purpose

Diverting or Distracting

Blocking out of mind.

Personal Attributes

- Sex; Gender
- Age
- Ethnicity
- Pre-existing and concurrent Health Conditions
- COVID Characteristics (Positive PCR test; length of time living with Long COVID)

CHARACTERISTICS OF PACING

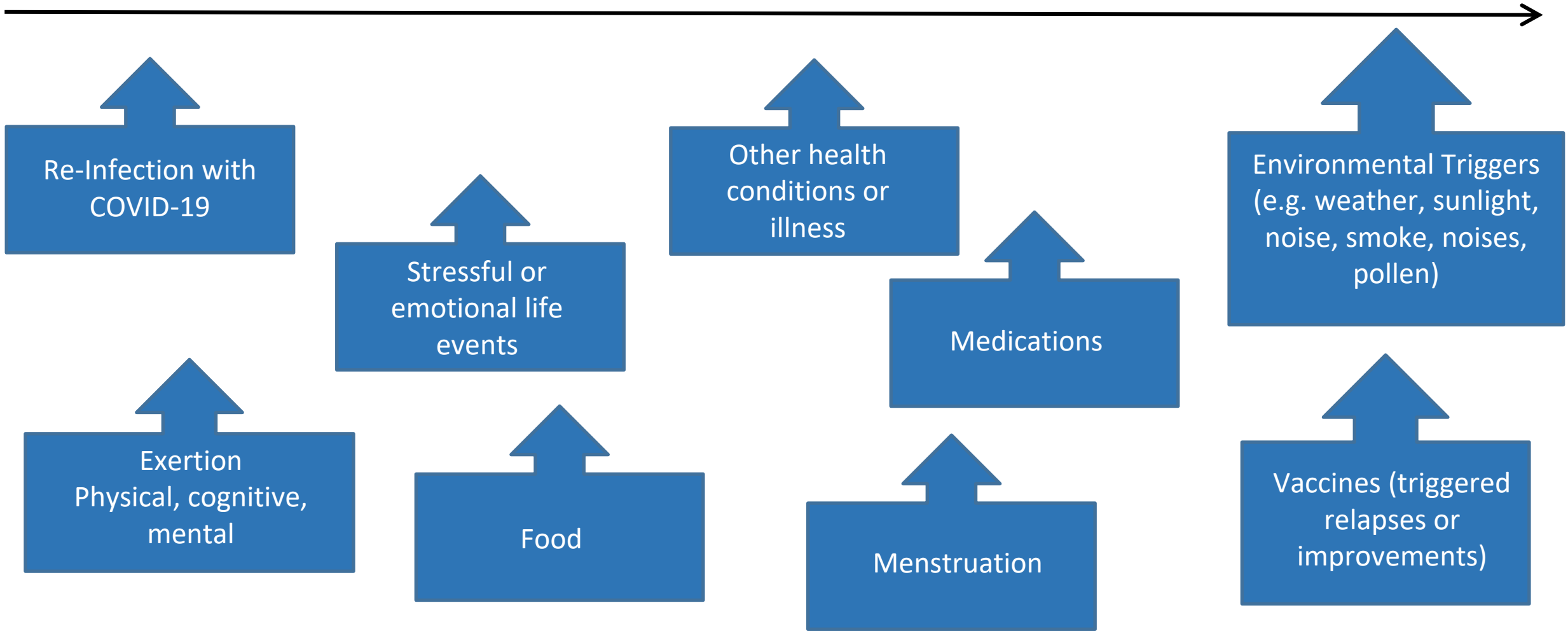
PACING IS A HELPFUL LIVING STRATEGY BUT IT IS NOT A CURE FOR LONG COVID

- Pacing was described as a **living strategy** and was **widely adopted** by the participants.
- Participants implemented pacing to:
 - Manage symptoms.
 - Avoid crashes.
- **Pacing was not described as treatment or cure for Long COVID.**
 - Pacing was described as **requiring ongoing effort and implementation** to reduce or avoid symptom exacerbation.

For me, I've understood more as time's gone on about pacing. So ... I would say it's a smoother ride now, but that's not because my symptoms are getting better. It's because I'm understanding more about my **limitations** and how much I have to pre-empt my body.
P19, UK



Time: Trajectory of Disability Living with Long COVID

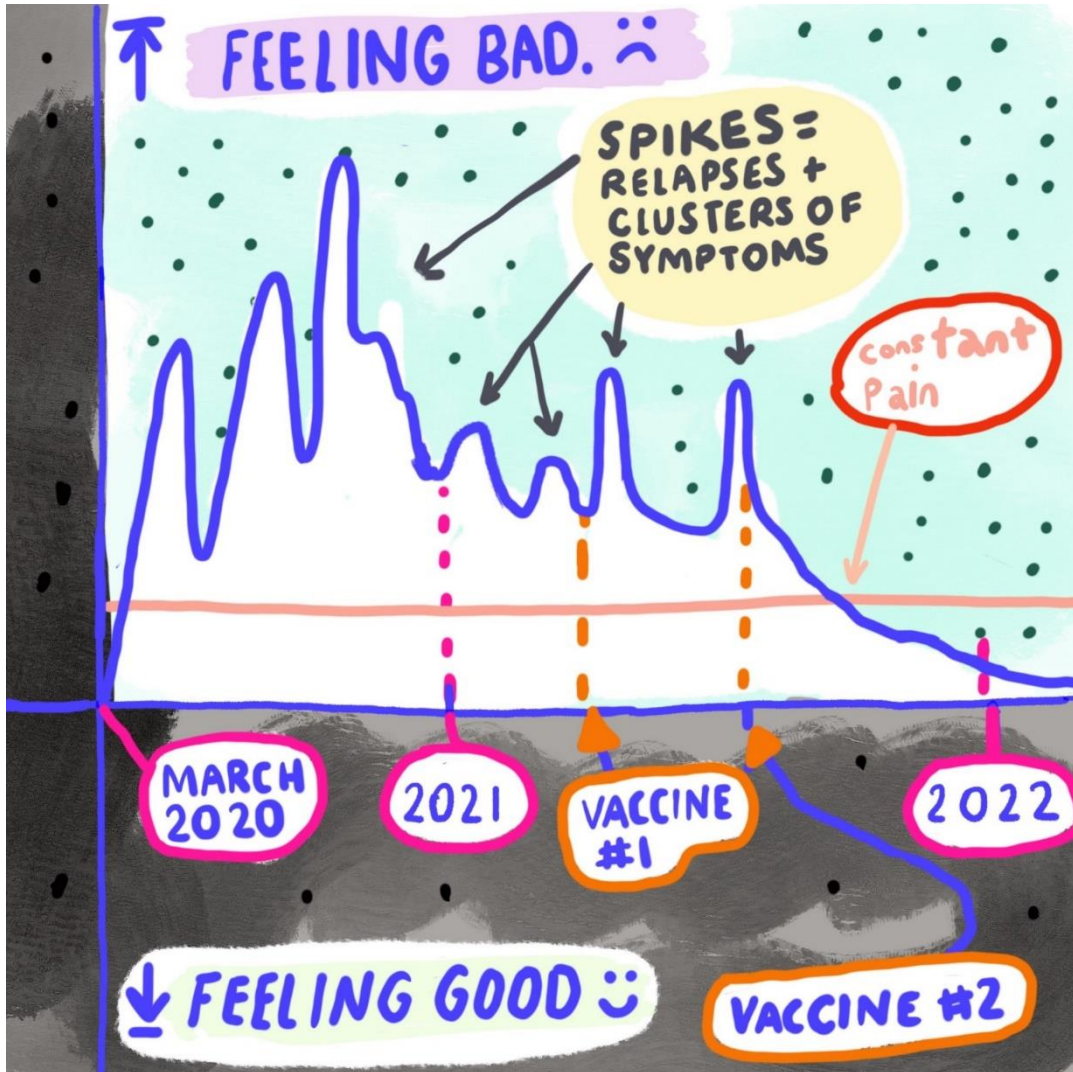


Triggers of Disability

Moments, stimuli, or events that initiated exacerbation or alleviation in episodes of disability

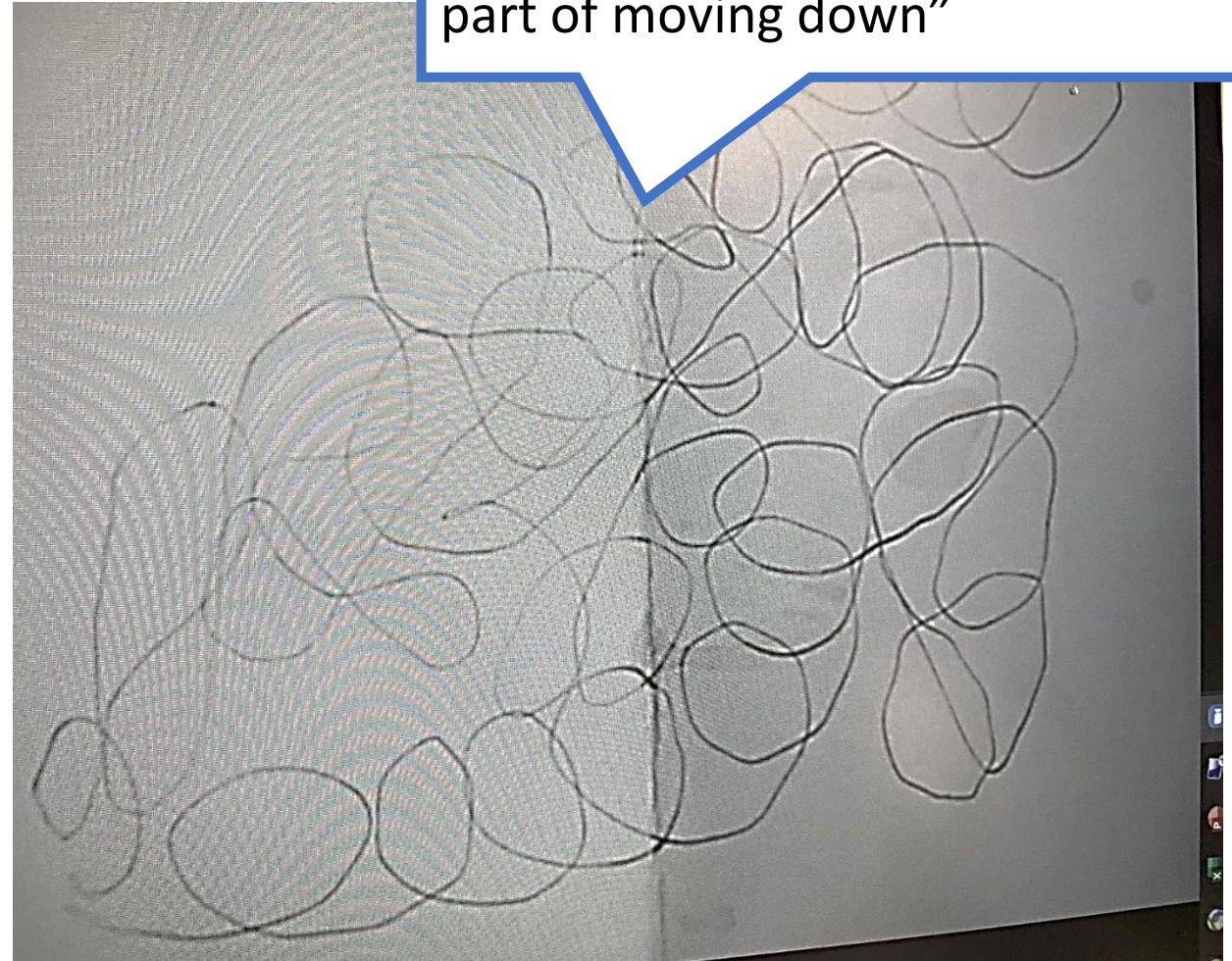
Timeframe of Episodic Disability

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”



In summary

- The **Episodic Disability Framework** conceptualizes experiences of disability among adults living with Long COVID including dimensions, contextual factors and triggers of disability.
- Provides a conceptual foundation to advance future measurement of disability and areas to target approaches for health and rehabilitation services and interventions.
- Rehabilitation has a role to address disability in the context of Long COVID



Principles of Safe Rehabilitation

Jessica DeMars, PT

Long COVID and Rehabilitation: Experiences of Physical Therapists Working with Adults Living with Long COVID in Canada



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Department of Physical Therapy, University of Toronto, Canada¹; Long COVID Clinic²; St. Michael's Hospital, University of Toronto, Canada³; Rehabilitation Science Research Network for COVID⁴; College of Health and Applied Sciences, University of KwaZulu-Natal, Durban, South Africa⁵; and Department of Physical Therapy, University of Toronto, Canada⁶

<https://www.medrxiv.org/content/10.1101/2024.03.10.24304061v1>

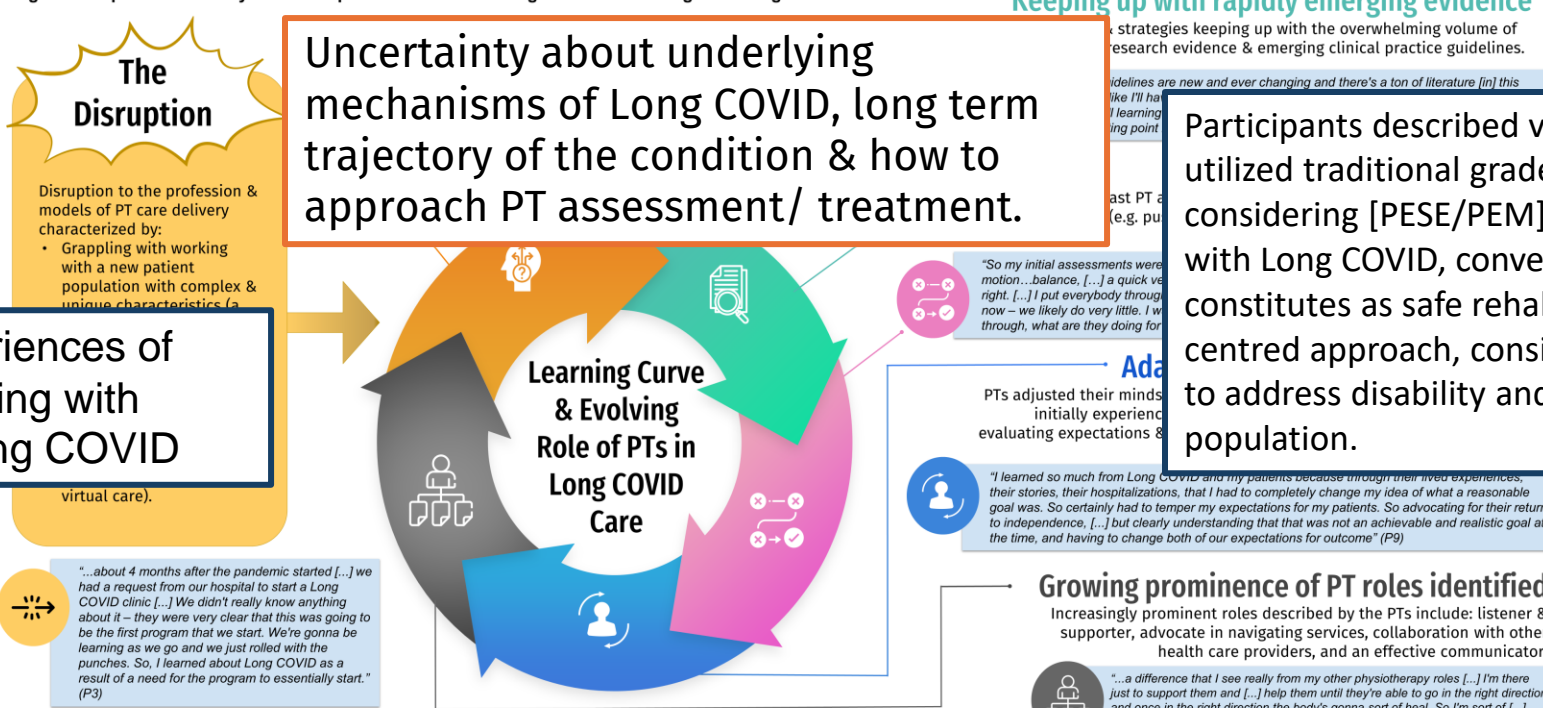
Introduction

- Long COVID is a condition first termed by people with lived experiences, that occurs when symptoms are experienced 3 months from the onset of COVID-19, and for at least 2 months that cannot be explained by an alternative diagnosis.¹
- Long COVID can present with a cluster of over 200 symptoms that can cause disability and impact quality of life.²⁻⁷
- Physical therapists (PTs) can have an important role in Long COVID rehabilitation, to facilitate symptom management, reduce disability, and return to function.⁸⁻¹²
- However, the experiences of PTs in Canada in Long COVID rehabilitation (e.g., perceptions of the role, knowledge, clinical practice and recommendations) are

To explore the experiences of PTs in Canada working with adults living with Long COVID

Study Design: Cross-sectional qualitative descriptive study.
Participants: PTs registered to practice in Canada who worked clinically in the past year with ≥1 adults living with Long COVID.
Sampling: Purposive and snowball sampling approach to capture diversity in level of clinical expertise, geographical PT practice location (urban vs. rural), and practice setting (private practice, outpatient/inpatient rehabilitation, community hospital).
Recruitment: We recruited through professional networks via word of mouth and researching contacts of Long COVID rehabilitation clinics online. We then emailed potential participants. After interviews, we asked participants to forward the initial recruitment email to other potential participants.
Data Collection: Semi-structured interviews involving two (members of the research team)-to-one (participant) via Zoom. Using an interview guide, we asked participants about their experiences, specifically pertaining to the perceptions of the role, knowledge, clinical practice, and recommendations working with adults living with Long COVID. We administered a demographic questionnaire to collect data on participants' age, gender, practice setting, and clinical experience working in Long COVID.
Data Analysis: Group-based descriptive thematic analysis.

Figure 1: Experiences of Physical Therapists in Canada Working With Adults Living With Long COVID



Discussion

- Experiences of PTs working with adults living with Long COVID were characterized as a disruption to the profession and models of delivery, followed by a cyclical journey involving learning curves and evolving roles.
- Safe Rehabilitation:** Participants described varied

training is crucial to prevent potential harm to patients. Future Long COVID research should be conducted in collaboration with other healthcare professionals.

- Strengths & Limitations:** A strength was the diversity in sampling characteristics (level of clinical exposure and geographical setting). The study is limited such that data collection ceased at 13 participants without reaching saturation, when no new categories emerged.

Conclusions

- Working as a PT in Long COVID rehabilitation is a dynamic and evolving process of experiencing a disruption, learning and evolving roles.
- Future practice should consider insights, notably the need for continuous learning and growth, to better equip PTs to provide safe and effective care for individuals living with Long COVID.

Acknowledgements & References

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Rehabilitation Science
Research Network
for COVID

The study is supported by a catalyst grant from the Rehabilitation Science Research Network for COVID.



We thank the participants for their time and sharing their insights. We thank Alyssa Minor, Mary Burke, and Kiera McDuff, for reviewing the interview guide and demographic questionnaire and for their feedback with a mock interview.

Table 1: Participant Characteristics (n=13)

Personal Characteristics of Participants	Number of Participants (%)	Clinical Characteristics of Participants	Number of Participants (%)
Median Age (years) (IQR)	41 years (33, 49)	Number of Patients Treated in Past Year With Long COVID	
Gender		1 to 25	5 (38%)
Man	5 (38%)	26 to 100	4 (31%)
Woman	8 (62%)	More than 100	4 (31%)
Ethnicity		Number of Years Working as a PT (IQR)	12 years (7, 25)
White	9 (69%)	Geographical Practice Setting	
South Asian	1 (8%)	Rural	2 (15%)
Asian	1 (8%)	Urban	11 (85%)
Middle Eastern	1 (8%)	Type of Practice Setting Delivering Long COVID Care	
Black or African	1 (8%)	Private Practice (Outpatient)	4 (31%)
Province		Rehabilitation Hospital (Outpatient or Inpatient)	5 (38%)
Ontario	5 (38%)	General/Community Hospital (with Outpatient Long COVID Clinic)	4 (31%)
British Columbia	2 (15%)		
Alberta	4 (31%)		
Quebec	1 (8%)		
Nova Scotia	1 (8%)		

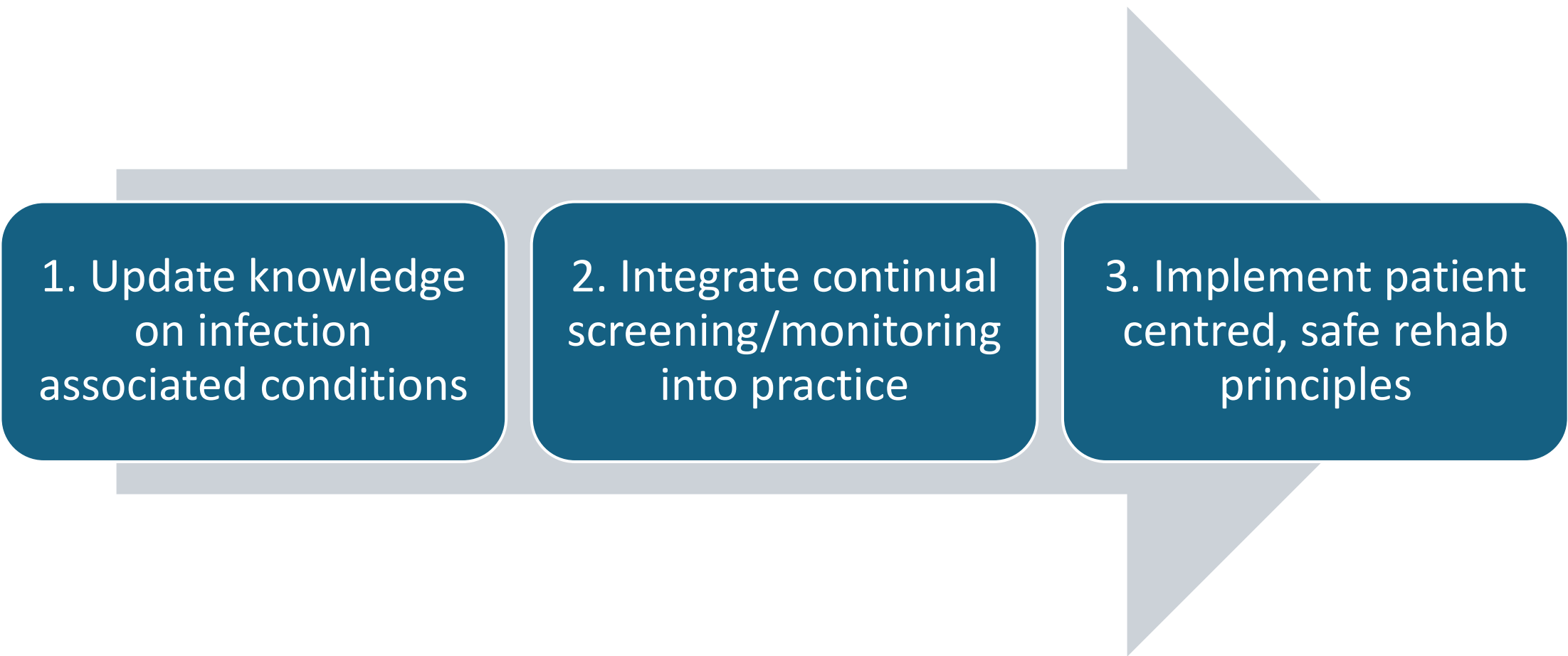
Table 2: Participant Recommendations For Effective and Up-To-Date Long COVID Care

Recommendation	Number of Participants (%)
Integrate Long COVID-specific education into physical therapy school curricula.	
Require continuing education on Long COVID for PTs.	
Improve patient access and timely financing for Long COVID care.	

Patient Experiences

- *“My disability insurance through my employer insisted that I do a functional assessment for my return to work recommendations. I was not even close to returning to work. I was referred to a large rehabilitation clinic that is well established in many provinces. I was assessed by an exercise therapist and an OT. The recommendations were: 3 times a week Physio program (2 hours in the gym), one hour of mental health counselling and one hour of OT support to assist with ADLs/IADLs per week. Plus travel time of 30 minutes both ways from my home. Some days that would amount to 5 hours with therapies and travel time. Completely impossible to do or sustain. Their idea of Rehab was to push yourself. Lacked insight about PEM.” -LW*
- *“It was quite early in my journey. The lead Physiotherapist that I saw had me lifting 5lb weights, but was just clutching at straws with zero information. At that time masks were still required, but he refused to use one. So I started seeing his colleague who was more specialized in neuro support. However, she still had me lifting 1lb weights in reps, and after one session I couldn't use my hands for 5 days. She had me working with bands both in the Physiotherapist's gym and at home, and it was just wiping me out.” - KG*

Integrating Safe Rehab into Practice

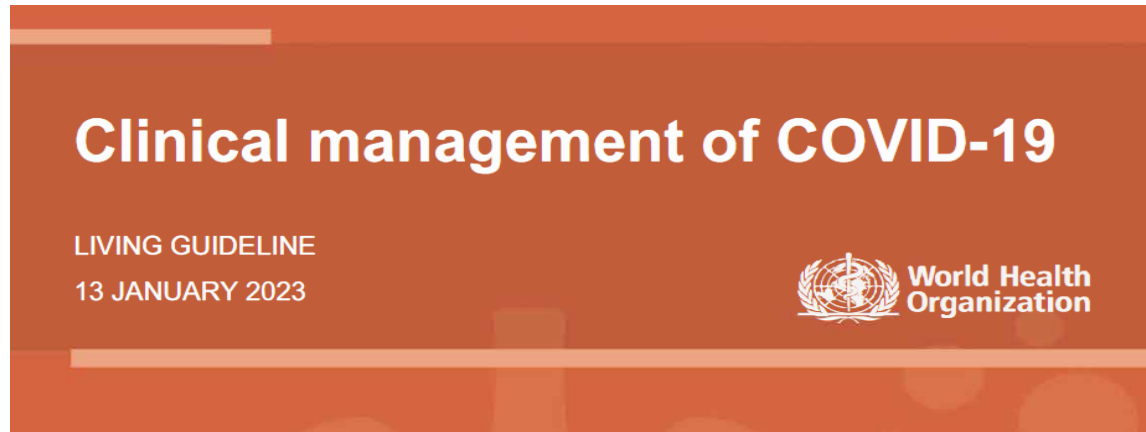


1. Update knowledge
on infection
associated conditions

2. Integrate continual
screening/monitoring
into practice

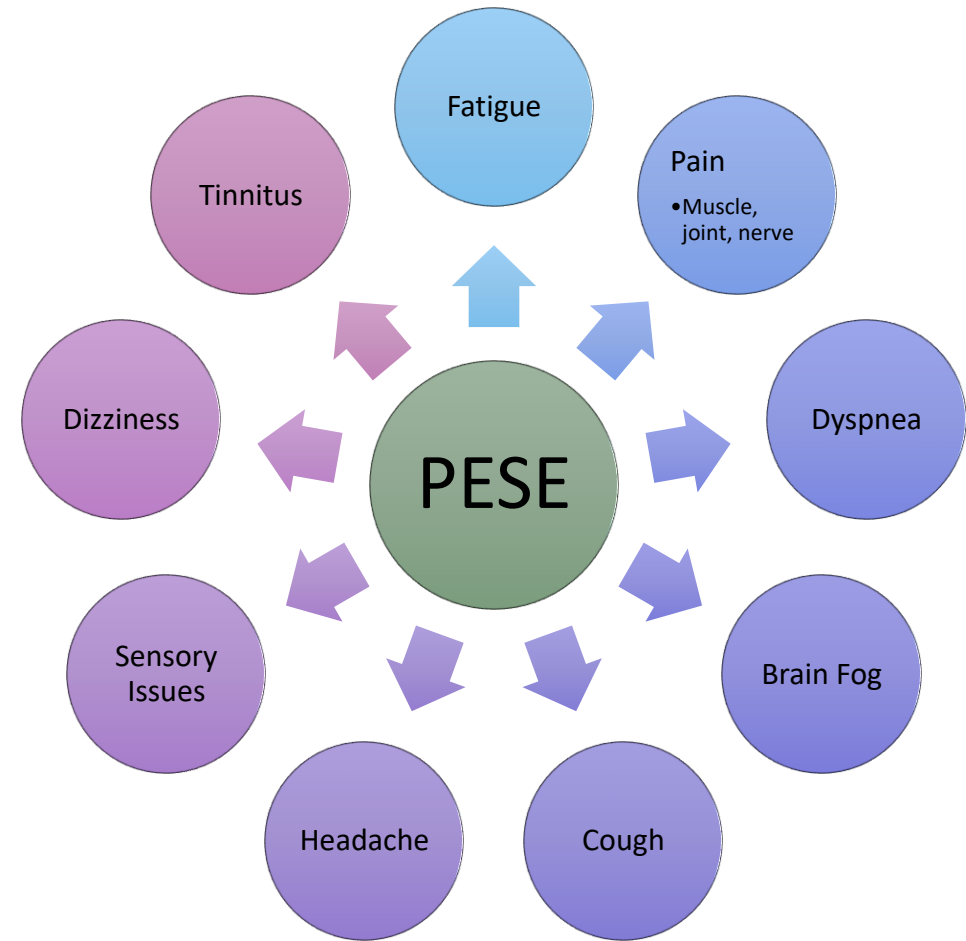
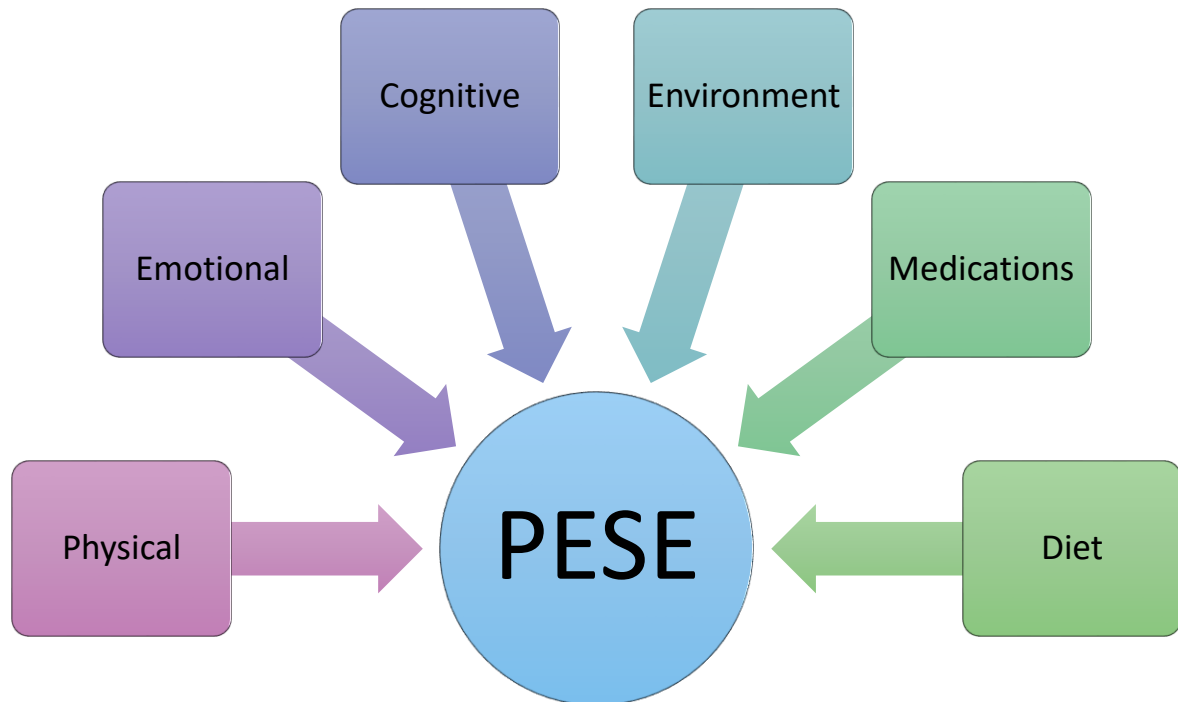
3. Implement patient
centred, safe rehab
principles

Step 1: Updating knowledge



PEM/PESE

- **Post Exertional Malaise/Post Exertional Symptom Exacerbation**
- This is not one specific symptom, but describes a physiological response to triggers that results in a worsening of any/all symptoms



Step 2: Continual Screening

- Long Covid has a high prevalence of:
 - PEM/PESE
 - Twomey et al (2022): 71.4% of patients were experiencing chronic fatigue and PESE
 - Pagen et al (2023): 48% of women and 41% of men have PESE
 - Dysautonomia/POTS
 - Eldokla et al (2022): 66% of 2,413 adults with COMPASS score >20
 - Saucier et al (2023): 77% of 320 adults with COMPASS score >16
 - Exertional Desaturation
 - Guarnieri et al, 2022 17% individuals will have exercise induced desaturation

Caution!



How physiotherapy may trigger PEM

This applies to **any** physiotherapy intervention, whether for ME or an unrelated matter

	Physical	Cognitive	Sensory	Emotional
Subjective assessment		✓	✓	✓
Position of patient	✓		✓	
Objective assessment	✓		✓	
Exercise	✓	✓	✓	
Passive stretches	✓		✓	
Manual therapy	✓		✓	
Providing advice		✓	✓	✓

As PEM is often delayed, it may not be apparent in session. Always check on a person's response to any intervention in the following 2-3 days to establish tolerance.

From: www.physiosforme.com

Screening Tools

- PESE:
 - De Paul Symptom Questionnaire PEM
 - Functional Capacity 27
- Dysautonomia:
 - NASA Lean Test
 - COMPASS 31
 - Orthostatic Intolerance Questionnaire
 - MALMO POTS

Lessons from Myalgic Encephalomyelitis/Chronic Fatigue Syndrome for Long COVID: Postexertional Symptom Exacerbation is an Abnormal Response to Exercise/Activity

AUTHORS

Todd E. Davenport, Staci R. Stevens, Jared Stevens, Christopher R. Snell, J. Mark Van Ness

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<https://doi.org/10.2519/jospt.blog.20220202>

Evidence-based Question	Patient/Client Response Indicating PESE
Does it take more than one day to recover to your usual baseline from activity?	"Yes."
Do you feel unwell, weak, don't sleep well, or have pain when recovering from activity?	"Yes" to at least one; diagnostic accuracy optimized for three or more.
Are you feeling limited in your ability to do your normal daily tasks after activity? Does exercise/activity positively affect you?	"Yes" to functional decrement and "No" to positive effect/mood.

Step 3: Patient Centred Care

- Throwing away pre-existing expectations and bias
- Being open to adjusting and adapting to episodic, unpredictable nature of Long COVID
- Changing our role from “fixer” to “coach”
- Finding strategies that are personalized and mindful of individual response

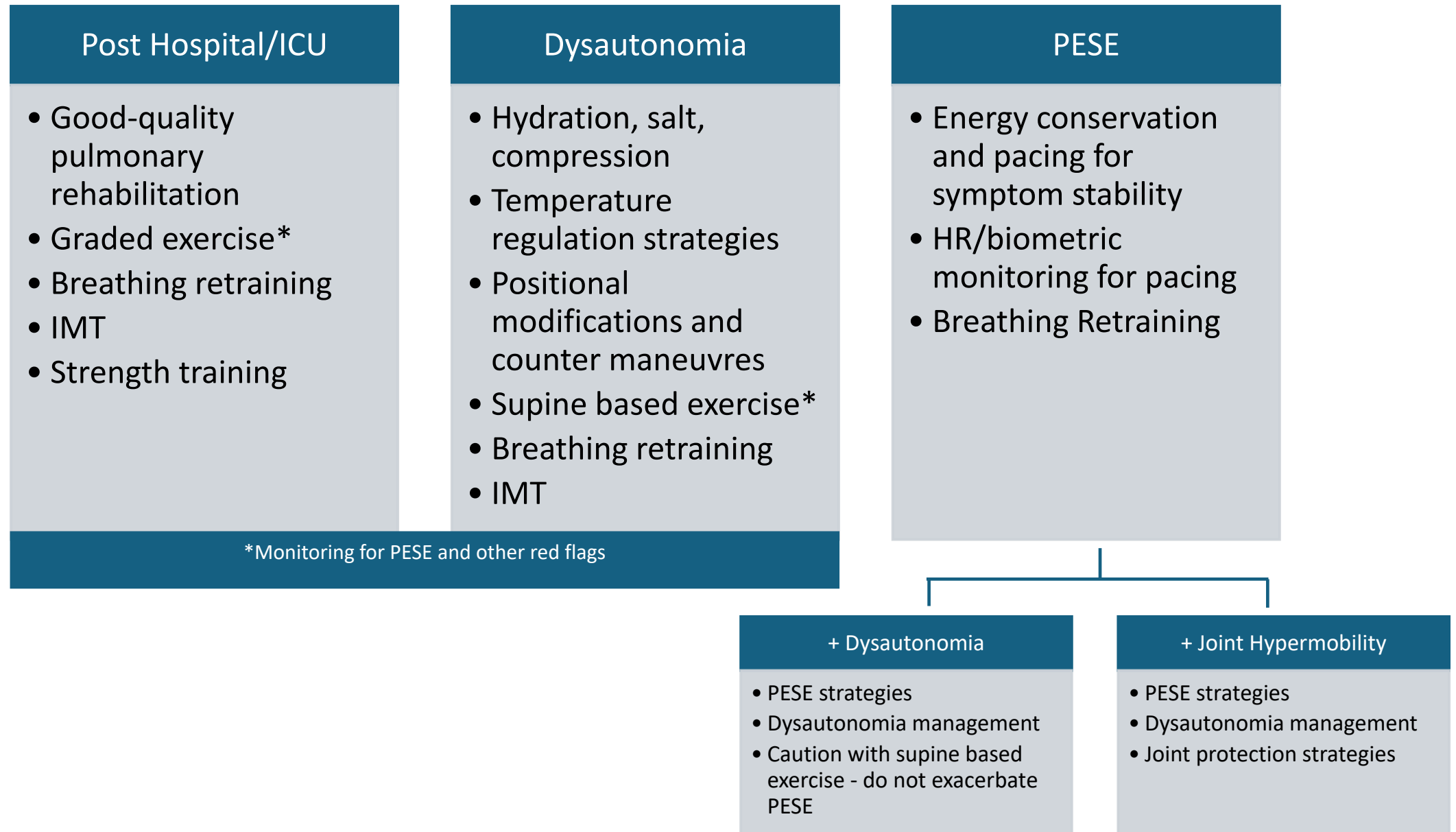
2022 Long COVID Physio International Forum

Journal of Occupational Rehabilitation

Table 1 Themes and Recommendations from the Long COVID Physio International Forum Discussion Session on Safe Rehabilitation of People Living with Long COVID

Theme	Justification	Recommendation
<i>Avoiding Acute Events and Symptom Flare Ups</i>	People living with Long COVID have experienced acute events, symptom exacerbation (i.e., Post-Exertional Symptom Exacerbation (PESE), or deterioration following traditional approaches to rehabilitation or other physical activity.	Rehabilitation professionals should screen for contraindications or precautions to activity and exercise prior to rehabilitation, plus incorporate modifications to rehabilitation interventions in the presence of PESE and orthostatic intolerances. The focus of rehabilitation is often stabilising fluctuations before building tolerance and activity.
<i>Personalization</i>	People living with Long COVID experience a wide diversity of symptoms, participation restrictions, and episodic disability.	Rehabilitation professionals should be flexible and tailor rehabilitation to the unique needs of each person living with Long COVID.
<i>Facilitating Expectations</i>	Recovery looks different for each person living with Long COVID and is often focused on mitigating disability, optimising functioning, and strategies to support living with disability, rather than a cure.	Rehabilitation professionals should hold clear and accurate expectations for rehabilitation from the beginning and help to inform clients, family members, employers, and other healthcare providers, or any others holding unrealistic expectations, about the role and scope of Long COVID rehabilitation.
<i>Psychologically Supportive</i>	People living with Long COVID need to feel heard and understood by their healthcare providers. Many experience disbelief and stigma, including from health professionals.	Rehabilitation professionals should be authentically non-judgemental and create psychologically safe spaces for rehabilitation.

PROPOSED REHABILITATION PATHWAY



Challenges of invisible illness/future directions?

- Identifying Long COVID in clinical practice
 - Broad definition
 - Identifying phenotypes (often with overlap)
 - No clinical diagnosis/biomarkers
- How do we document energy limitations?
- How do we capture impact of PESE without causing PESE?
- How can we objectively measure “brain fog?”

Helen - About Me

2020:

- Fit and well prior to first COVID infection in March 2020. Enjoying my life!
- Long COVID symptoms started

2021:

- Postural Orthostatic Tachycardia Syndrome (POTS)
- Bouncing in and out of work – reasonable adjustments, phased returns, using annual leave.

2022:

- Reduced hours 2022
- Reinfection - 2022
- Germany (2022) – micro clots and severe platelet clumping
- Glimmer of stability end of 2022 – Still functionally limited, just work.

2023:

- Changed job/specialty Jan 2023 but reinfected in between.
- Huge deterioration after this reinfection including PE despite blood thinners.
- Bounced in and out of work and then long term sick

2024:

- Worked from home start of year as part of return to work
- Contract ended March 2024
- More blood clots
- Chronic Migraine

Role of Occupational Therapy

Occupational Therapy for Long COVID

By Tadi Hondonga

What is Long COVID?

"Long COVID" (post-acute covid-19) is a term used to describe the persistence of COVID-19 symptoms beyond three weeks from the initial SARS-CoV-2 infection (Greenhalgh et al., 2020).

What are some of the common symptoms of Long COVID?

- Headache
 - Joint/ muscle pain
 - Diarrhea
 - Dizziness
 - Difficulty sleeping
 - Mood changes
 - Change in smell/ taste
 - cough
 - Tiredness or fatigue
 - Post-exertional malaise
 - Heart palpitations
 - Shortness of breath
 - Chest or stomach pain
 - Brain fog
 - Anxiety and depression
- (CDC, 2020)



Of adults reported 1 or more symptoms 4-12 weeks after initial infection (Government of Canada, 2021)



Of children reported 1 or more symptoms 4-12 weeks after initial infection (Government of Canada, 2021)

Occupational Therapy Solutions for Long COVID

Occupational therapists can help clients participate in activities that are meaningful to them through:



Energy conservation strategies



Symptom self-management strategies



Ergonomic assessments & adaptations



Occupational schedules



Mental health assessments & treatments



Physical & cognitive rehabilitation

(Wilcox & Frank, 2021)

Cognition

- OTs are well placed to address this but it seems to be being overlooked
- Cognitive dysfunction (more than “brain fog”)
- Common symptom in both hospitalised and non-hospitalised (Altuna, Sánchez-Saudinó et al., 2021)
- 21% Canadians reported symptoms affecting their ADLs often/always. 39% Canadians with Long COVID experiencing “brain fog” (Statistics Canada, 2023)&
- Affects all aspects of daily life – activities, meaningful roles, relationships, work (Chasco et al., 2022).
- Multiple potential mechanisms – viral persistence, neuroinflammation, structural changes, vascular damage & cerebral hypoperfusion (Davis et al., 2023)

Altuna M, Sánchez-Saudinós MaB, Lleó A. Cognitive symptoms after COVID-19. *Neurology Perspectives*. 2021;1:S16-S24. doi:<https://doi.org/10.1016/j.neurop.2021.10.0057>

Government of Canada SC. Experiences of Canadians with long-term symptoms following COVID-19. www150.statcan.gc.ca. Published December 8, 2023.

<https://www150.statcan.gc.ca/n1/pub/75-006-x/2023001/article/00015-eng.htm>

Chasco EE, Dukes K, Jones D, Comellas AP, Hoffman RM, Garg A. Brain Fog and Fatigue following COVID-19 Infection: An Exploratory Study of Patient Experiences of Long COVID. *International Journal of Environmental Research and Public Health*. 2022;19(23):15499. doi:<https://doi.org/10.3390/ijerph192315499>.

Davis HE, McCorkell L, Vogel JM, Topol EJ. Long COVID: major findings, mechanisms and recommendations. *Nature Reviews Microbiology*. 2023;21(3):1-14. doi:<https://doi.org/10.1038/s41579-022-00846-2>

PESE

- Not just physical exercise! In a study of people living with ME it was the cognitive task which made most participants exceed their anaerobic threshold (Clague-Baker et al., 2023).
- All exertion including activities of daily living (ADLs), cognitive tasks, emotional & sensory energy.
- Difficult because of the delayed onset and also the presentation/duration changes sometimes.

Day	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Activity	Work	Work	Day off/Virtual Appt	Work	Work	Rest	Rest
Rating	OK	OK	Bad	Bad	Bad	Bad	OK

OT Input - Assessment

Assessment:

- Screen for PESE
- Ask about orthostatic symptoms
- Ask about daily activities/routine – is there a gap? E.g. working but nothing else
- Journals/apps etc useful

Cognition:

- Ask about cognitive symptoms
- Be mindful that cog assessment not always sensitive enough to detect issues (higher level)
- Be aware of episodic disability/resting for appt may mask impairments
- May need multiple sessions to enable pacing

PESE:

- Identify triggers/patterns

OT Input - Intervention

Equipment e.g. shower chair etc

Avoid PESE triggers

Pacing = difficult/sacrifice

- Individualised
- Activity Diaries (be aware of PESE)/apps
- Cognitive pacing = even more difficult!
- Timed/planned rest breaks – based on symptoms
- Occupational science – time use, “tempo” & temporality

Positioning

- POTS/orthostatic intolerance

Pemberton S, Cox D. Perspectives of Time and Occupation: Experiences of People with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis. *Journal of Occupational Science*. 2013;21(4):488-503. doi:<https://doi.org/10.1080/14427591.2013.804619>

Pemberton S, Cox D. What Happened to the Time? The Relationship of Occupational Therapy to Time. *British Journal of Occupational Therapy*. 2011;74(2):78-85. doi:<https://doi.org/10.4276/030802211x12971689814043>

Return To Work Recommendations

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

Return to Work for People Living with Long COVID



Recommendations include²⁰⁻²⁵:



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

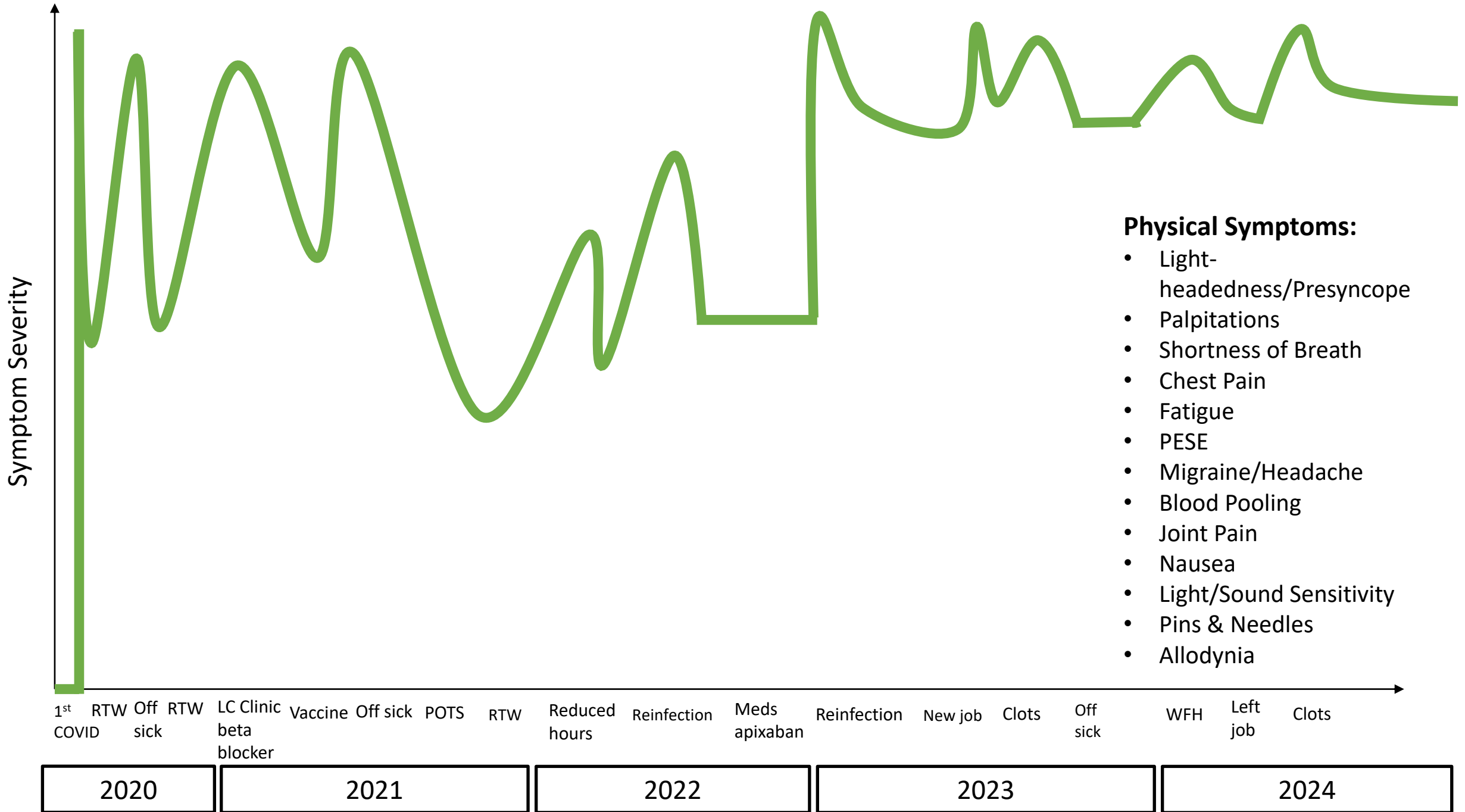


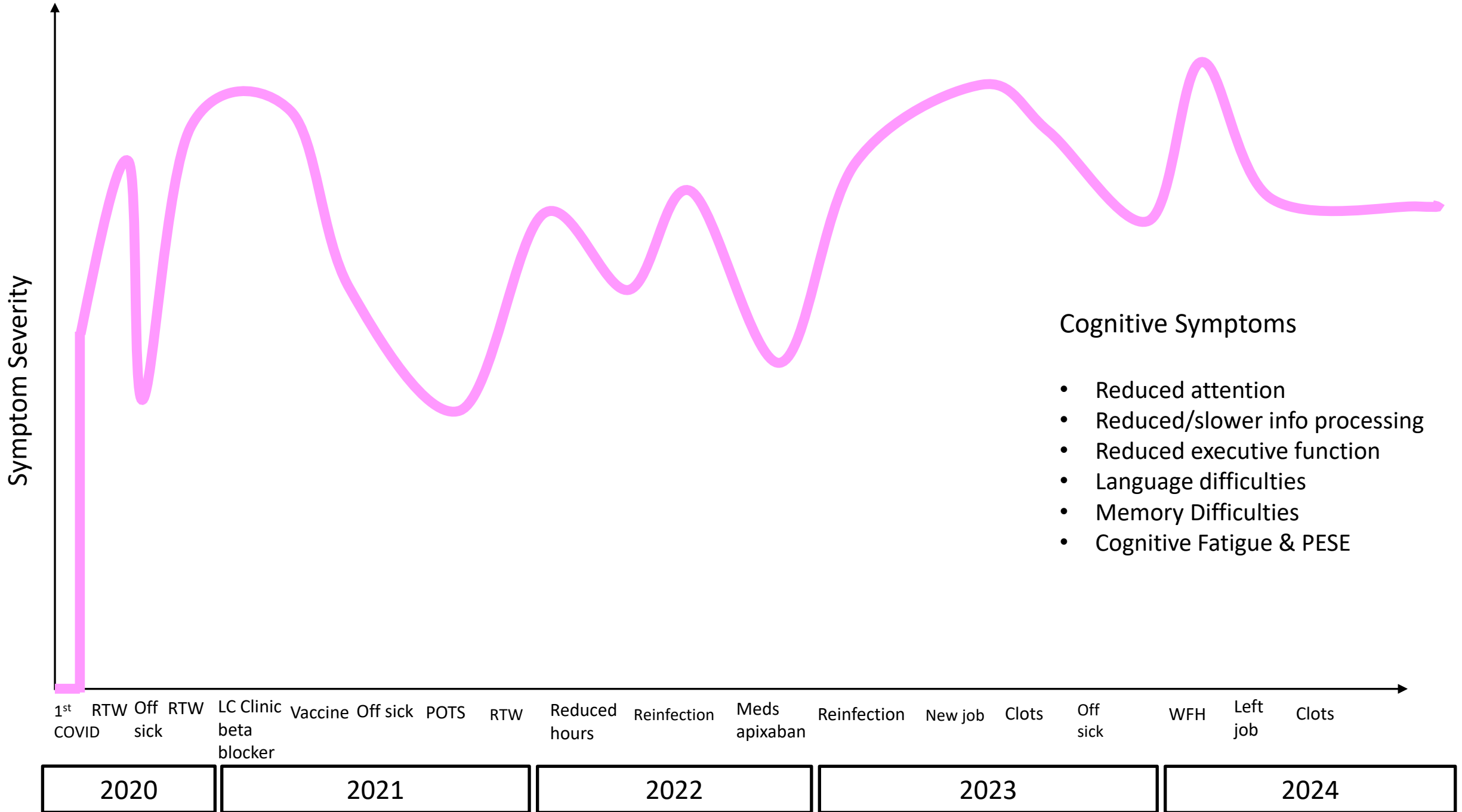
Altered tasks,
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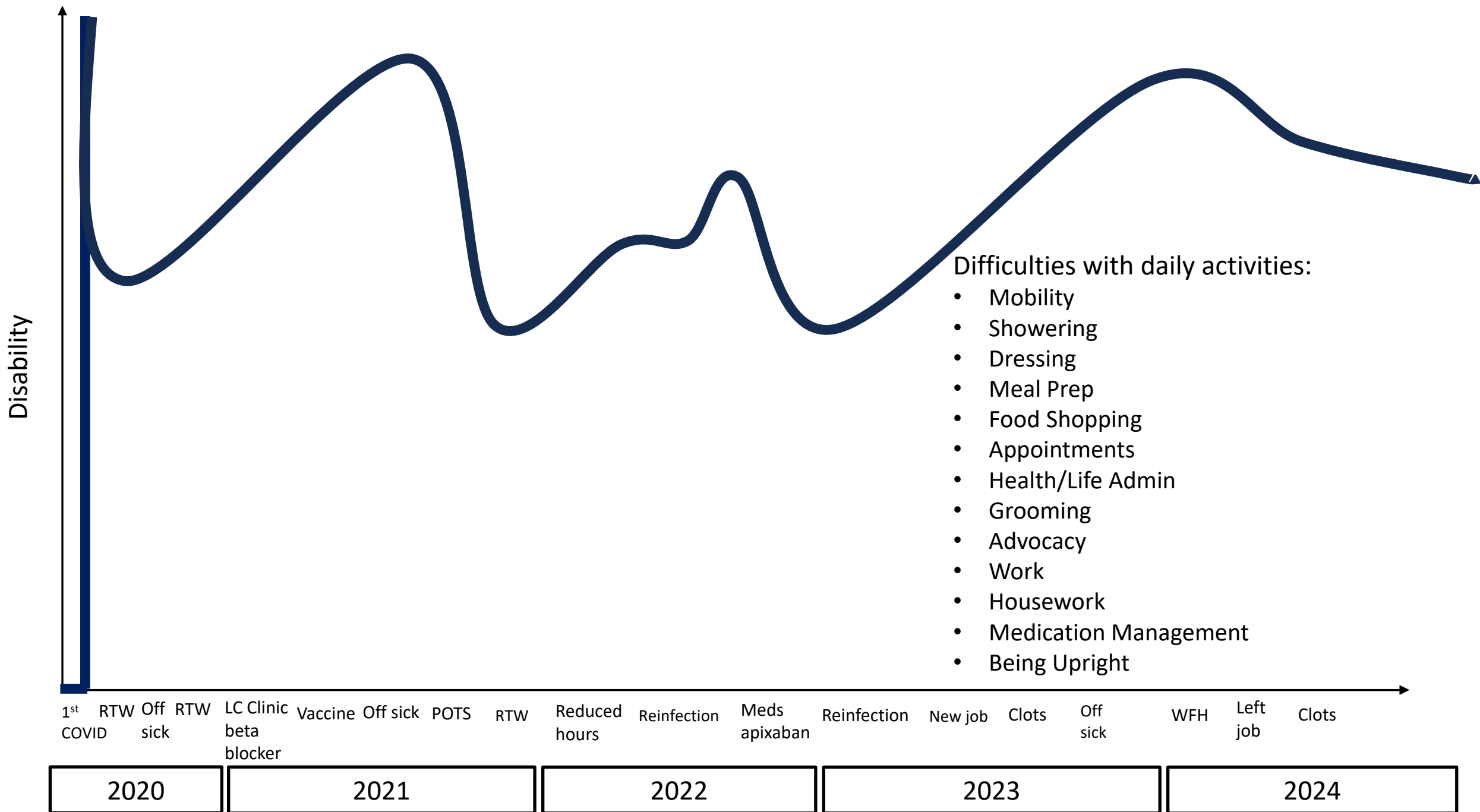


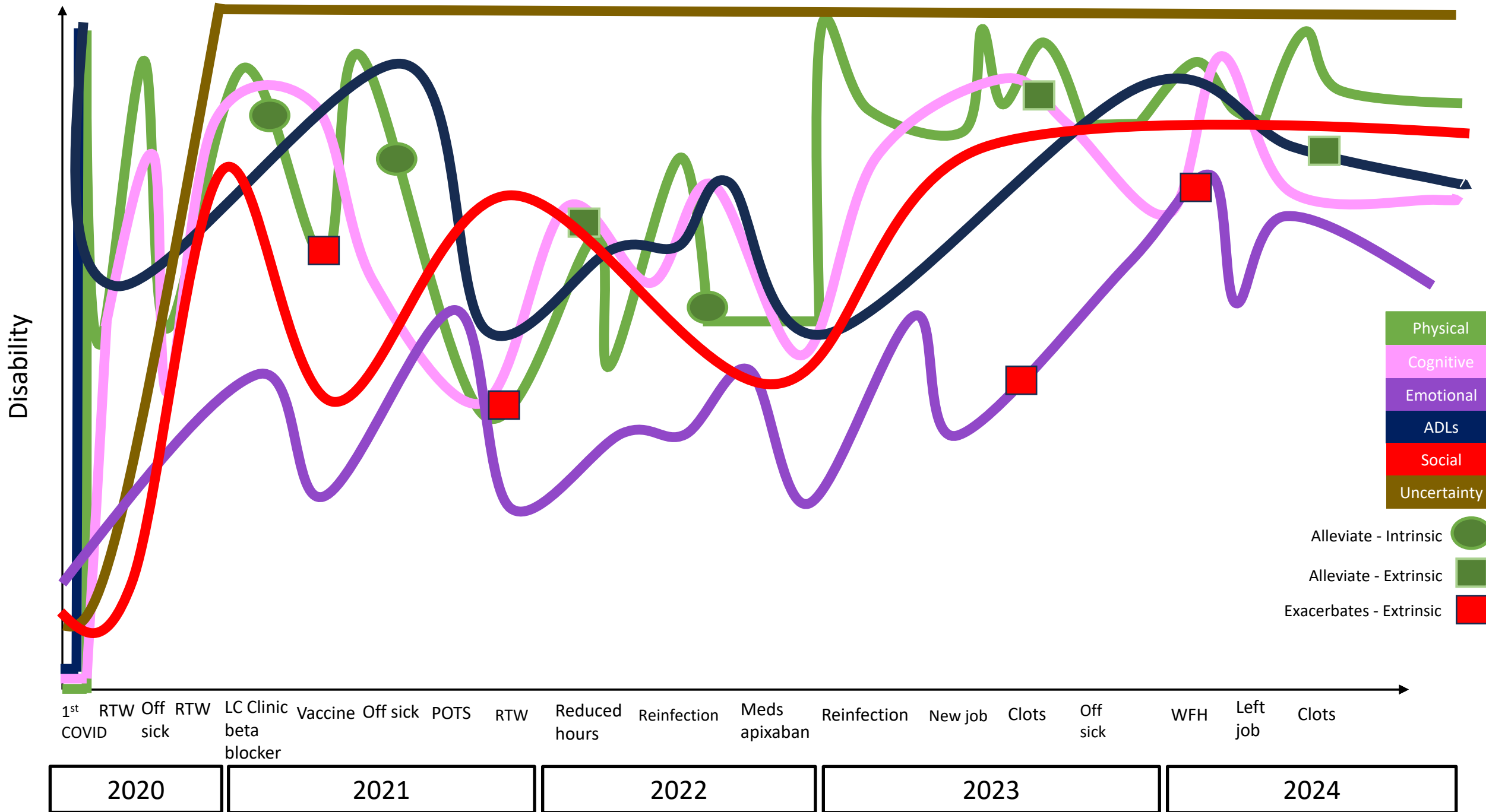
Rest-time
accommodations

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









In Summary – Take Home Messages

- Disability – multidimensional; episodic
- Uncertainty – key component
 - intersected with the episodic nature of disability, characterized as unpredictability of episodes, their length, severity and triggers, and uncertainty of Long COVID over the long-term, which had implications on broader health.
- Community engaged approaches are key
- Rehab professionals must screen for/be mindful of PESE to ensure safe rehab
- Rehab interventions must be individualized
- Think cognitive dysfunction not brain fog!



**PATIENT-LED
RESEARCH
COLLABORATIVE**



**LONG
COVID
PHYSIO**



CIHRRC

Canadian-International HIV and Rehabilitation Research Collaborative



Thank you & Acknowledgements



LONG COVID WEB



UNIVERSITY
OF SUSSEX



Sunnybrook
HEALTH SCIENCES CENTRE



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



University of Colorado
Denver



Physical Therapy
UNIVERSITY OF TORONTO



ST. JAMES'S
HOSPITAL

Chelsea and Westminster Hospital
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Lisa Avery

University Health Network

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University of Toronto

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University of Sussex, Brighton, UK

Catherine Thomson

Long COVID Physio

Niamh Roche

Long COVID Ireland

Ruth Stokes

Long COVID Ireland

Susie Goulding

COVID Long Haulers Support Group
Canada

Margaret O'Hara

Long COVID Support, UK

Hannah Wei

Patient Led Research Collaborative

Lisa McCorkell

Patient Led Research Collaborative

Hannah Davis

Patient Led Research Collaborative

Patriic Gayle

Gay Men's Health Collective, UK



University of Colorado
Denver



Chelsea and Westminster Hospital 
NHS Foundation Trust





Physical Therapy
UNIVERSITY OF TORONTO



Rehabilitation Science Research
Network for COVID



TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO

TemertyMedicine

Thank you & Questions?



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CIHR IRSC

Canadian Institutes of Health Research
Institut de recherche en santé du Canada

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

Some Resources

Clinical Management Guidelines

Clinical management of COVID-19

LIVING GUIDELINE

13 JANUARY 2023



Considerations

- Pacing.
- Energy / activity management.
- Planned activity + planned rest.
- Environmental modifications.

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

World Physiotherapy Response to COVID-19 Briefing Paper 9. Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise. London, UK: World Physiotherapy, 2021. ISBN: 978-1-914952-00-5.

Rehabilitation for Clients with Post COVID-19 (Long COVID): Guidance for Canadian Rehabilitation and Exercise Professionals – Canadian Physiotherapy Association

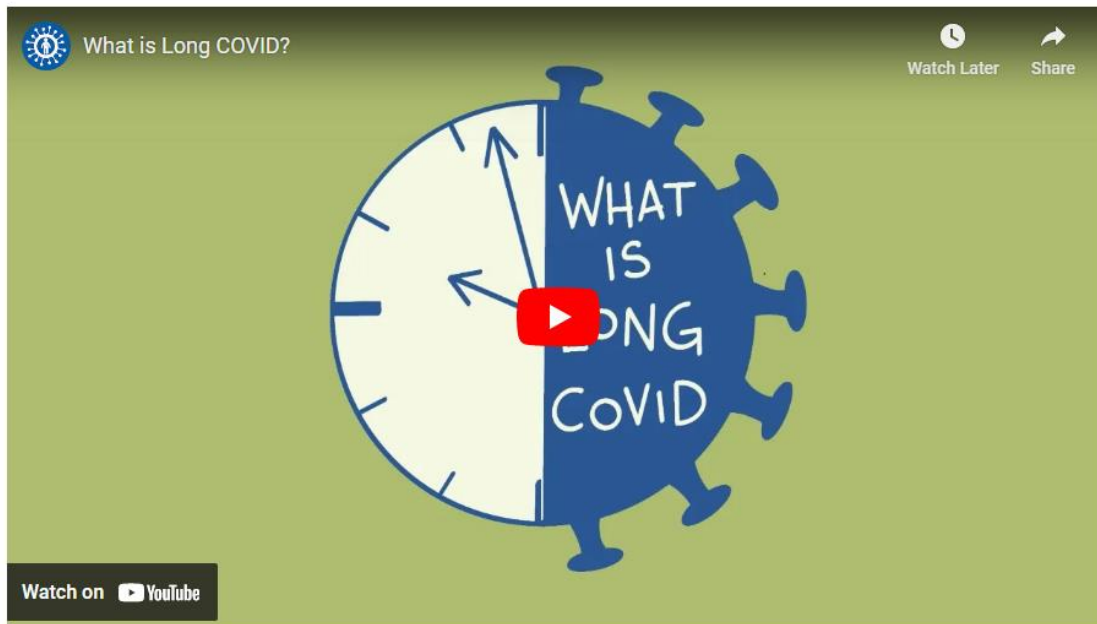
NICE Cautions against graded exercise therapy for patients recovering from COVID-19:

<https://www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-longterm-effects-of-covid19-pdf-51035515742> (March 2022)

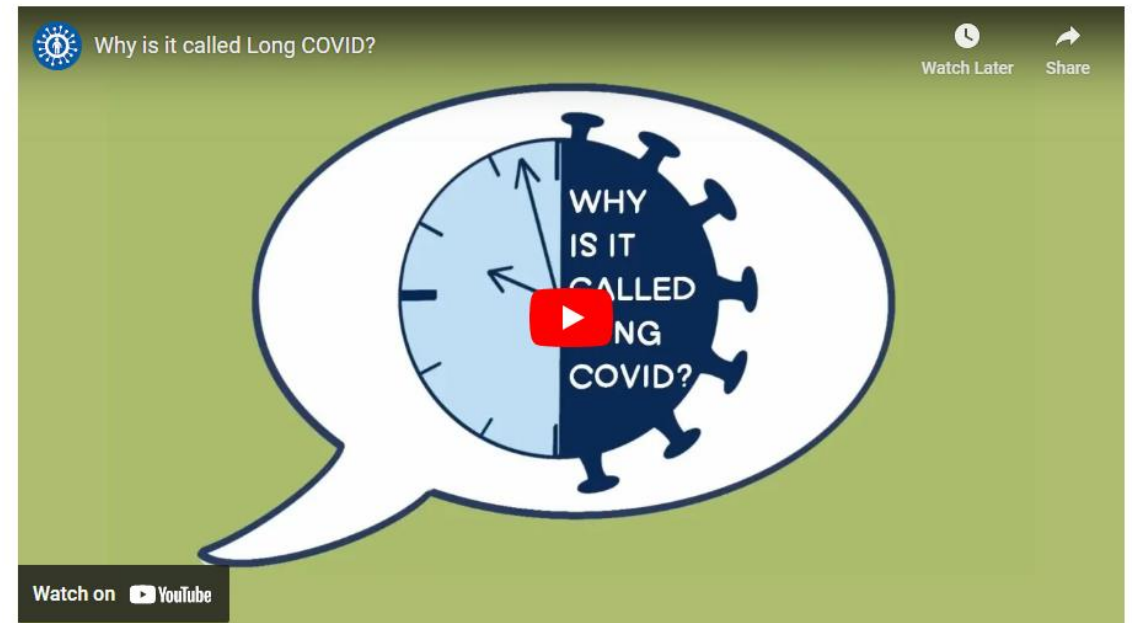


Founded in Nov 2020 - International peer support, education and advocacy, patient-led association of Physiotherapists living with Long COVID and allies.

Work internationally across advocacy, policy, guideline development and research. Education outputs are for anybody living with Long COVID and people wanting to learn more.



<https://tinyurl.com/what-is-long-covid>



<https://tinyurl.com/why-is-it-called-long-covid>

Recommendations on Return to Work

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

DECEMBER 3, 2022

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apists



Association canadienne des ergothérapeutes

Long COVID, Episodic Disability and Labour Force Participation

<https://rehabcovidnetwork.med.utoronto.ca/news/new-policy-brief-long-covid-and-labour-force-participation>

Calls to Action

**for Government, Employers, Human
Resource (HR) Professionals, Insurers
and Benefit Providers:**

**Canada, Ireland, United Kingdom (UK),
United States of America (USA)**

September 2024