Understanding Long COVID

Realize – Disability and Work in Canada Conference,
Episodic Disability and Employment in Canada
Friday December 2, 2022

Rehabilitation Science Research Network for COVID

TEMERTY FACULTY OF MEDICINE
UNIVERSITY OF TORONTO

TemertyMedicine

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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**

World Health Organization, October 2021

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% of adults with confirmed or suspected COVID infection experienced longer term COVID symptoms.
Of those….

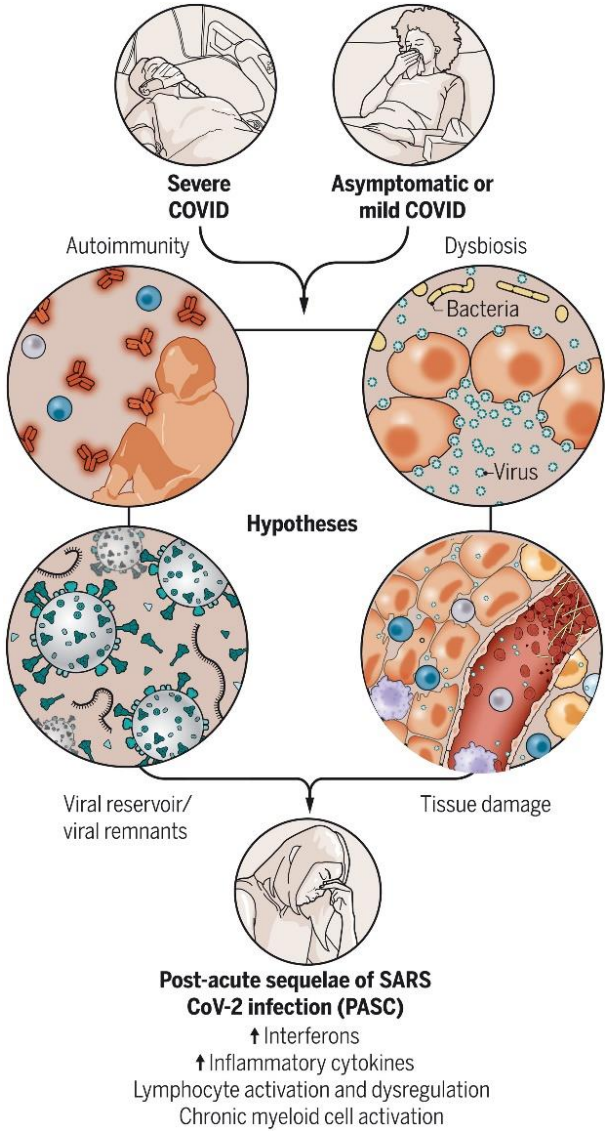
- **47.3%** - experienced symptoms for a year or more
- **21.3%** - indicated their symptoms often or always limited their daily activities.
- **74%** among those employed missed some work or school due to symptoms.

Most common symptoms:
Fatigue, tiredness, or loss of energy (72% of those with self-reported long COVID)
Coughing (39%)
Shortness of breath or difficulty breathing (38%)
Difficulty thinking or problem solving (33%)
General weakness (31%).

With increasing disability there is a role for rehabilitation

https://health-infobase.canada.ca/covid-19/post-covid-condition/

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

Castanares-Zapatero e al, Pathophysiology and mechanism of Long COVID: a comprehensive review. Ann Med. 2022; 1473-1487. https://www.tandfonline.com/doi/full/10.1080/07853890.2022.2076901
Merad et al. The immunology and immunopathology of COVID-19. Science, 375, 6585 (2022); 1122-1127 https://doi.org/10.1126/science.abm8108
Mehandru et al. Pathological sequelae of long-haul COVID. Nature Immunology. 2022; 194-202. https://www.nature.com/articles/s41590-021-01104-y

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

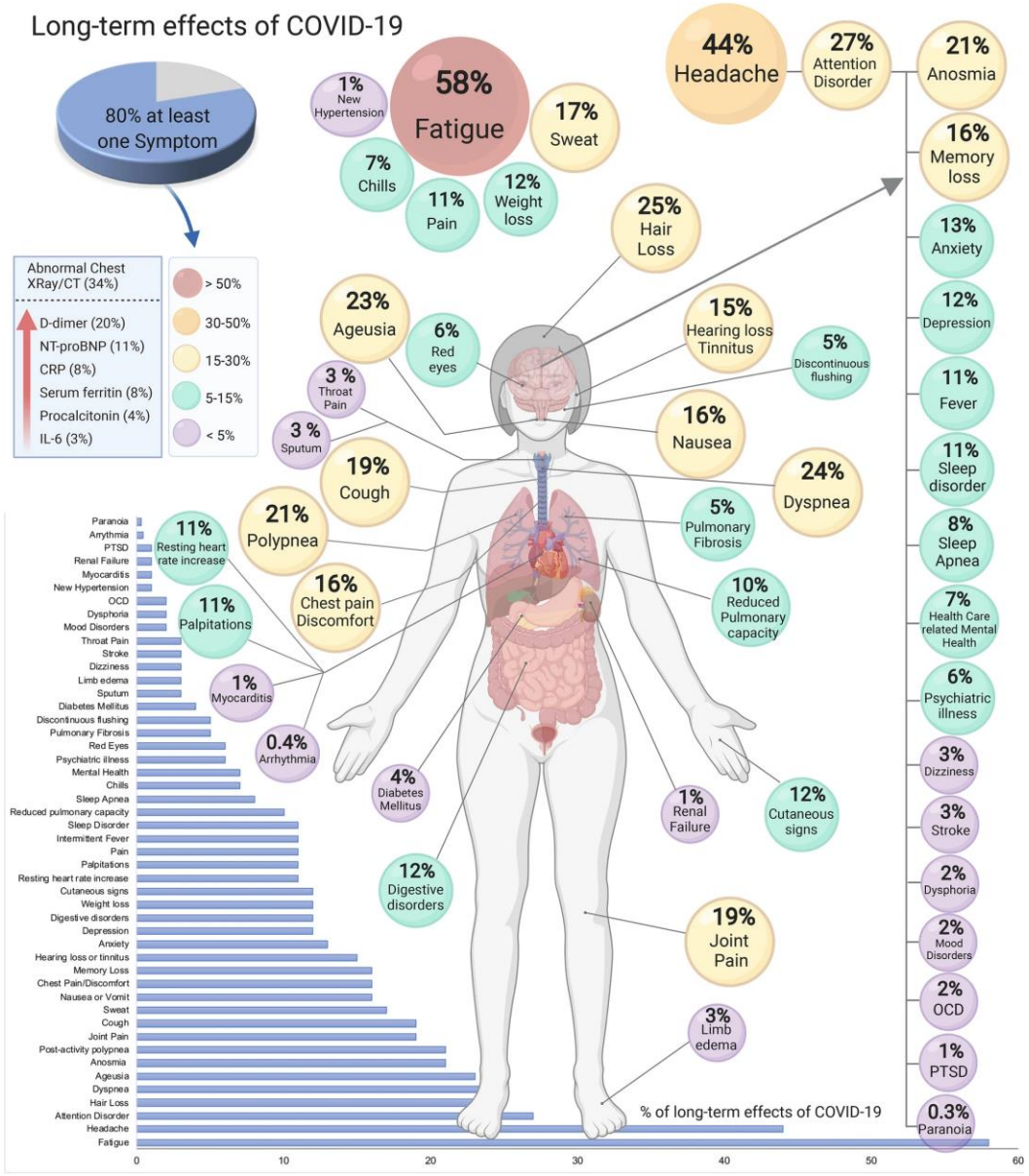
- Anticipate disability and recognize its potentially **episodic nature**
- Understand that disability dimension '**uncertainty** or worrying about the future' may play a role
- Consider stigma, health inequities, social consequences
- Build on existing research networks
- Develop disability and rehabilitation-focused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

1 – Anticipate disability and its potentially episodic nature

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.

Long COVID - Anticipate disability and potential episodic nature



Systematic review and meta-analysis

80% of Covid + have at least one symptom beyond 2 weeks

5 most common symptoms were

- Fatigue
- Headache
- Attention disorder
- Hair loss
- Dyspnea

Multi-system

Develops regardless of initial disease severity

Lopez-Leon, S., Wegman-Ostrosky, T., Perelman, C. et al. More than 50 long-term effects of COVID-19: a systematic review and meta-analysis. Sci Rep 11, 16144 (2021). https://doi.org/10.1038/s41598-021-95565-8

Cognitive Impairment in Long COVID

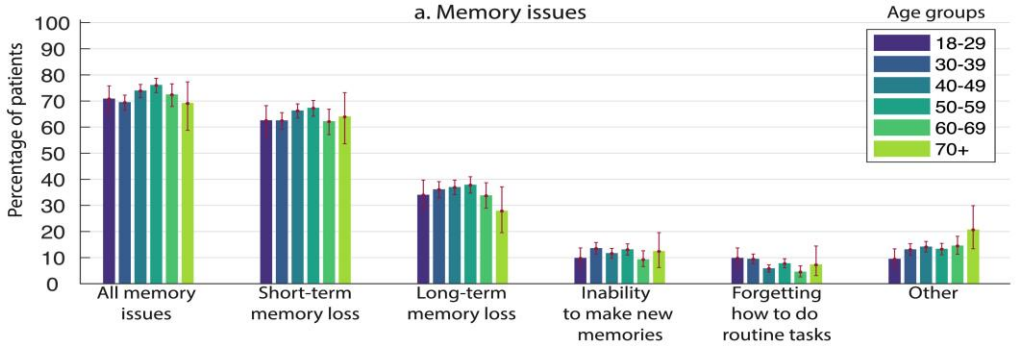
- 9 Neuropsychiatric sub-groups: cognitive dysfunction, speech and language, memory, headaches, smell and taste, sleep, emotion and mood, hallucinations, sensorimotor
  - >85% of participants experienced cognitive symptoms

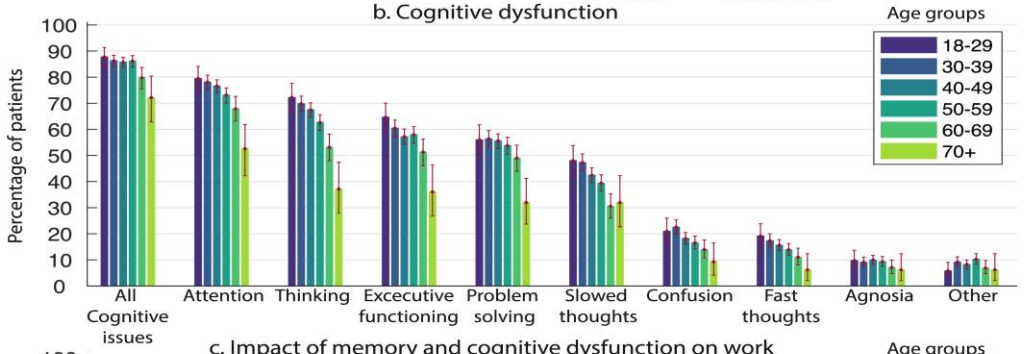
- Patients identified cognitive symptoms as one of the top three most debilitating symptoms (among fatigue and breathing issues)

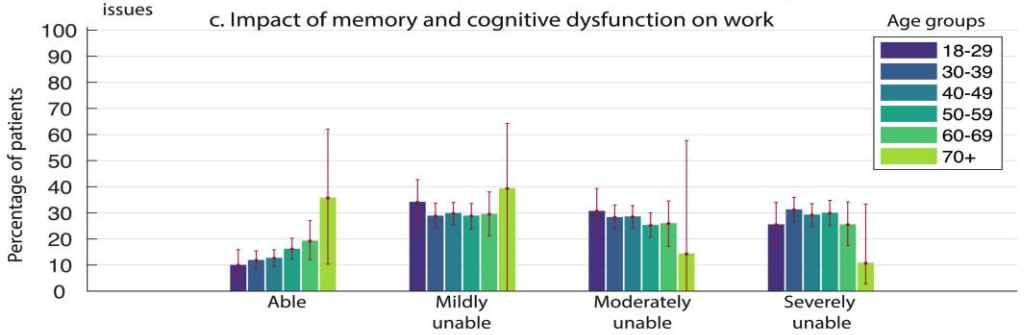
- Cognitive symptoms are persistent

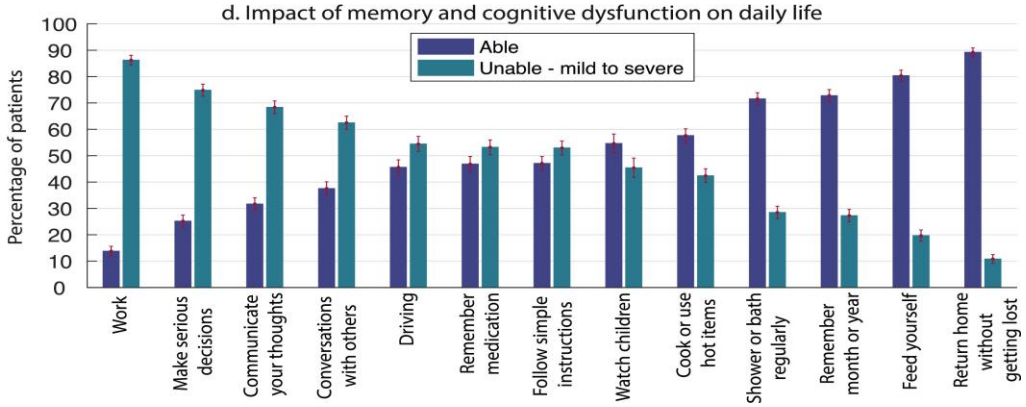
- Cognitive symptoms include: poor attention, executive functioning, problem solving, and decision making

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









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

Community-led online survey with people with suspected (n=2742) or confirmed (n=3762) covid-19 with illness lasting over 28 days and onset prior to June 2020.
Data collected from Sept-Nov 2020 across 56 countries.

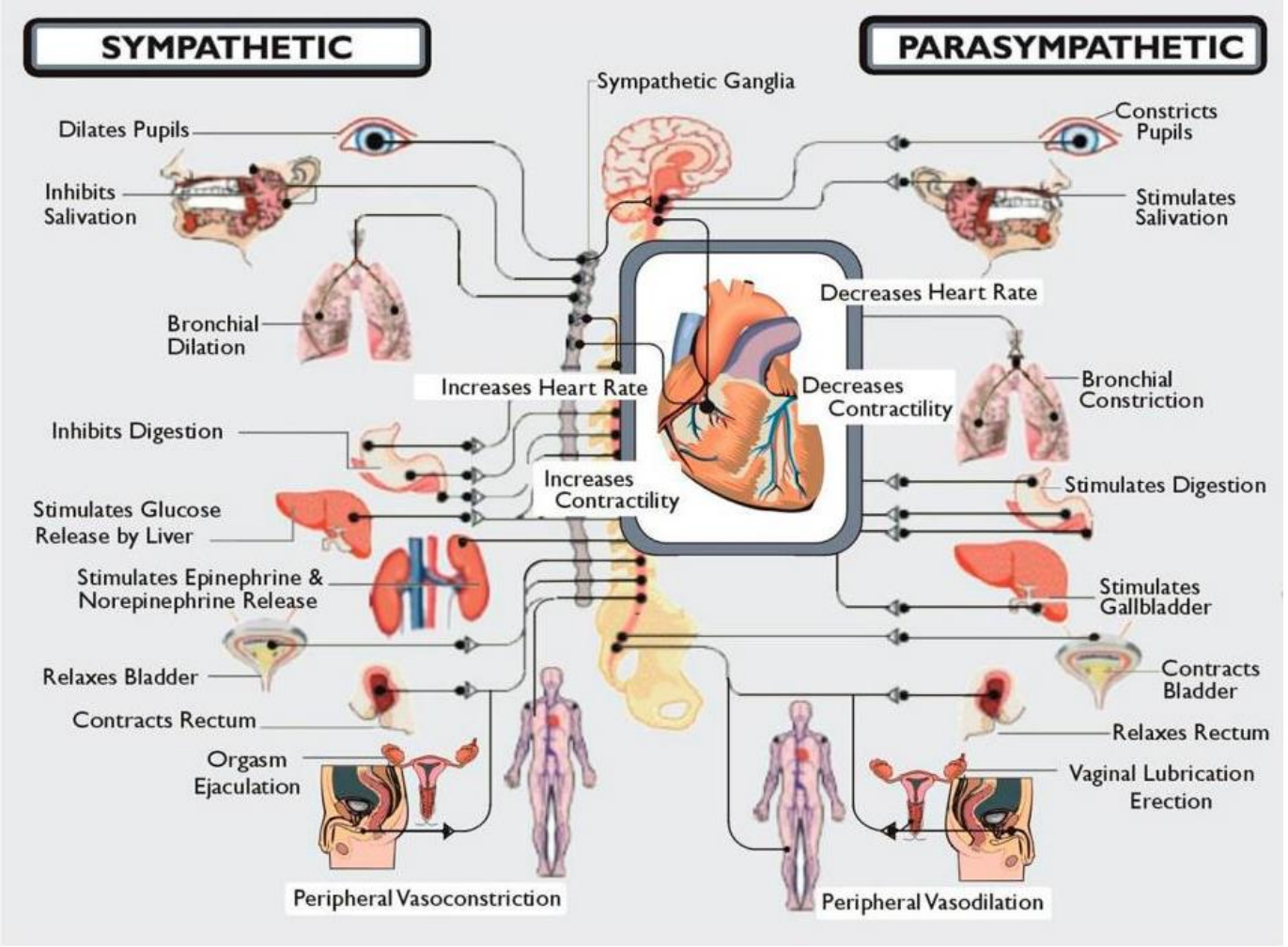
- More than 91% - time to recovery >35 weeks.
- Average of 56 symptoms across 9 organ systems.
  - Fatigue
  - PEM
  - Cognitive dysfunction
- 86% experienced relapses
  - Triggers: exercise; physical or mental activity; stress.

Among unrecovered

- 27% were working as many hours as they were prior to becoming ill at the time of survey
- 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.

Post Exertional Malaise (PEM) Post Exertional Symptom Exacerbation (PESE)

- When symptoms such as disabling fatigue or exhaustion, difficulty thinking, pain, and exercise intolerance are made worse by exertion, this is called post-exertional symptom exacerbation.
- Post-exertional symptom exacerbation (PESE) may also be called post-exertional malaise (PEM).
- Can be triggered by any physical, cognitive, mental or emotional exertion, and varies among different people.
- The worsening of symptoms by exertion can happen immediately or can happen 24-72 hours after exertion.
- *Myalgic Encephalomyelitis community



Dysautonomia

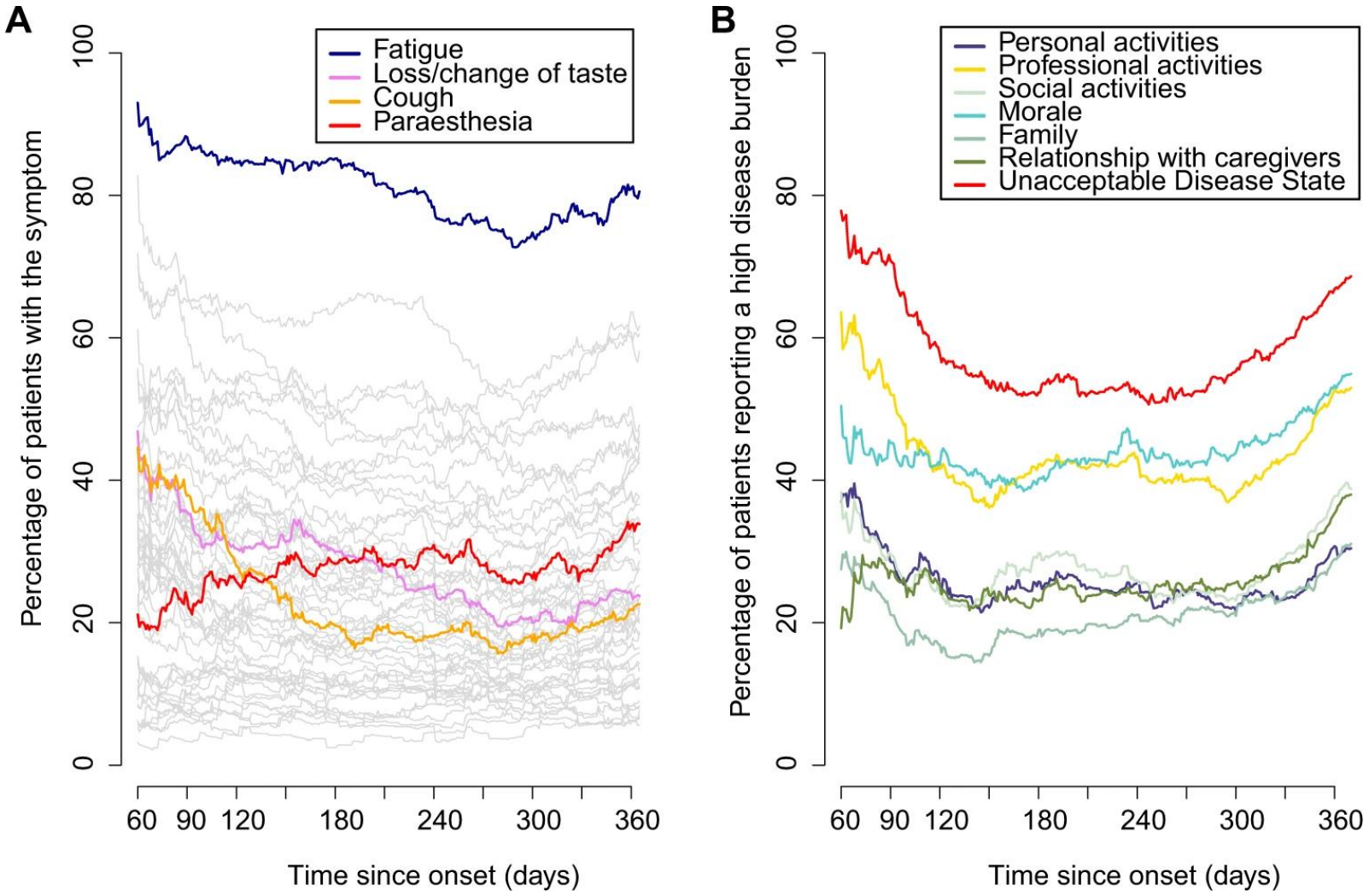
- Malfunction of the autonomic nervous system
- Affects 70 million people worldwide
- Symptoms include: lightheadedness, breathlessness, fatigue, digestive dysfunction, abnormal heart rates, syncope

Postural orthostatic tachycardia syndrome (POTS)

- Postural orthostatic tachycardia syndrome
- Abnormal increase in heart rate upon standing
- Diagnostic criteria is increase of 30bpm or over 120bpm within first 10 minutes of standing
- Symptoms include fatigue, headaches, lightheadedness, heart palpitations, exercise intolerance, nausea, cognitive dysfunction, chest pain and shortness of breath

Long COVID – Potential episodic nature

Persistent symptom burden over time.



Among patients symptomatic after 2 months, 85% still reported symptoms one year after their symptom onset.

Relapsing and remitting

Tran, VT., Porcher, R., Pane, I. et al. Course of post COVID-19 disease symptoms over time in the ComPaRe long COVID prospective e-cohort. Nat Commun 13, 1812 (2022). https://doi.org/10.1038/s41467-022-29513-z

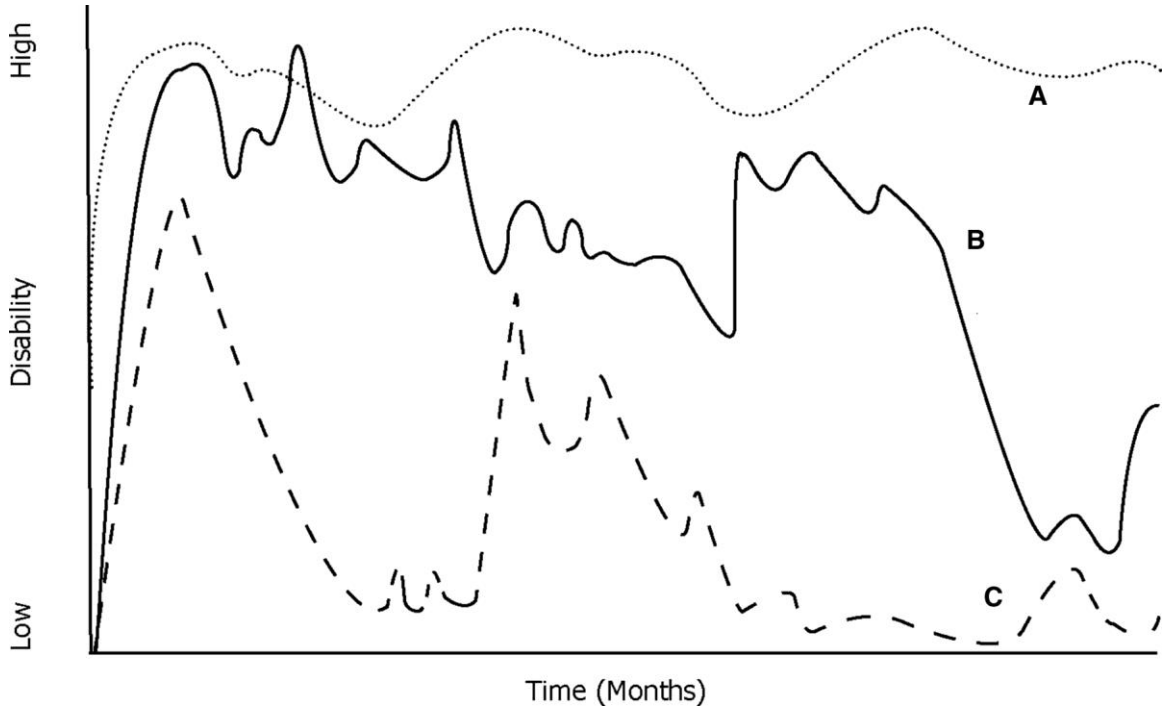
In Canada – Long COVID Impact Survey

- Survey May 2021
- 1,048 respondents with Long COVID from 10 provinces and 3 territories.
- Participants ranged in age from under 18 to over 90.
  - **Nearly 60% were aged 40 to 59.**
- More than 87% of respondents identified as women.
- Before having COVID-19,
  - nearly 63% of respondents did not have a long-term health condition.
- More than **85%** of participants were not admitted to hospital during their initial infection.
- Nearly **70%** of respondents had to take leave from work.
- **More than half had to reduce working hours with 74% reducing their working hours by 50% or more**.

Report on Pan-Canadian Long Covid Impact Survey June 8th 2021. Viral Neuro Exploration (VINEx), COVID Long-Haulers Support Group Canada, and Neurological Health Charities Canada. https://imgix.cosmicjs.com/d8d3d3b0-c936-11eb-ba89-e7f98c8c358b-FINAL---Report-on-Long-Covid-Impact-Survey---June-8-2021.pdf

Conceptualising Long COVID as an Episodic Health condition

Examples of potential trajectories of episodic disability in people living with Long COVID.



Fluctuating
Relapsing and remitting
Dynamic
Potential unpredictability

Episodic ≠ total health or total illness
not all or nothing
not all good or all bad
not on or off

Brown DA, O'Brien KK, 2021. Conceptualising Long COVID as an episodic health condition. BMJ Global Health
https://gh.bmj.com/content/6/9/e007004

2- Understand that disability dimension ‘uncertainty or worrying about the future’ may play a role

Uncertainty is a key dimension of disability

Disability Uncertainty

- Uncertainty of when an episode of disability might arise, source of symptoms, triggers, the severity and duration of that episode and the long-term implications on health are unknown; spans disability dimensions and contextual factors

Diagnostic uncertainty

- Diagnostic clarity of Long COVID can be difficult to ascertain, particularly for those without a COVID-19 PCR, antigen or antibody test; uncertainty of cause.

Financial and Housing Uncertainty

- Uncertainty about if/when/how able to return to workforce.

Uncertainty among health care providers

- How to assess and treat.

Uncertainty among employers, HR professionals

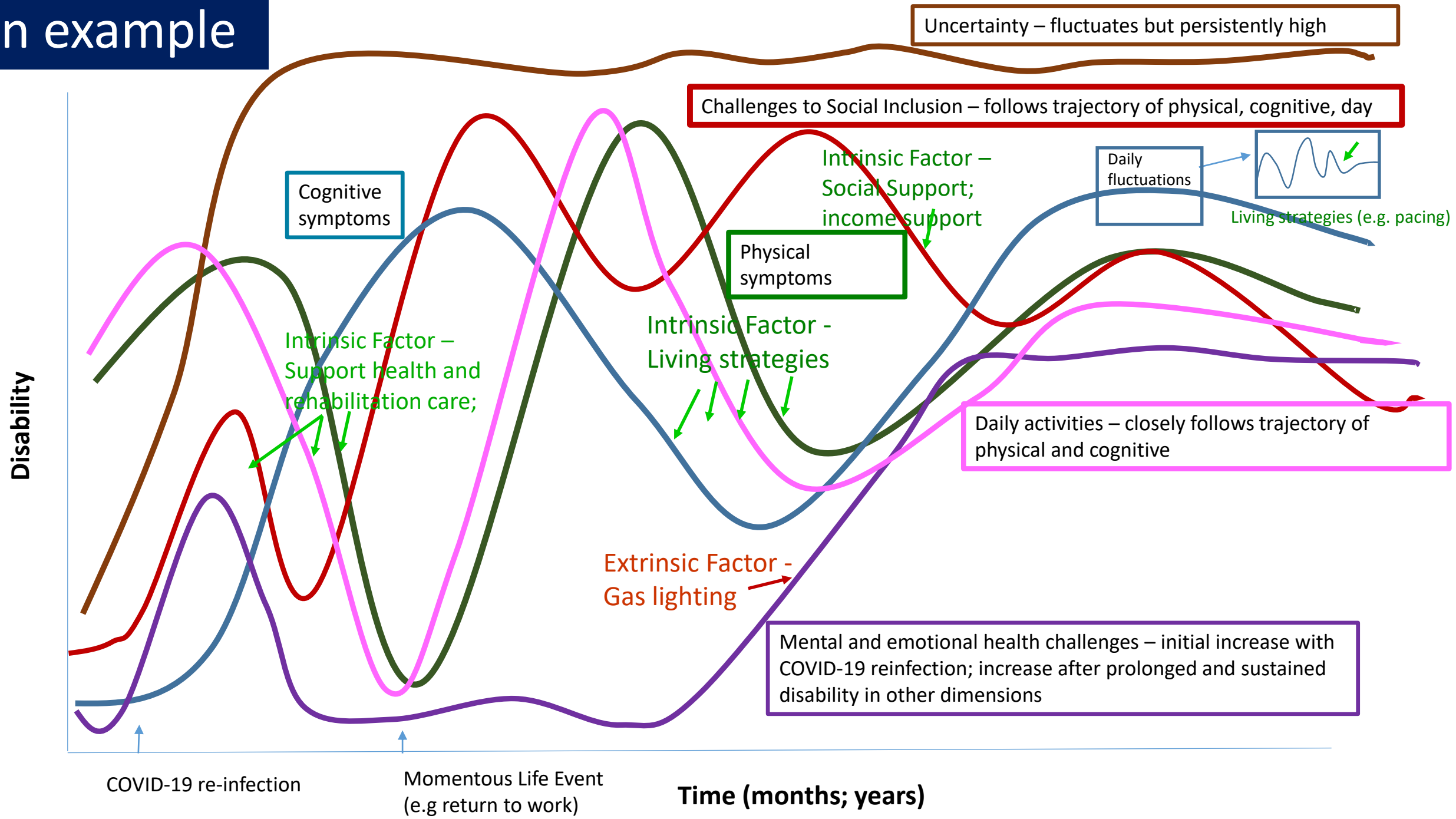
- How to accommodate, RTW programming

Uncertainty of Long Term Trajectory & Recovery

- What will trajectory of Long COVID be over time; Will it improve? not improve? access to treatment and support? Long term impact (e.g. family planning, future health)

Acknowledging uncertainty in the context of COVID-19 may improve capacity for self-management and improve outcomes.

An example


Uncertainty – fluctuates but persistently high
Challenges to Social Inclusion – follows trajectory of physical, cognitive, day
Cognitive symptoms
Physical symptoms
Intrinsic Factor – Social Support; income support
Daily fluctuations
Living strategies (e.g. pacing)
Intrinsic Factor – Support health and rehabilitation care;
Intrinsic Factor - Living strategies
Daily activities – closely follows trajectory of physical and cognitive
Extrinsic Factor - Gas lighting
Mental and emotional health challenges – initial increase with COVID-19 reinfection; increase after prolonged and sustained disability in other dimensions
Disability
COVID-19 re-infection
Momentous Life Event (e.g return to work)
Time (months; years)

Long COVID and Episodic Disability Study

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 [1,2,3,4] Darren A Brown [5,6] Colm Bergin [7,8]
Kristine M Erlandson [9] Jaime H Vera [10,11] Lisa Avery [12,13]
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Richard Harding [17] Lisa McCorkell,[18] Margaret O'Hara,[19] Larry Robinson,[20]
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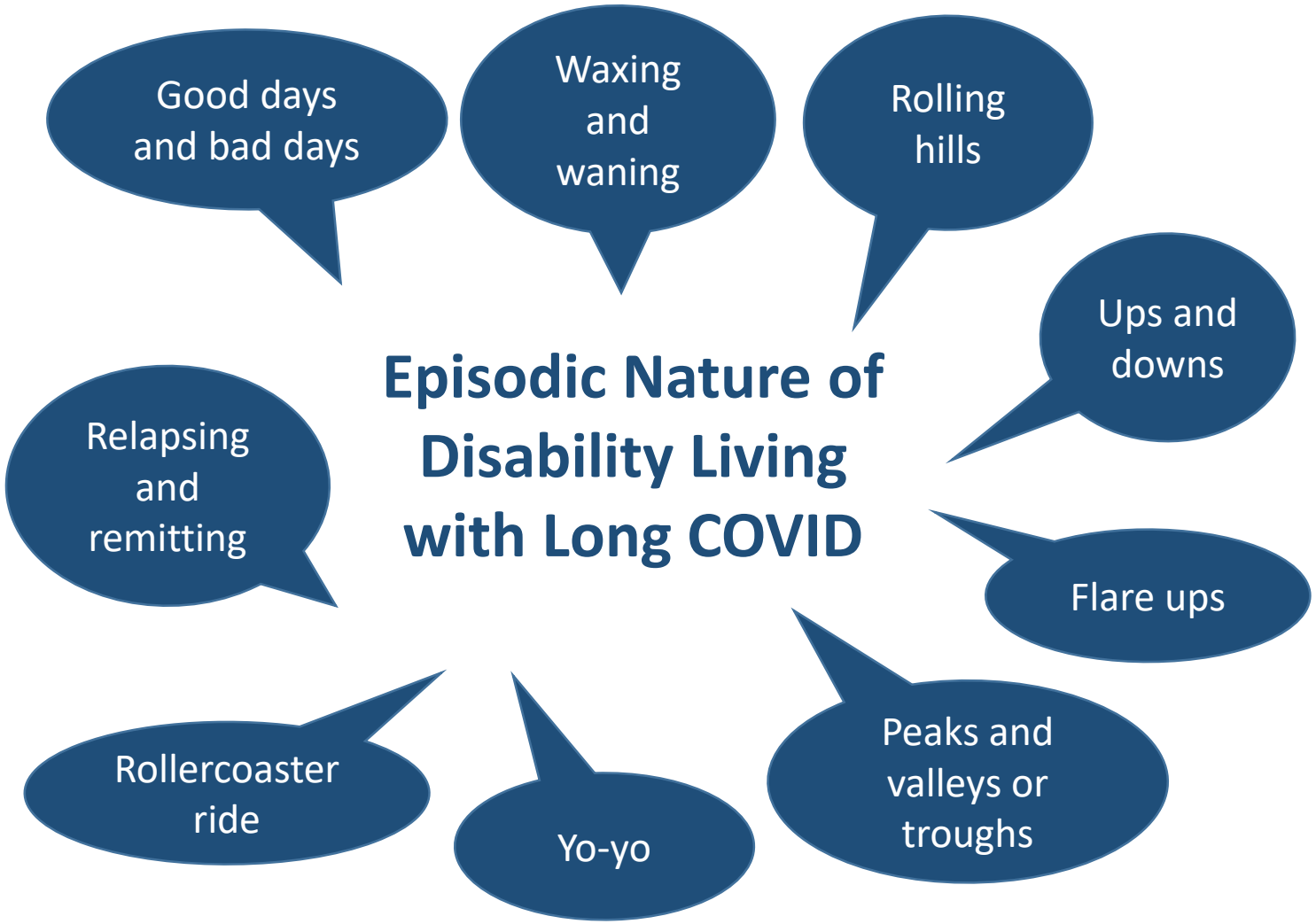
CIHR IRSC
Canadian Institutes of Health Research / Instituts de recherche en santé du Canada

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

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

Characterizing the Episodic Nature of Long COVID



Methods

Semi-structured interviews

40 adults living with HIV

- Canada
- United Kingdom
- United States
- Ireland

Participants

Median age: 39 years

63% female

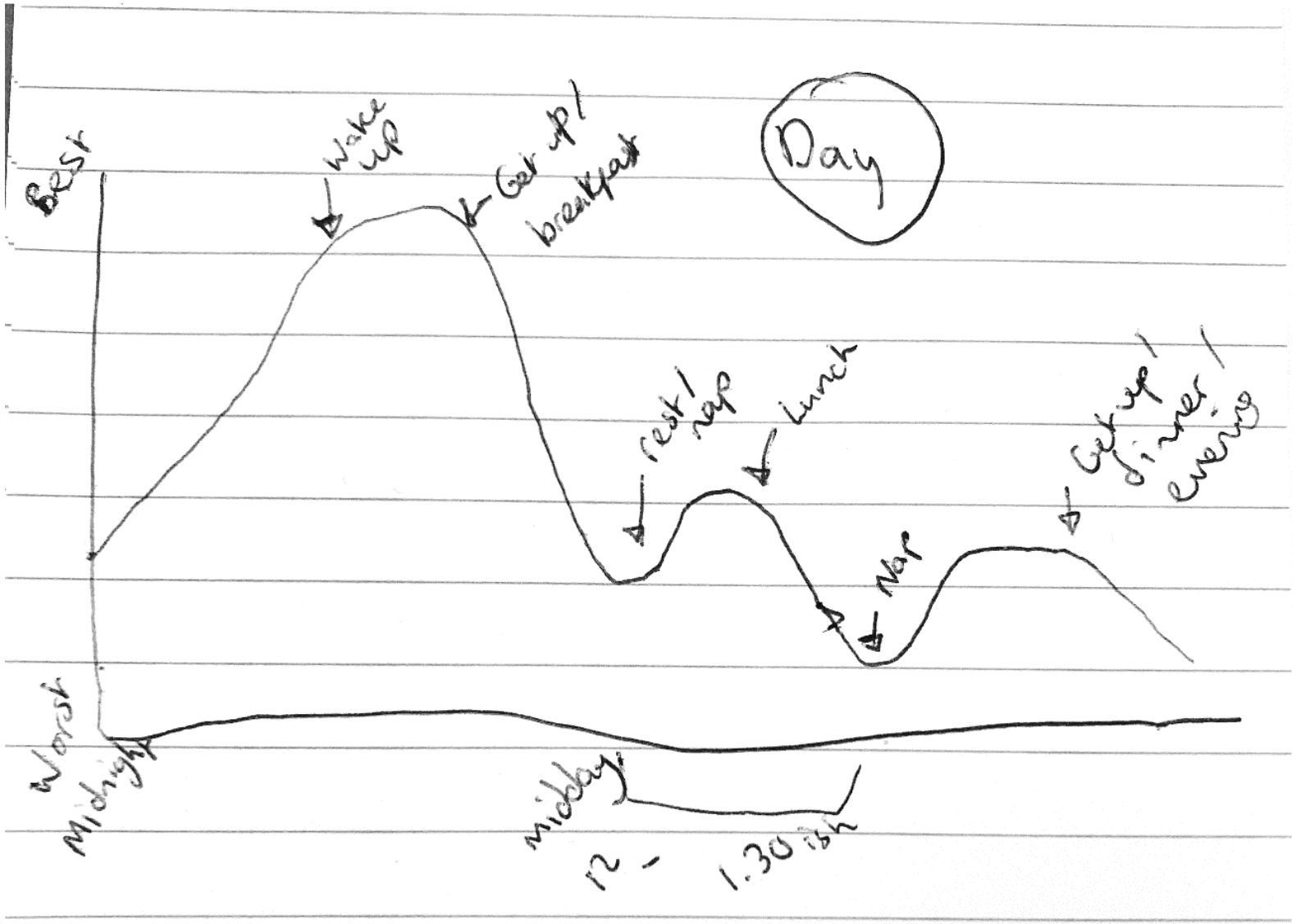
50% unable to work

83% living with Long COVID ≥1 year

93% experienced relapse in symptoms

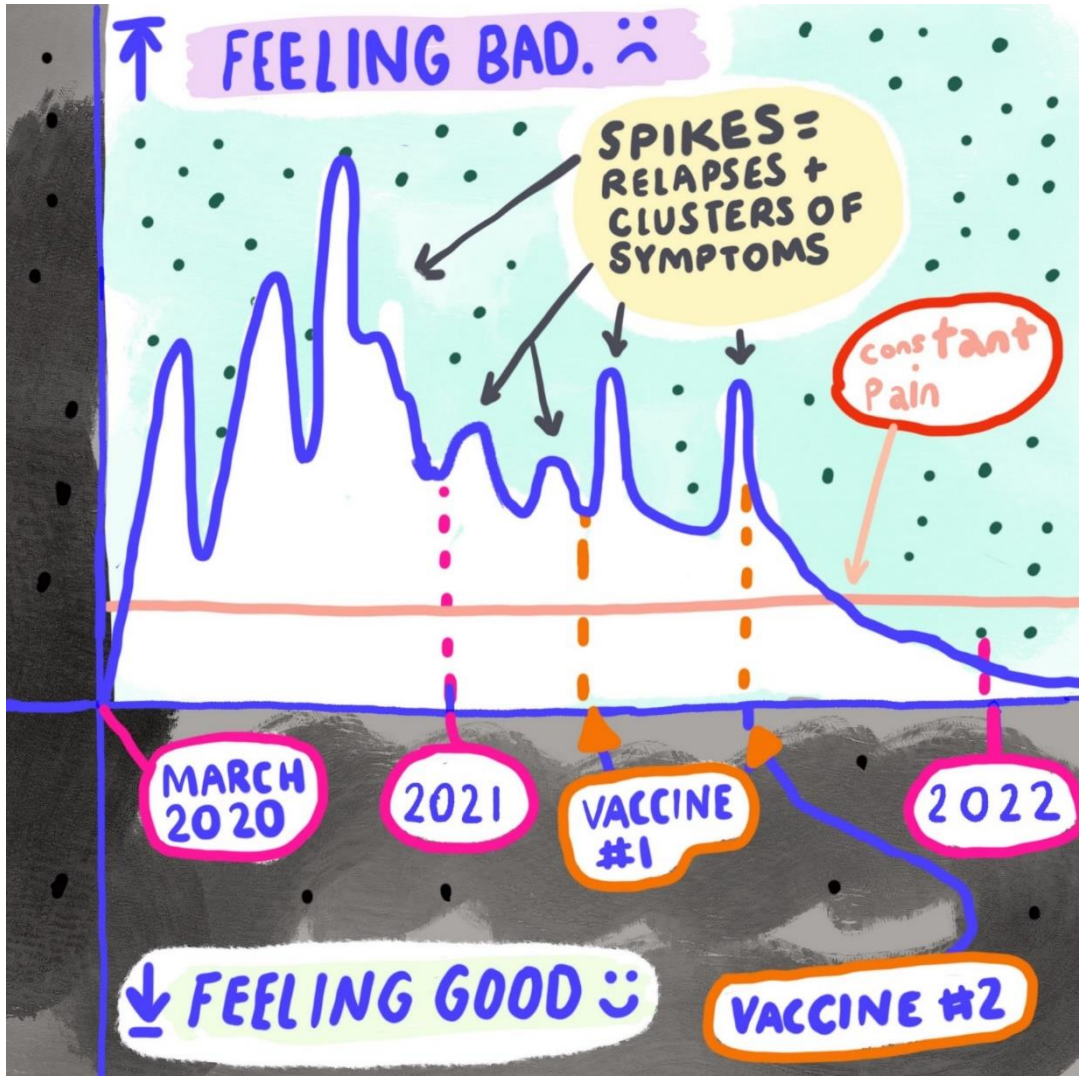
Timeframe of Episodes – Daily or within the day

Episodic Disability – within a day



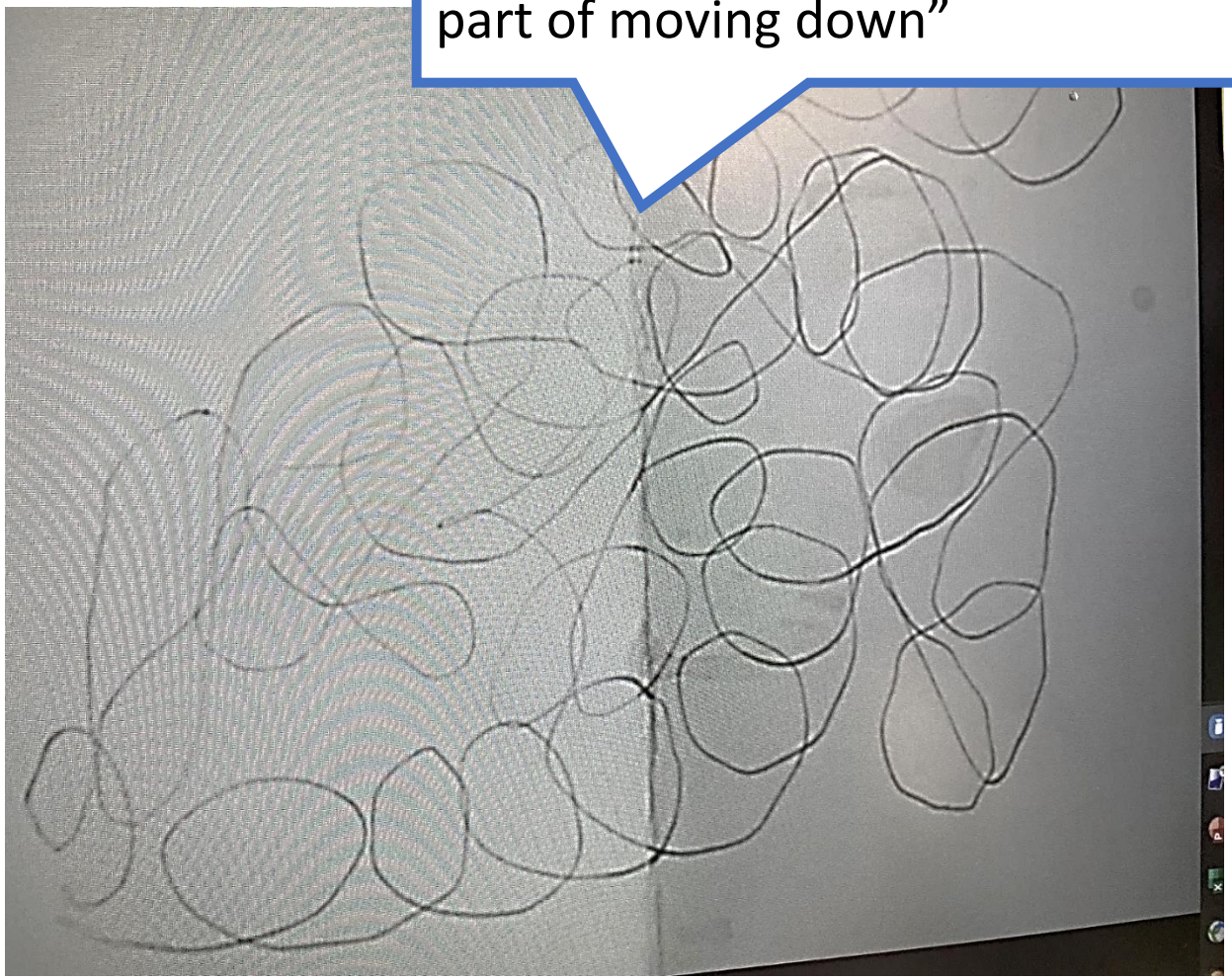
Timeframe of Episodic Disability

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 of Disability: Social Inclusion

Participants described a wide range of impacts of Long COVID on social inclusion:

- Challenges engaging in leisure activities
- Social isolation
- Challenges/impact on relationships
- Challenges fulfilling caregiver roles
- Financial instability and financial burden of living with Long COVID
- Challenges engaging in work/employment or school

- Many participants unable to return to work
- Unable to meet physical and/or cognitive demands of the work
- Impairments to communication (cognition) made it difficult to perform well at work or in job interviews
- Catch 22 of needing to work to support oneself financially, while also needing time away from work to focus on taking care of one's own health and well-being
- Some participants had a sense of loss/grief around their job/careers

Extrinsic Contextual Factor: Social Support

FINANCIAL/ECONOMIC/INCOME SUPPORTS

- Navigating the maze of income support
- Heightened uncertainty surrounding eligibility for income support when unable to engage in employment
- Having access to income support and financial support was a source of 'peace of mind' (greater certainty)
- Those without a positive PCR test faced additional challenges accessing health and disability support

"The harshest period by far was when I was waiting for my disability, my long term disability leave to be approved and when I had already run out of my sick bank. So that meant no income. That meant no benefits**. That meant a question mark whether the disability would be approved. So **that was full on trauma. That was losing cognitive functioning, not brain fog, fully losing cognitive functioning due to that level of stress. That was multiple trips to emergency due to the effects of the extreme stress."

Extrinsic Contextual Factor: Social Support

SUPPORT FROM EMPLOYERS, HR PROFESSIONALS, WORK COLLEAGUES

- Support from employers for those unable to work
  - Offering flexible return to work models
  - Flexible hours
  - Work from home (if applicable)

- Lack of flexibility = you can work or you can get better

> *"People who have disabilities, it's not that we don't want to work. It's that we really can't and so* ***we need things that are tailored to us and have that flex time*** *and stuff like that…* ***I can only do maybe a max of 10 hours a week if that. But through all that I'm still trying...*** *it's taken a long time to find things but I'm still trying to find even that so that I can earn that little bit of extra income because I know even for me and part of it…****feeling useful in society****. Like I like to feel at least useful and helpful to people. So* ***I haven't given up*** *in trying to find at least a little bit of something but it's still I could never support myself."*

So what does this mean for employment & return to work?

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.

Topic 16 Return to everyday activities and 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-2022.2

In summary

- Disability – multidimensional; episodic
- Uncertainty – key component
  - Impact on social engagement, work, relationships, financial security
- Lessons learned from HIV providing a foundation
- Community engaged approaches are key
- Important implications for return to work
  - Guidelines on Long COVID management
  - Role for Rehabilitation

LONG COVID PHYSIO

https://longcovid.physio/long-covid-video-series

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PATIENT-LED RESEARCH COLLABORATIVE

LONG COVID PHYSIO

LONG COVID SUPPORT

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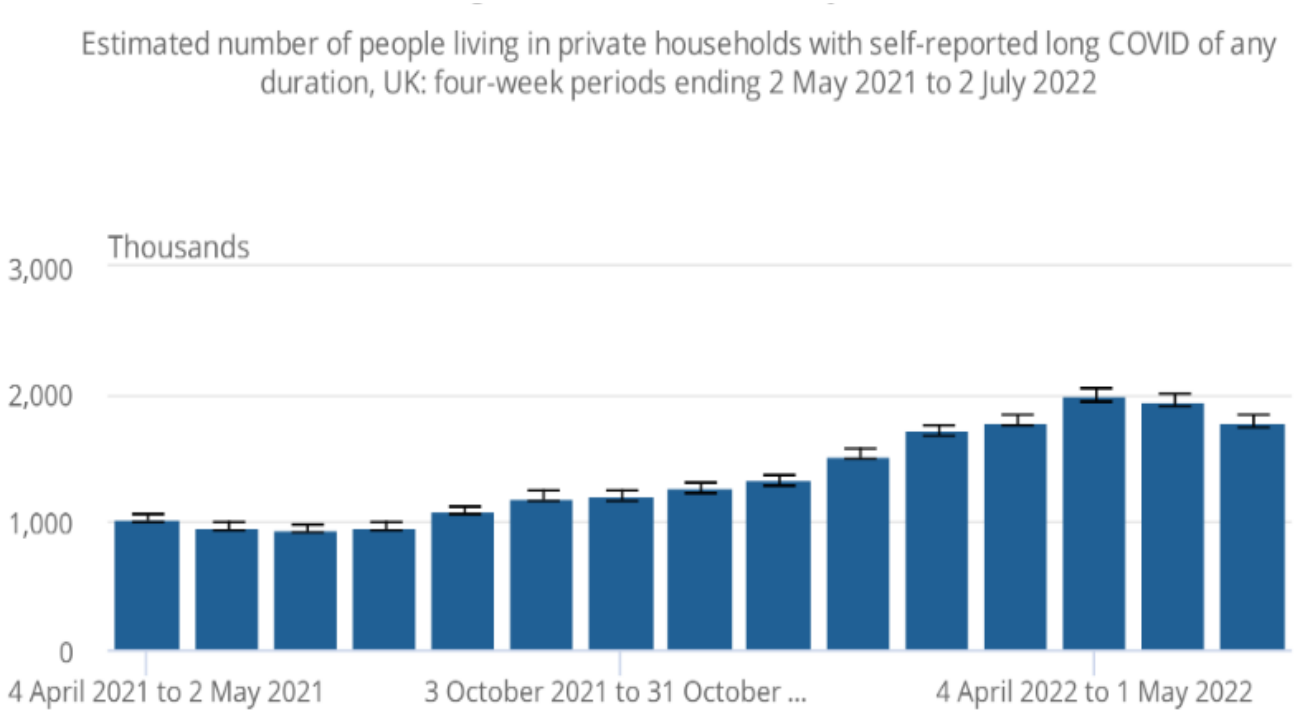
As of September 1, 2022: 2.0 million people in the UK were experiencing self-reported long COVID



Office for National Statistics

"Would you describe yourself as having 'long COVID', that is, you are still experiencing symptoms more than 4 weeks after you first had COVID-19, that are not explained by something else?"

Most common symptoms:
Fatigue (62% of those with self-reported long COVID),
Shortness of breath (37%)
Difficulty concentrating (33%)
Muscle ache (31%).

Disproportionally affects – higher prevalence:

- people aged 35 to 69 years
- females
- people living in more deprived areas
- working in social care
- those with another activity-limiting health condition or disability.

Develops regardless of initial disease severity or type of variant

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1september2022