

Myalgic Encephalomyelitis as a Public Health Challenge

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Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome"

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Elimination = Epidemiology 101

- Modeling (e.g., Kelso et al., BMC Public Health, 2013): **delayed response multiplies both economic cost, morbidity, and mortality**
- Flu 1918, SARS 2003, H1N1 2009, COVID-19: early suppression → highest GDP recovery + lowest excess morbidity and mortality



Image: ChatGPT



Elimination → best for public health, economy, and civil liberties

- SARS-CoV-2 elimination, not mitigation, creates best outcomes for health, the economy, and civil liberties; Miquel Oliu-Barton et al., Lancet, 2021

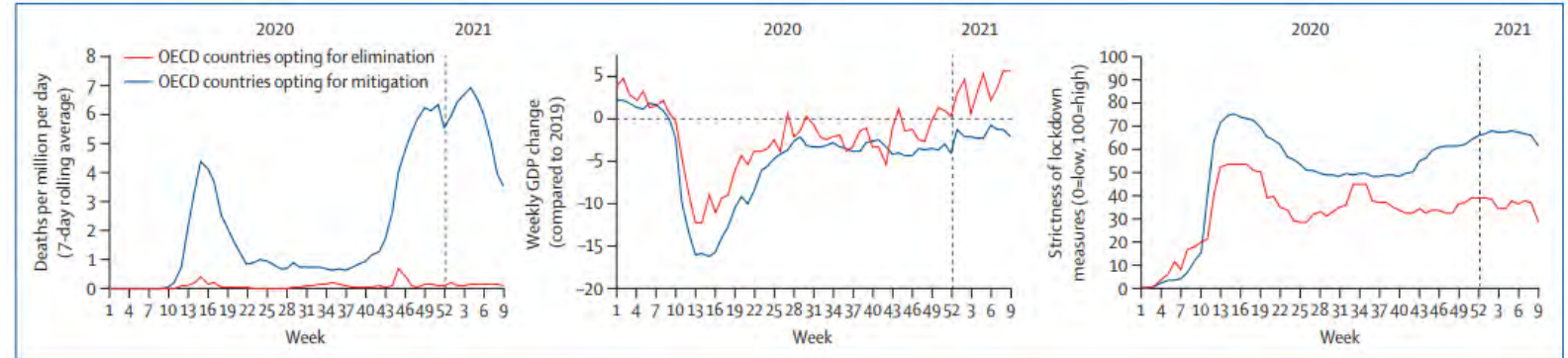
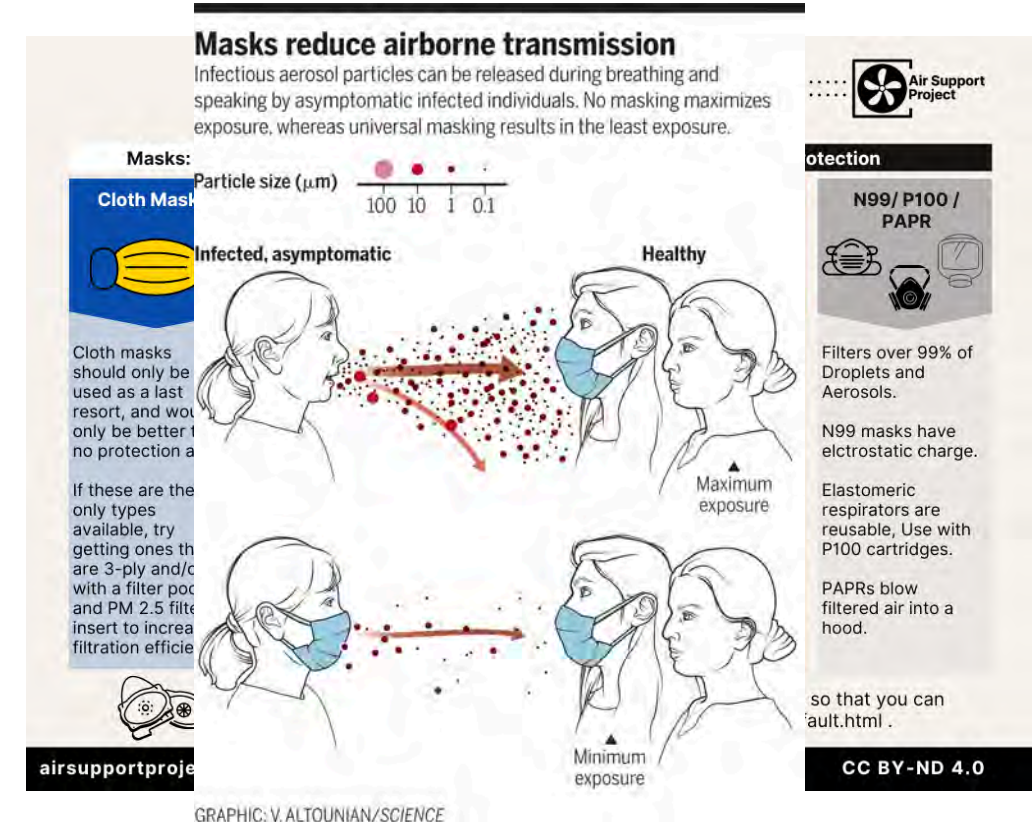


Figure: COVID-19 deaths, GDP growth, and strictness of lockdown measures for OECD countries choosing SARS-CoV-2 elimination versus mitigation
OECD countries opting for elimination are Australia, Iceland, Japan, New Zealand, and South Korea. OECD countries opting for mitigation are Austria, Belgium, Canada, Chile, Colombia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Latvia, Lithuania, Luxembourg, Mexico, the Netherlands, Norway, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey, the UK, and the USA. Data on strictness of lockdown measures are from Oxford COVID-19 government response tracker.² Data on COVID-19 deaths are from Our World in Data.³ Data on GDP growth are from OECD Weekly Tracker of economic activity.⁴ GDP=gross domestic product. OECD=Organisation for Economic Co-operation and Development.



Elimination = Epidemiology 101

- WHO and CDC pandemic plans:
- **Comprehensive contact tracing** (*forward and backward*); effective isolation and quarantine
- **Aerosol control: *masking, ventilation, air filtration, avoidance of crowding***
- Temporary border measures and travel restrictions
- Targeted social distancing measures
- SARS 2003: controlled within 8 months, global elimination within 2 years



Aerosols, not surfaces

Droplets and surfaces are very convenient for people in power - all of the responsibility is on the individual.

On the other hand, if you admit it is airborne, institutions, governments and companies have to do something.

- Jose-Luis Jimenez -



"Criminal incompetence"



"The level of criminal incompetence exposed by recent witnesses to the UK COVID-19 Inquiry...has proven that many, if not most, of over 230 000 deaths were preventable."

See Comment page 1735

World Report

Sudan facing humanitarian crisis of "epic proportions"
See page 1738

Articles

Endovascular thrombectomy for acute ischaemic stroke
See page 1751

Articles

Methotrexate to treat hand osteoarthritis with synovitis
See page 1764

Articles

Amisulpride for irritable bowel syndrome
See page 1773

Viewpoint

β blockers switched to first-line therapy in hypertension
See page 1782

- UK COVID inquiry: High incidence strategy is "criminal incompetence"
- "Historical catastrophe" based on "disastrous groupthink" (Dominic Cummings, Boris Johnson's advisor)



Biosafety Level 3 virus circulating freely in schools



In the laboratory, SARS-CoV-2 is a level 3 biological hazard [like anthrax, yellow fever, malaria, West Nile virus, tuberculosis].

In schools, the virus is not an issue. I don't think these two statements are compatible with each other.

(Colin Furness, epidemiologist; "Most N.B. schools that tested high for CO₂ , still lack proper ventilation, data reveals")



"I currently expect that between twenty and forty thousand people in Switzerland will die from COVID-19. Perhaps 5 percent will suffer permanent health damage for months or for the rest of their lives."

Dr. André Seidenberg, NZZ 10/27/2020

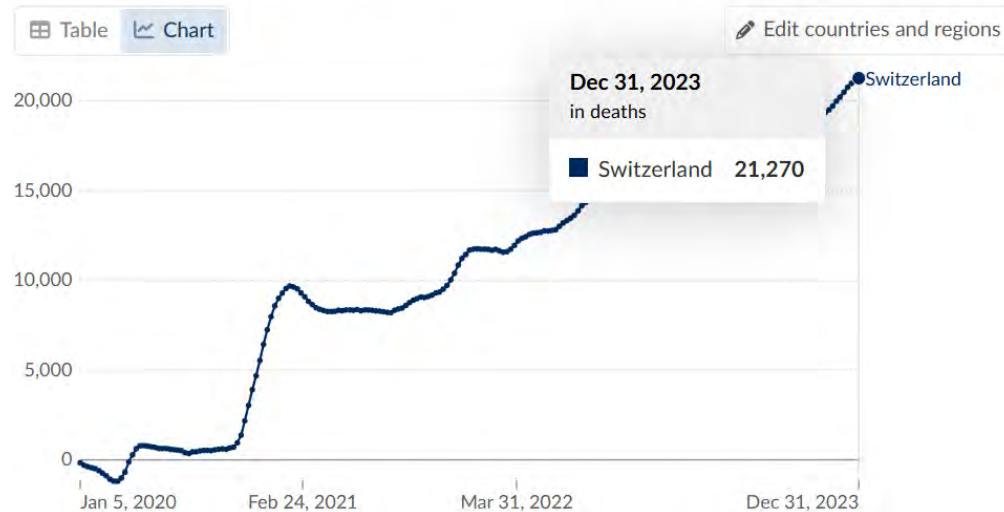


Continuing excess mortality

Excess mortality: Cumulative deaths from all causes compared to projection based on previous years

The cumulative difference between the reported number of deaths since 1 January 2020 and the projected number of deaths for the same period based on previous years.

Our World
in Data



- Until December 31, 2023: excess mortality of 21,270
- >10,000 after lifting of all protective measures April 2022
- Extrapolated excess mortality Switzerland: approximately 27,940 until end of 2025



COVID-19 as a multisystem risk factor

Impact of reinfections from COVID

on hazard ratio from various conditions,
US Veterans Affairs population

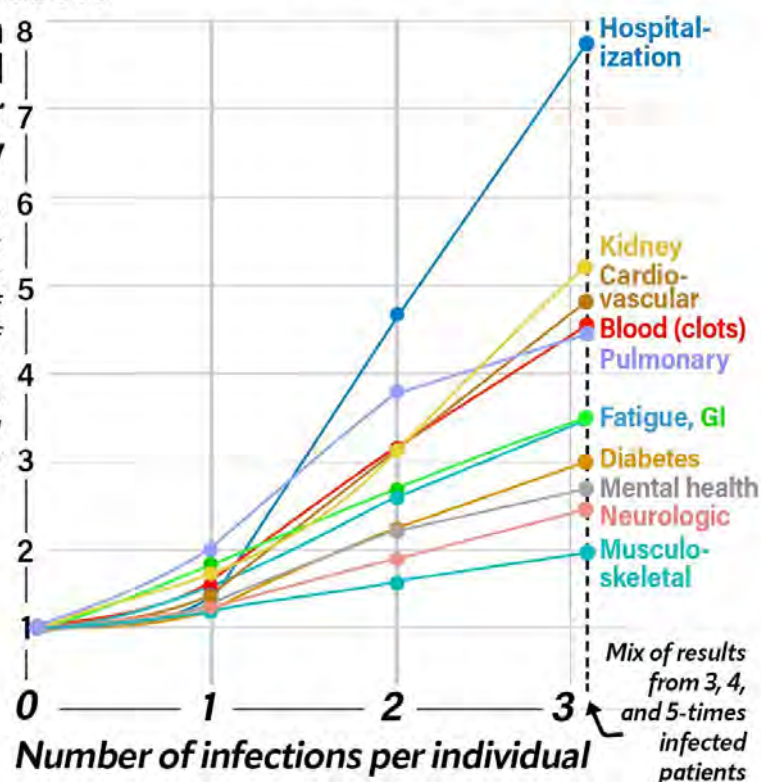
Excess risk above
that which
would
occur
naturally

(Hazard ratio
for specific
condition as
a function of
number of
reinfections,
compared to
uninfected
individuals)

Table recreated
proportionally;
please refer
to original
for maximum
accuracy

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Graphic Design
angiecibis.com



Source: Acute and postacute sequelae associated
with SARS-CoV-2 reinfection, Al-Aly et al., 2022

Bowe B, Xie Y, Al-Aly Z. Acute and postacute
sequelae associated with SARS-CoV-2
reinfection. Nat Med. 2022;28(11):2398-2405.
doi:10.1038/s41591-022-02051-3



COVID-19 increases risk of HPV-related cancer

Table 2 HRs and 95% CIs for the risk of HPV-related cancers and carcinoma in situ according to the status of COVID-19 infection ($n=1,281,997$)

	Patients with outcome (n)		HR(95% CI)	
	SARS-CoV-2 infection	Non-SARS-CoV-2 infection		
Cervical carcinoma in situ	3007	2270	1.336 (1.266,1.411)	
Vaginal carcinoma in situ	169	106	1.609 (1.262,2.052)	
Vulva carcinoma in situ	974	565	1.738 (1.567,1.927)	
Anal carcinoma in situ	270	139	1.960 (1.598,2.405)	
Oropharyngeal carcinoma in situ	124	70	1.783 (1.330,2.390)	
Cervical cancer	1123	679	1.674 (1.521,1.841)	
Vaginal cancer	217	95	2.313 (1.817,2.944)	
Vulva cancer	943	481	1.986 (1.779,2.216)	
Anal cancer	427	225	1.921 (1.634,2.257)	
Oropharyngeal cancer	124	70	1.783 (1.330,2.390)	



4.8 million female patients

Over a 3-year follow-up period, after SARS-CoV-2 infection significantly higher risks of developing HPV-related cancers

+ 67% cervical cancer

+ 131% vaginal cancer

+ 98% vulvar cancer

+ 92% anal cancer

+ 78% oropharyngeal cancer

Shih YH, Yang CY, Lung CC. SARS-CoV-2 infection heightens the risk of developing HPV-related carcinoma in situ and cancer. *Discov Oncol.* 2025;16(1):1552. Published 2025 Aug 14. doi:10.1007/s12672-025-03403-4



Increase in congenital heart disease

- COVID-19 in pregnancy: pathological heart ultrasound among neonates 10.08%, control group 4.13% ($p = 0.012$)
- Critical: up to 8 weeks after gestation
- Significant rise in congenital heart disease since the pandemic

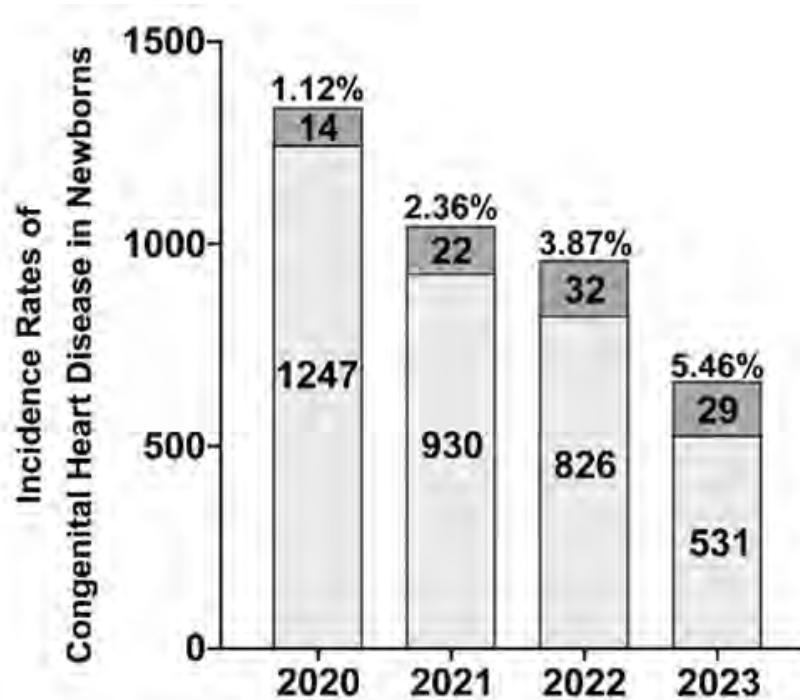


Figure 1. Incidence rates of congenital heart disease in newborns (2020–2023).



Long-term risks of SARS-CoV-2?

ZEIT ONLINE: Sie wollen also nicht ausschließen, dass es nach einer Sars-CoV-2-Infektion Folgeschäden gibt, die erst in ein paar Jahren auftreten werden?

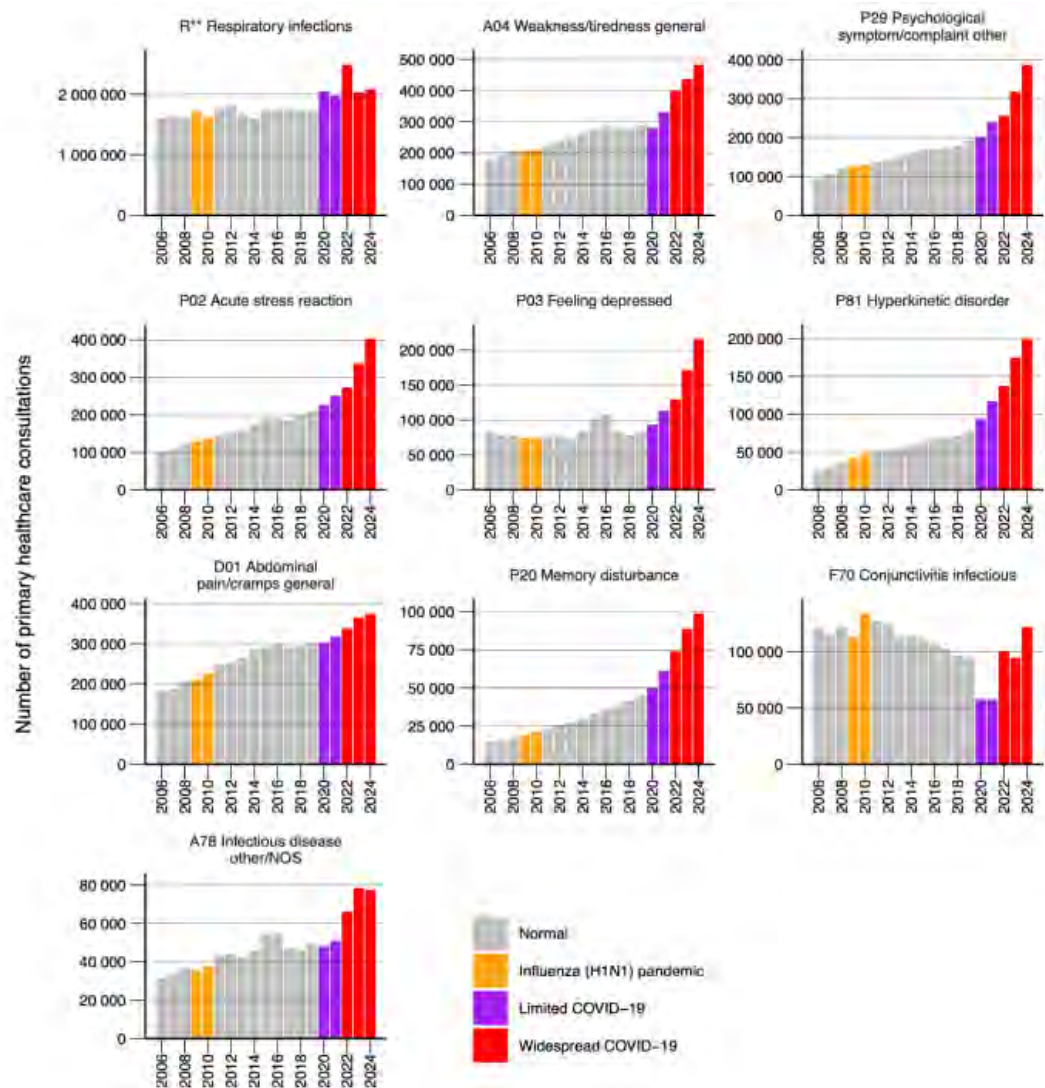
Iwasaki: Nein, absolut nicht. Wir sehen in einigen Studien bei Long-Covid-Patienten und Corona-Infizierten im Allgemeinen einen Anstieg von bestimmten Markern im Blut, von denen wir wissen, dass sie bei neurodegenerativen Erkrankungen erhöht sind. Ich frage mich: Selbst wenn diese Menschen jetzt kein Long Covid haben, wo stehen sie dann in ein paar Jahren oder Jahrzehnten? Haben weite Teile der Bevölkerung aufgrund ihrer Corona-Infektion ein erhöhtes Risiko für Alzheimer oder Parkinson, ohne dass sie davon wissen? Das wird man erst im Rückblick sehen.

Prof. Akiko Iwasaki, Yale:

- **Increase in certain markers** in the blood of long COVID patients and people infected with coronavirus in general, **associated with neurodegenerative diseases**
- **Do large sections of the population have an increased risk of Alzheimer's or Parkinson's due to their coronavirus infection without knowing it?** We will only see that in retrospect.



Increase in consultations



- Norway 2024: Marked and continued rise in consultations in primary care
- Lasting health effects of repeated SARS-CoV-2 infections, especially among women, children, adolescents, and young adults
- Richard Aubrey White, Beatriz Valcarcel Salamanca, Aslaug Angelsen et al. Excess primary healthcare consultations in Norway in 2024 compared to pre-COVID-19-pandemic baseline trends, July 30, 2025, PREPRINT (Version 1) available at Research Square [<https://doi.org/10.21203/rs.3.rs-7184987/v1>]



Record levels of absenteeism

Figure 1. National Excess Health-Related Absences From Work vs COVID-19 Wastewater Viral Activity Levels, January 2010 to December 2024

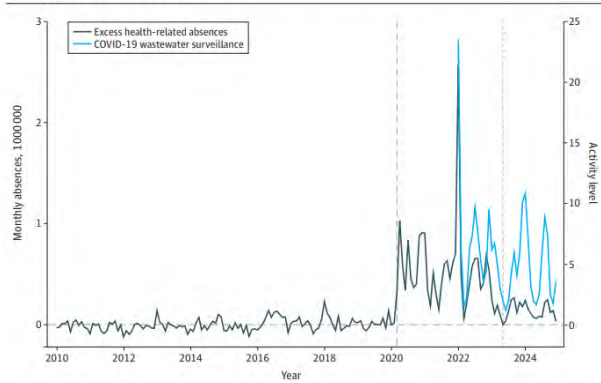


Figure 4. National Excess Labor Force Exits After a Health-Related Absence, January 2010 to December 2024

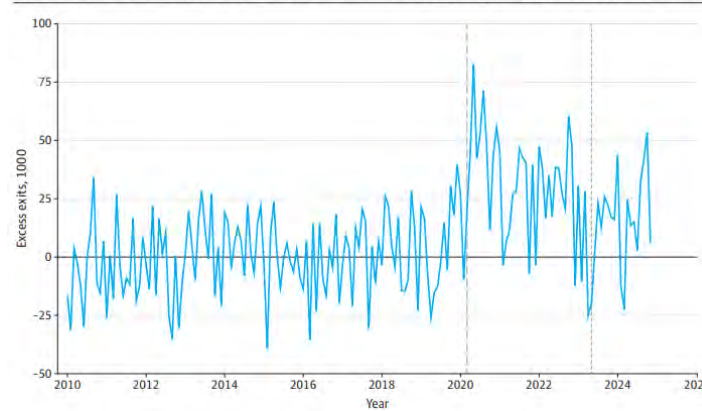
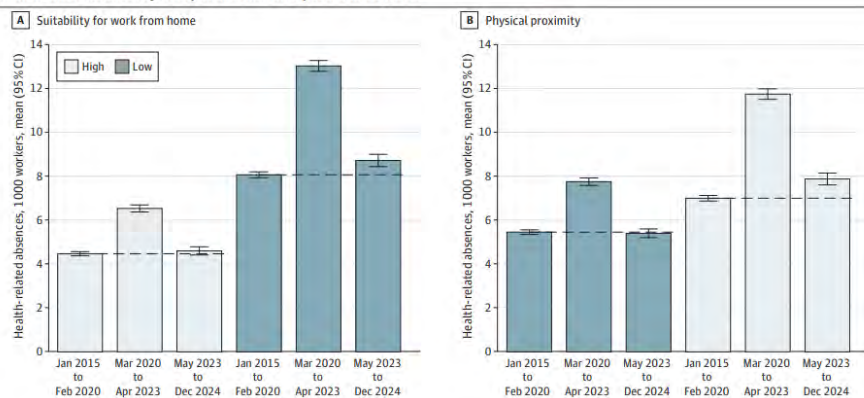


Figure 3. Health-Related Absences by Occupational Risk of Exposure to COVID-19



Compared to the pre-pandemic period:

- health-related absences still 13% higher
- health-related exits from the labor force remain 13% higher

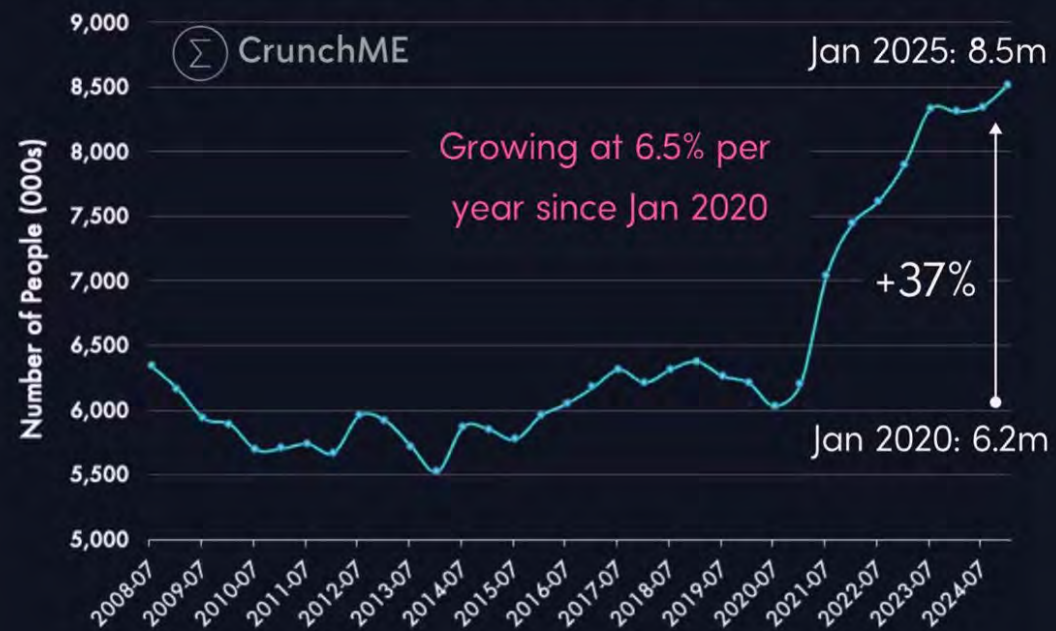
Dennett JM, Soltas EJ, Goda GS, Thornhill TA, Werner K, Gonsalves GS. Enduring Outcomes of COVID-19 Work Absences on the US Labor Market. JAMA Netw Open. 2025;8(10):e2536635. doi:10.1001/jamanetworkopen.2025.36635



Increase in chronic illness

Since the Pandemic Started, Disability Rates in the U.S. Labor Force Have Increased by Over A Third

People in the U.S. Civilian Labor Force (16+) with a Disability



Data Source: US Bureau of Labour Statistics (LNU01074597) via fred.stlouisfed.org

Note: y-axis is truncated to start at 5m, to help highlight variations over time

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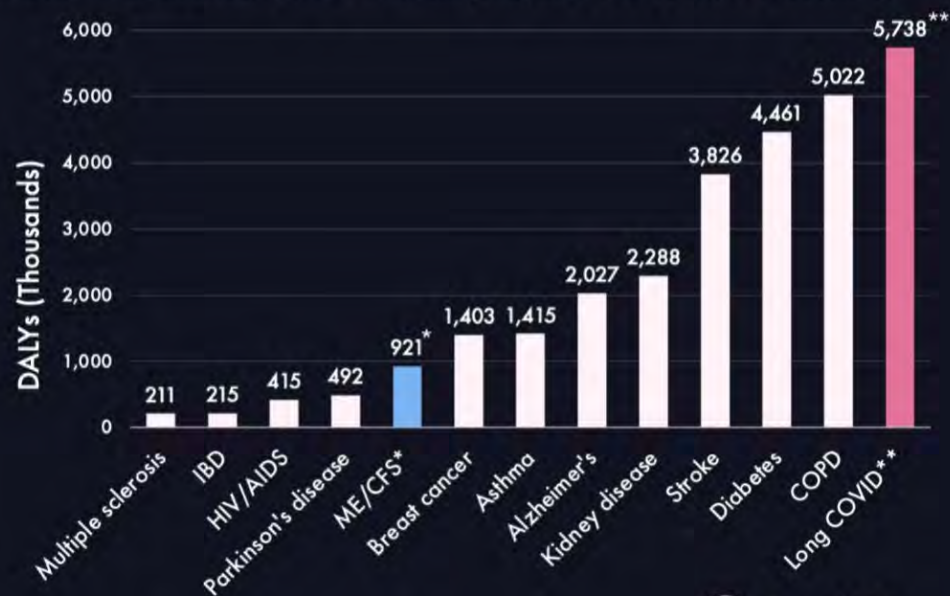
- USA: Since the pandemic, the number of people with disabilities has risen by 37%
- 6.5% per year



Rise of ME and Long COVID

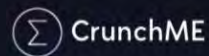
Long COVID, including COVID-triggered ME/CFS, is now amongst the most burdensome diseases in the USA

Disease Burden in USA (DALY = Disability-Adjusted Life Years, in Thousands)



* Pre-pandemic ** Includes COVID-triggered ME/CFS

Data Source: ME/CFS disease burden in 2020 from Dimmock et al (2022); Long COVID from CrunchME 'Future is a Policy Choice' report; Other conditions from IHME GBD Results (2024)



- Long COVID, ME: among the most burdensome diseases in the USA

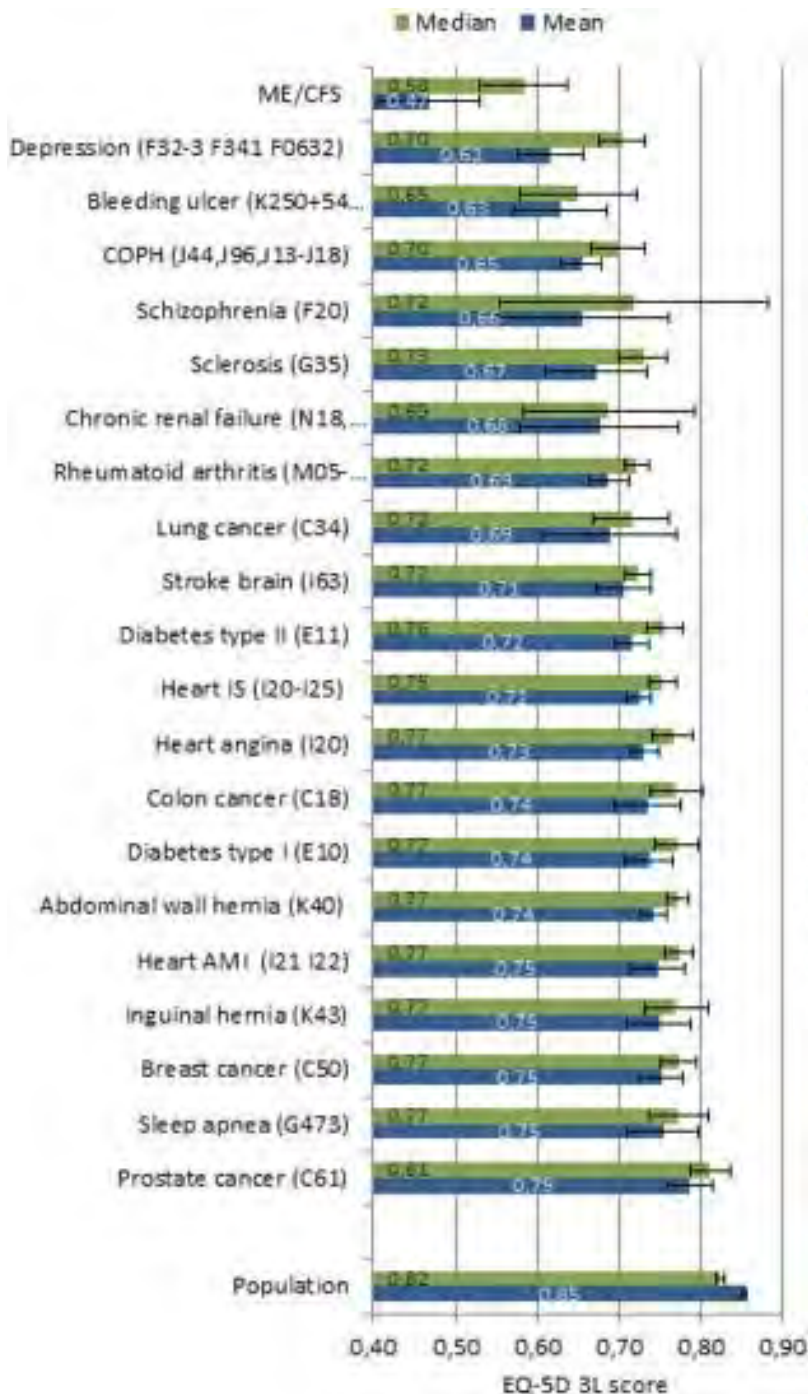


Post-acute infection syndromes – History

- Myalgic encephalomyelitis/chronic fatigue syndrome = severe *neuroimmunological* form of a post-acute infection syndrome
- Outbreak at London's Royal Free Hospital in 1955, ≥ 200 employees chronically ill: *myalgic encephalomyelitis*
- Triggers: viral or bacterial infections, accidents, childbirth, no identifiable trigger
- 1969: WHO recognizes ME as a neurological disease!



ME: low quality of life



Centers for Disease Control and Prevention
CDC 24/7: Saving Lives. Protecting People.™

Press Briefing Transcripts

NOVEMBER 3, 2006, 10 a.m. ET
Speakers

DR. WILLIAM REEVES,
CHIEF, CHRONIC VIRAL DISEASES BRANCH,
CENTERS FOR DISEASE CONTROL AND PREVENTION

We've documented, as have others, that the level of functional impairment in people who suffer from CFS is comparable to multiple sclerosis, AIDS, end-stage renal failure, chronic obstructive pulmonary disease. The disability is equivalent to that of some well-known, very severe medical conditions.

- QoL with ME significantly worse than in other chronic illnesses such as colon cancer, breast cancer, depression, schizophrenia
- Comparable to the terminal stage of AIDS or cancer

Falk Hvidberg M, Brinth LS, Olesen AV, Petersen KD, Ehlers L. The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS).



ME: Medical care in Switzerland

“One of the first diagnoses was burn-out; doctors asked me then to do a lot of sports, which worsened my symptoms terribly. Then around ten doctors said it was psychosomatic, and I was sent to the psychiatrist, who said I was mentally healthy, and it was somatic, and I was sick. Then I was finally diagnosed with ME/CFS by a CFS specialist.” (*Male, 38, ZH*)



- International studies: 84-91% of all ME patients never receive a diagnosis
- Switzerland: From initial manifestation to initial diagnosis Ø 6.7 years, 11.1 consultations, 2.6 misdiagnoses
- 90.5% misdiagnosis as "psychosomatic"
- Only one-third of all adolescents receive a diagnosis before their 18th birthday
- 13.5% go abroad for a correct diagnosis
- Often incorrectly treated: Graded exercise therapy → sometimes irreversible deterioration



ME: psychological stress in Switzerland

Self-reported types of perceived stigmatization by 107 ME/CFS patients.

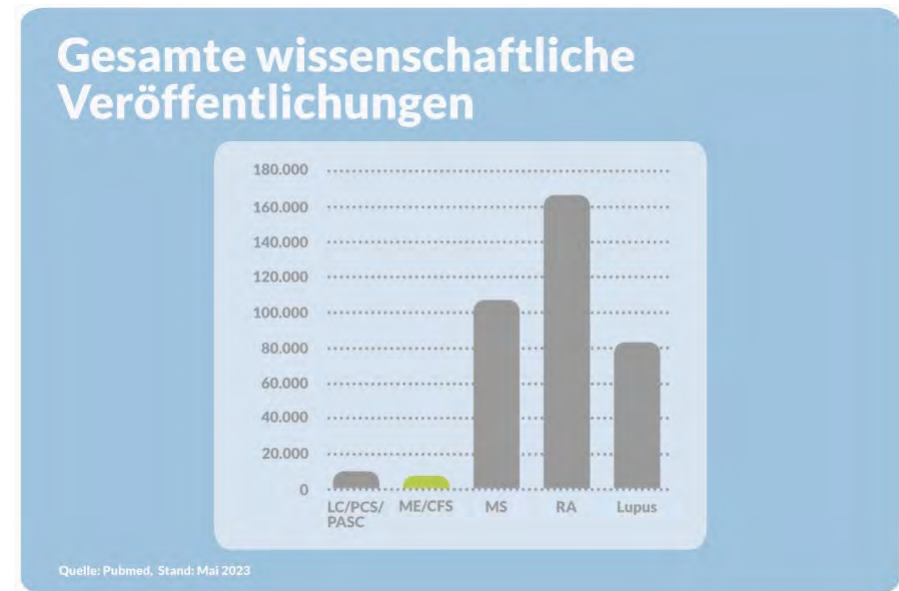
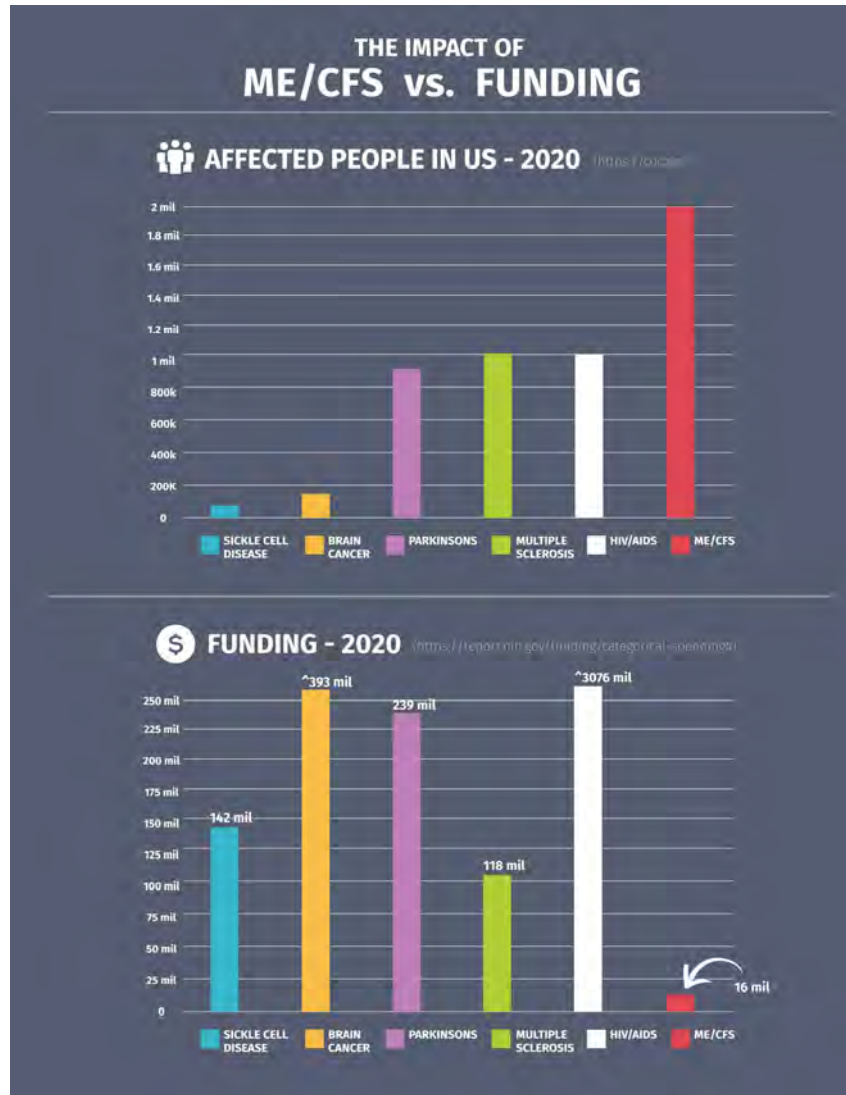
Misperception about the disease	88
Not be taken seriously, lack of understanding,	40
Mistaken for being mentally ill, being a liar, a simulator; the disease is thought to be imaginary	22
Giving senseless or counterproductive advice/comments	13
Disbelief in the severity of the condition, trivializing symptoms	12
Belief that symptoms are due to the misuse of drugs/alcohol (brain fog)	1
Blame and judgment	45
Considered to be a "social parasite"/freeloader, accused of being lazy/avoiding work in purpose	21
Accused of being weak, hypersensitive and told to complain less	10
Accused of exaggerating the symptoms, being a hypochondriac	6
Being judged by the activity level	5
Be blamed for the disease	3
Discriminatory behavior	29
Social avoidance/rejection	21
People around patients change their behavior	5
Other people make patient feel diminished	2
Patients are considered as unfriendly	1
Inappropriate behavior	13
Paternalizing and patronizing behavior	7
Overwhelmed in dealing with the condition	5
Forgetting the limitations of the disease	1



- 68.5% of people with ME experience stigmatization
- One-third have suicidal thoughts (half among men)
- Main factors contributing to suicidal tendencies: the claim that ME is psychosomatic (89.5%), lack of understanding from others (80.7%), no will to live (80.7%)
- 14.8% have secondary depression



ME: no approved treatment, insufficient research



Myalgic Encephalomyelitis

- Very serious illness, reduced life expectancy (vascular, cancer, suicide)
- **Most common reason for unexplained long absences from school and work**
- No approved treatment to date
- Inadequate medical care and recognition by social insurance providers
- Far too little research

And then the pandemic hit...



Subgroups of COVID sequelae

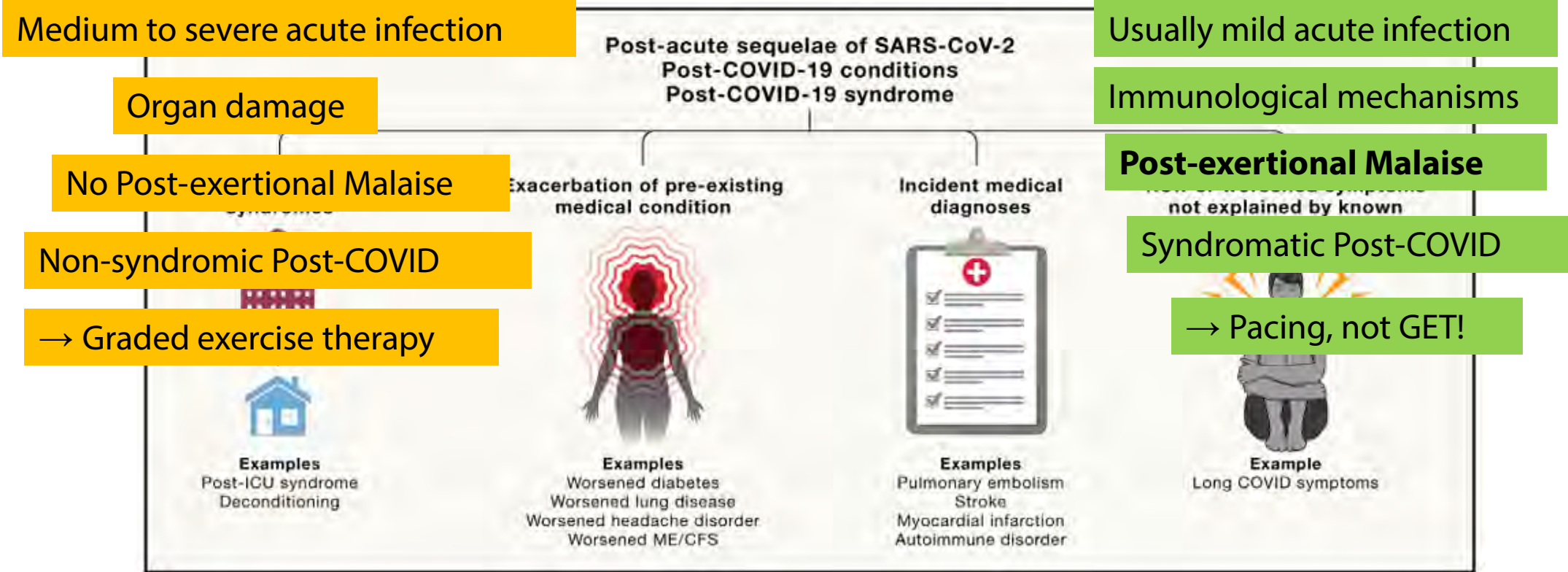


Figure 1. Proposed framework for defining PASC

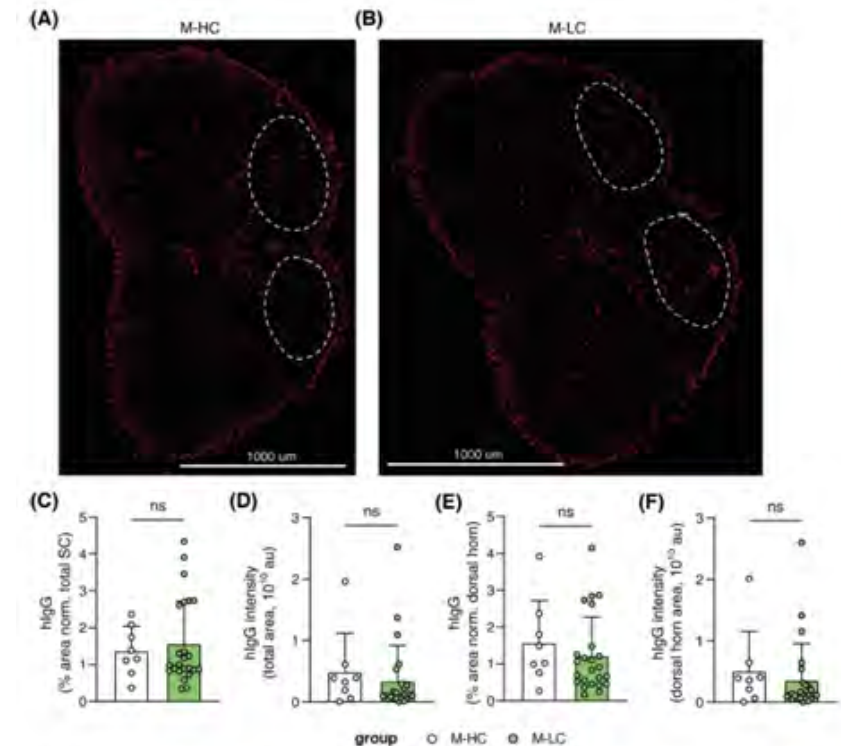
Until the biology is better understood, we favor a framework using post-acute sequelae of SARS-CoV-2 infection (PASC), as an umbrella term comprising post-hospitalization syndromes, new or worsened medical conditions, and unexplained symptoms (long COVID). We use long COVID to refer specifically to unexplained symptoms. While some biological mechanisms may turn out to overlap, such a framework ensures clarity of case definitions in research studies, limits heterogeneity and misclassification, and maximizes the chances of defining the underlying pathophysiology.



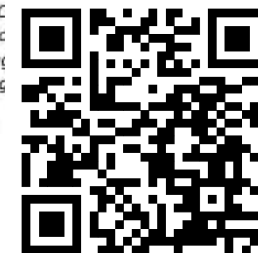
Long COVID transmissible with antibodies

- Transfer of immunoglobulin G from LC patients to healthy mice leads to LC symptoms in the mice
- Two control groups: IgG from healthy individuals before the pandemic, IgG from individuals who fully recovered after mild COVID-19 → no LC symptoms in mice
- *UK: explicit ban on blood donation in cases of symptomatic long COVID*

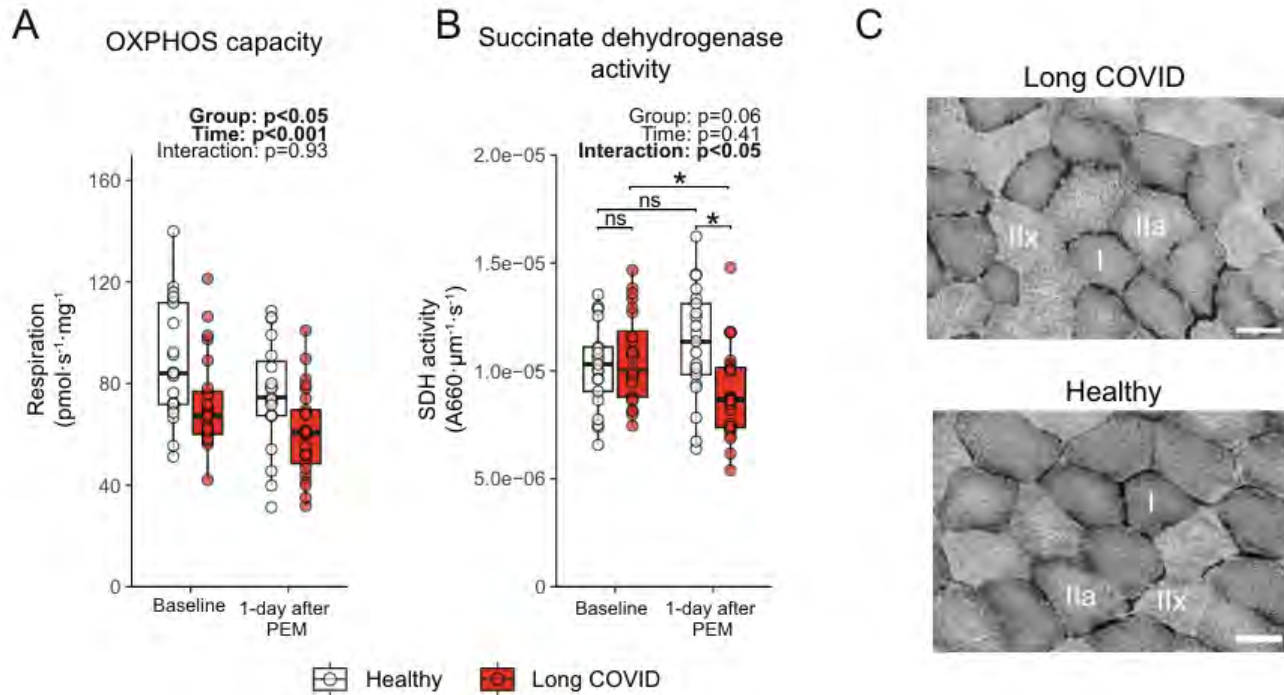
Transfer of IgG from Long COVID patients induces symptomology in mice. Hung-Jen Chen et al. bioRxiv 2024.05.30.596590; doi: <https://doi.org/10.1101/2024.05.30.596590>



Supplementary Figure 4: Injected human IgG (hIgG) of Long COVID (LC) patients and healthy donors (HC) detected in murine spinal cord. Representative staining of hIgG (red) from the spinal cord of (A) mice injected with HC IgG antibodies (M-HC) and (B) M-LC. The white dotted line indicates the dorsal horn area. (C) Quantification of hIgG staining intensity normalized to total spinal cord area per mouse. (D) Quantification of hIgG staining intensity in total spinal cord per mouse. (E) Quantification of hIgG staining intensity normalized to dorsal horn area per mouse. (F) Quantification of hIgG staining intensity in dorsal horn area per mouse. Parametric data were analyzed using t-tests. ns; non-significant.



Muscle pathology worsened by PEM



Muscle biopsy

- Mitochondrial dysfunction
- Myopathy
- Tissue infiltration with amyloid deposits

Even more pronounced in post-exertional malaise

Appelman B, Charlton BT, Goulding RP, et al. Muscle abnormalities worsen after post-exertional malaise in long COVID. Nat Commun. 2024;15(1):17. Published 2024 Jan 4. doi:10.1038/s41467-023-44432-3



Pathomechanisms

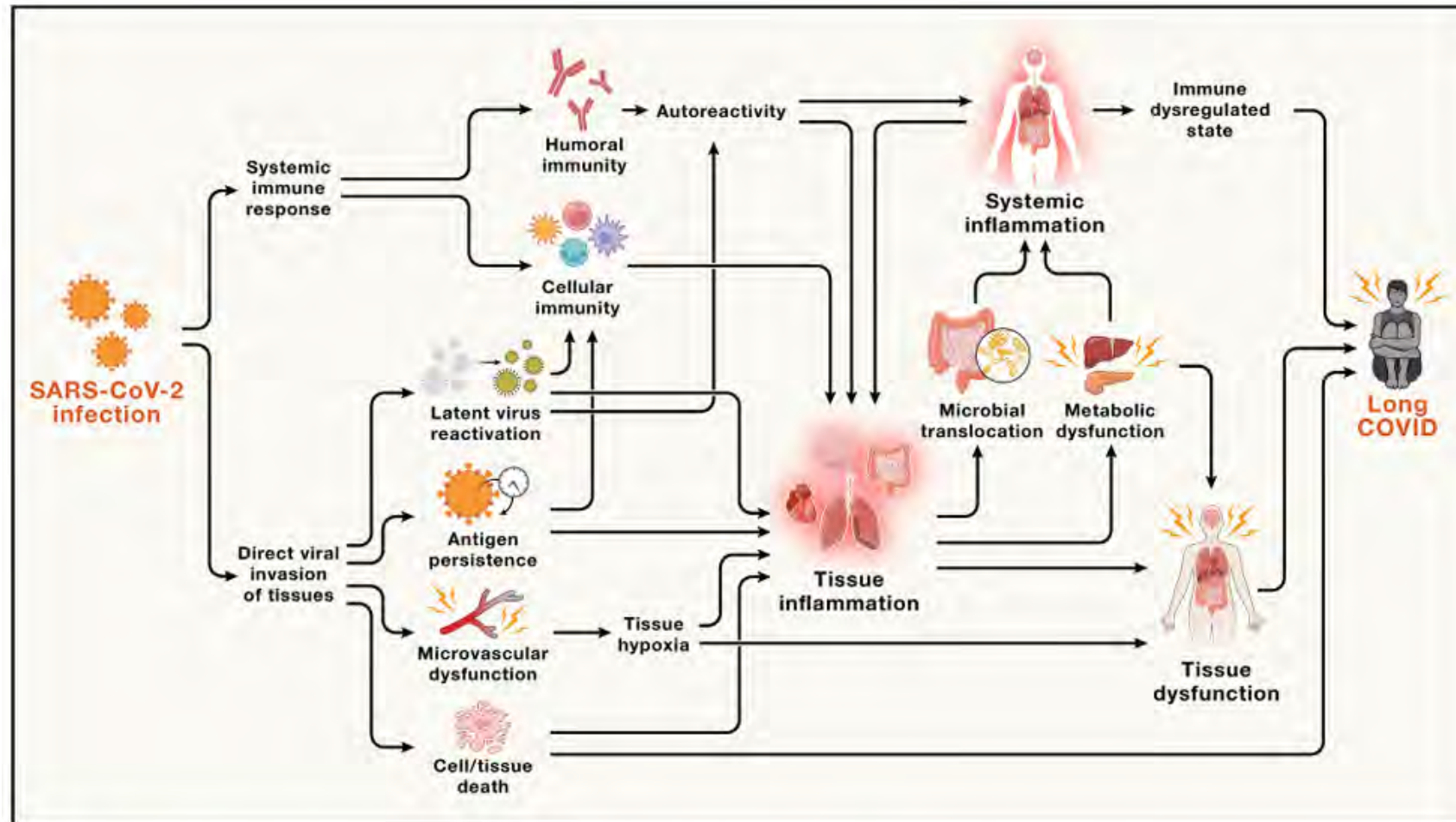


Figure 5. Potential relationships between the biological mechanisms of long COVID

The proposed mechanisms interact in complex ways to ultimately drive downstream physiologic changes that result in long COVID symptoms.



Replicated findings

Replizierte Befunde bei ME/CFS und Long COVID



Befund	ME/CFS	Long COVID
Reduzierter Zerebraler Blutfluss	Ichise, 1992 Schwartz, 1994 Schwartz, 1994 Goldstein, 1995 Costa, 1995 Goldberg, 1997 Abu-Judeh, 1998 Kuratsune, 2002 Yoshiuchi, 2006 Biswal, 2011 Shungu, 2012 Gay, 2016 Natelson, 2017 Campen, 2020 Campen, 2021 Li, 2021 Campen & Visser, 2022	Campen, 2021 Novak, 2021 Marcic, 2021 Campen & Visser, 2022 Campen & Visser, 2022 Kim, 2022
Endotheliale Dysfunktion	Newton, 2011 Scherbakov, 2020 Blauensteiner, 2021 Sorland, 2021 Haffke, 2022 Bertinat, 2022 Flaskamp, 2022	Ambrosino, 2021 Nandadeva, 2021 Mejia-Renteria, 2021 Charfeddine, 2021 Haffke, 2022 Flaskamp, 2022 Mahdi, 2022
Autoantikörper gegen G-Protein gekoppelte Rezeptoren	Tanaka, 2003 Yamamoto, 2012 Loebel, 2016 Fujii, 2020 Bynke, 2020 Szkalski, 2021 Freitag, 2021 Gravelsina, 2022 Sotzny, 2022	Wallukat, 2021 Mardin, 2022 Szewczykowski, 2022 Sotzny, 2022 Schlick, 2022 Paniskaki, 2022
Regionaler Hypometabolismus im Zentralen Nervensystem	Tirelli, 1998 Siessmeier, 2003	Guedj, 2021 Morand, 2021 Sollini, 2021 Verger, 2022 Goehring, 2022
Verringerte periphere Sauerstoffversorgung	McCully & Natelson, 1999 Tanaka, 2002 McCully, 2004 Neary, 2008 Vermeulen, 2014 Melamed, 2019 Joseph, 2021	Singh, 2021 Al-Hakeim, 2022
Erhöhte ventrikuläre Laktatlevel	Mathew, 2008 Murrough, 2010 Shungu, 2012 Natelson, 2017 Natelson, 2017 Mueller, 2019	Etter, 2022
Arterielle Steifheit	van de Putte, 2005 Spence, 2008 Stomko, 2021 Bond, 2021	Oikonomou, 2022
Überaktivierte Blutplättchen und kleinste Blutgerinnsel	Nunes, 2022 Jahanbani, 2022 Ahmed, 2022	Pretorius, 2021 Pretorius, 2022 Camera, 2022 Constantinescu-B, 2022
Verminderte Verformbarkeit roter Blutkörperchen	Saha, 2019	Kubankova, 2021

© Deutsche Gesellschaft für ME/CFS

- Unambiguously replicated, objective findings of multisystem disease
- However: Long COVID and ME are clinical diagnoses, no validated biomarkers so far!



How many people have Long COVID?

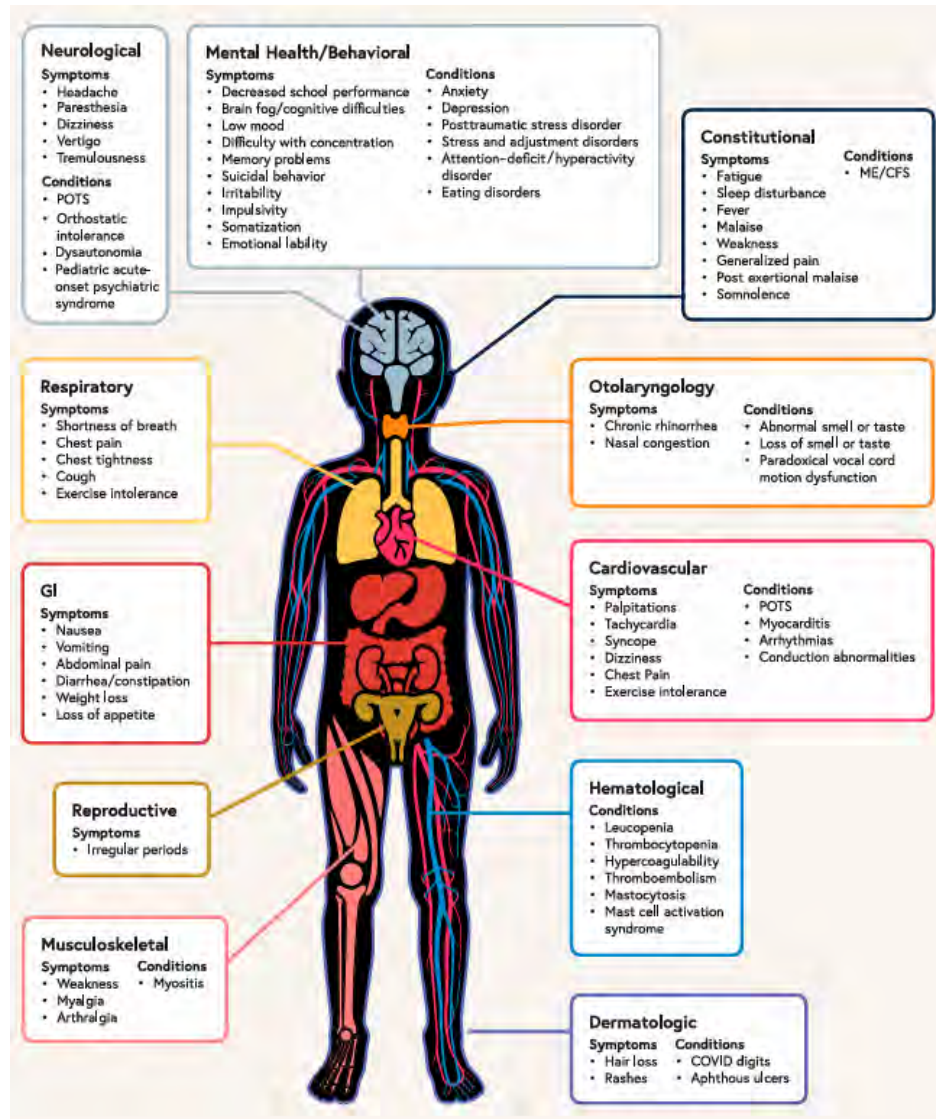
Estimated percentage of people living in private households with self-reported long COVID by duration since first experiencing long COVID symptoms, England and Scotland, four-week period ending 7 March 2024



- 06/25: globally 6% (AL Cheng et al.; PM R), of which 50% since Omicron became dominant → continued rise since protective measures were lifted
- Children and adolescents: 1%
- CH: 540,000??? (no registry...)
- Capacity of St. Jakob-Park Stadium 38,500 → *Swiss LC sufferers fill the "Joggeli" 14 times*
- Comparison: 2019: 247'000 with federal disability pension



Long COVID: 200 known symptoms



- Wide variety of possible symptoms

- Frequently multisystem disease

- Rao S, Gross RS, Mohandas S, et al. Postacute Sequelae of SARS-CoV-2 in Children. Pediatrics. 2024;153(3):e2023062570. doi:10.1542/peds.2023-062570



Long COVID also affects children <5 y

Table 2. The Long COVID (LC) Research Index^a

Age group	Symptom	Log odds ratio	Score
Infants/toddlers (0-2 y)	Poor appetite	0.47	5.0
	Trouble sleeping	0.34	3.5
	Wet cough	0.32	3.5
	Dry cough	0.27	3.0
	Stuffy nose	0.05	0.5
Preschool-aged children (3-5 y)	Daytime tiredness/sleepiness or low energy	0.64	6.5
	Dry cough	0.28	3.0

^a To fit a logistic regression model to identify which symptoms could be used to identify which participants have LC-probable vs LC-unspecified status, least absolute shrinkage and selection operator (LASSO) was used, resulting in these log odds ratio estimates. In this model, the symptoms were the exposures, and the outcome was infection status. The log odds ratio estimates were divided by 0.10 and rounded up to the nearest 0.5 to calculate individual

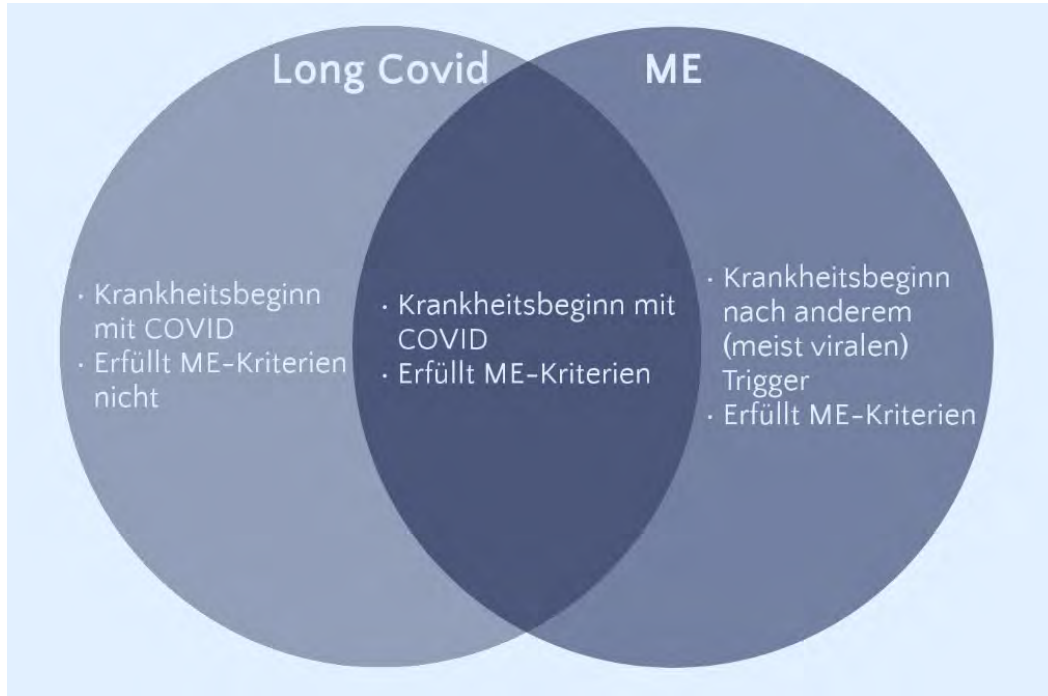
symptom scores. An individual's LC research index is calculated by summing the scores for each prolonged symptom a participant reported. A prolonged symptom is defined as a symptom that the participant experienced for at least 4 weeks since the beginning of the COVID-19 pandemic and is still experiencing at the time of enrollment. The index is derived separately for infants/toddlers and preschool-aged children.



- 0-2 y: Poor appetite, trouble sleeping, wet cough, dry cough, stuffy nose
- 3-5 y: Daytime tiredness/sleepiness or low energy, dry cough
- Gross RS, Thaweethai T, Salisbury AL, et al. Characterizing Long COVID Symptoms During Early Childhood. *JAMA Pediatr.* 2025;179(7):781–792. doi:10.1001/jamapediatrics.2025.1066



Long COVID symptoms (ME type)



- Fatigue
- Intolerance to exertion* (physical, cognitive, emotional; incl. stimuli)
- **Post-exertional malaise*** ("crash")
- Cognitive deficits
- Sleep disorders
- Orthostatic intolerance

* *Three different aspects of the same phenomenon, not synonymous!*

* *PEM is **the** defining and limiting symptom of long COVID.*



ME diagnostic criteria

	CANADIAN CONSENSUS CRITERIA	INTERNATIONAL CONSENSUS CRITERIA	INSTITUTE OF MEDICINE
Name of Disease	ME/CFS	ME	SEID*
New Onset		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Level of Functional Impairment	Substantial	50% Decreased	Substantial
Minimal Duration	6 months	No Minimum	6 Months

SYMPTOM REQUIREMENTS FOR EACH DIAGNOSTIC CRITERIA			
Persistent Fatigue	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Cognition Problems (CP)			Either CP or OI
Motor-Sensory Disturbances	2 out of 3 Required		
Short-Term Memory Issues		3 out of 5 Required	
Pain	<input checked="" type="checkbox"/>		
Sleep Disturbances	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>
Post-Exertional Malaise (PEM)	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Recurrent Flu-Like Symptoms			
Infection Susceptibility	1 out of 3 Required		
Food/Chemical Sensitivities		3 out of 5 Required	
Gastro-Intestinal Tract Issues			
Genitourinary Problems	1 out of 3 Required		
Orthostatic Intolerance (OI)			Either CP or OI
Respiratory Problems			
Cardiovascular Problems	1 out of 4 Required	3 out of 5 Required	
Temperature Intolerance			
Thermostatic Intolerance			

- ME: severe neuroimmunological form of postacute infection syndrome
- Mild ME: functional impairment of at least 50%
- ME: Different sets of diagnostic criteria

https://www.physio-pedia.com/Myalgic_Encephalomyelitis_or_Chronic_Fatigue_Syndrome



Long COVID vs. ME

- Long COVID and ME: no approved therapy
- **However**, for ME, there are **pragmatic treatment approaches** that have been tried and tested for decades **with a pathophysiological rationale based on recognized entities** (POTS; MCAS; small fiber neuropathy).
- *Evidence class 2*
- → just as effective for the ME type of Long COVID!

(recommended by "Multidisciplinary collaborative guidance on the assessment and treatment of patients with Long COVID: A compendium statement" 04/22/2025; "Long COVID global expert consensus" 20.04.2025; "Interdisciplinary, collaborative D-A-CH consensus statement on the diagnosis and treatment of myalgic encephalomyelitis/chronic fatigue syndrome" 2024; US ME/CFS Clinician Coalition; Mayo Clinic; Prof. Scheibenbogen, Charité; Practice guidelines for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and corresponding forms of long COVID and post-COVID syndrome; List of indicated medications for PAIS and ME/CFS in Austria; Germany: Therapy compass from the Long COVID Off-Label Use expert group)



LONG COVID: SCHÉMA DE DIAGNOSTIC ET DE TRAITEMENT

En date de mars 2025

Diagnostic de base

Anamnèse détaillée (accompagnée du questionnaire en ligne) [<https://www.neuropraxis-solothurn.ch/long-covid-solothurn/>]

Examen physique, y compris l'état neurologique, 10 min de test passif en position debout, ECG, température, fréquence respiratoire, saturation en oxygène, dermatographie

Laboratoire

Hémogramme différentiel, INR, pTT, fibrinogène, D-dimères, CRP, glucose, créatinine, électrolytes, transaminases, complément C3/C4, protéines totales, TSH, fT4, cortisol basal, ACTH, Ferritine, holotranscobalamine, 25-OH-Vitamine D, auto-anticorps anti-cardiolipine (IgG et IgM), ANA, anticorps anti-ADNdb, bilan urinaire

En cas de symptômes cardiaques, en plus CK, CK-MB, troponine I (hs), NT-proBNP

En cas de troubles intestinaux, en plus IgA totales, IgA anti-transglutaminase et calprotectine dans les selles

Chez les enfants : toujours inclure également IgA anti-transglutaminase et les IgA totales

Evt, récepteurs de neurotransmetteurs Ac (disponible chez Viallier), sous-populations lymphocytaires, MBL (mannose binding lectin), profil journalier des niveaux de cortisol dans la salive, immunoglobulines IgG, IgA et IgM et sous-classes d'IgG, cytokines TNF-alpha et interleukine-6 et récepteur soluble de l'interleukine-2, SARS-CoV-2 IgG qn protéine spike (immunité après infection ou infection) et/ou SARS-CoV-2 IgG nucléocapside (immunité après infection), EBV-VCA-IgM et -IgG, EBNA-IgG, Vitamines B1, B6, acide folique, zinc

Thérapie et conseil, les bases principales

- Intolérance à l'effort : physiothérapie et/ou ergothérapie pour l'apprentissage du pacing (pas de graded exercise therapy !)
- Syndrome d'activation des mastocytes (MCAS) : essai thérapeutique : fexofénadine 120-180 mg, éventuellement daosine aux repas (si la prise alimentaire exerce un effet significatif)
En cas d'absence de réponse à la fexofénadine, essai de kétotifène, acide cromoglicique (3 x 200 mg) ou acide alpha-lipoïque (2 x 200-600 mg)
- Conseils en nutrition : essayer un régime pauvre en histamine pendant quelques semaines
- Essai de compléments alimentaires : L-arginine 5.0 g (si réaction de l'herpès, en plus L-lysine 1-3 g); vitamine C liposomale 500 mg 1-0-1; nattokinase 2000-

8000 FU le matin à jeun; niacine formulation «no flush» 250-500 mg le matin; vitamine D 1000-3000 UI/j; L-tryptophane 500 mg 1-0-1 à jeun; N-acétylcystéine 600 mg 1-0-1; zinc 15 mg 0-0-1; sélénium 50 µg 1-0-0; quercétine 250 à 500 mg 1-0-1

- La vaccination contre le COVID-19 entraîne une amélioration des symptômes chez environ 25% des personnes atteintes du Long Covid et peut donc être envisagée (pas en cas de post-Vac !)
- Conseils avisés pour éviter d'autres infections (porter systématiquement des masques FFP2 dans les lieux publics intérieurs; veiller à ce que l'air ambiant soit de bonne qualité (optimal : filtre à air et aération régulière !), si possible aussi dans les salles de classe des enfants des personnes touchées; autotest avant toute rencontre)
- Hypotension orthostatique : chute de la tension artérielle >20 mm Hg systolique ou >10 mm Hg diastolique
- Syndrome de tachycardie orthostatique posturale POTS : augmentation du pouls à >120/min ou de >30/min (ou >40/min entre 12 et 19 ans).

Même si les critères pour HTO ou de POTS ne sont pas tout à fait remplis, des mesures non médicamenteuses sont recommandées :

- Boire suffisamment (au moins 3 l/jour) avec un apport régulier de liquide, notamment en se réhydratant suffisamment avant de se lever le matin (jusqu'à 500 ml plus du sel, p. ex. bouillon)
- Un apport suffisant en sel, environ 8 g/jour. Recette pour une boisson électrolytique, à répartir sur la journée, surtout le matin : 250 ml de jus de fruit et 750 ml d'eau avec 0,5 cuillère à café rase de sel de cuisine
- Se lever lentement
- Bas de contention classe 2 (ou 3), pour les femmes aussi ceinture abdominale compressive
- Douches alternées, bains de pieds froids en cas de chaleur
- Absence d'alcool, peu de café
- Plusieurs petits repas

Options médicamenteuses :

- En cas d'hypotension orthostatique Pyridostigmine 10 mg 1-0-0. Si bien toléré, augmentation tous les 7 jours jusqu'à un maximum de 3 x 120 mg
- En cas de POTS, ivabradine 2,5 mg 1-0-0, augmentation à 5 mg 1-0-0 après 7 jours selon l'effet/la tolérance, éventuellement jusqu'à 7,5 mg 1-0-0 (l'ivabradine ne modifie pas la tension artérielle)
- En cas de POTS et d'hypertension : bisoprolol 1 x 5-10 mg
- Autres options thérapeutiques en cas de POTS : Fludrocortisone 0,1-0,2 mg, Midodrine 3 x 5-10 mg, Véricuat 2, 5 à 10 mg, Méthylphénidate 3 x 5-10 mg,

Bupropion 150-300 mg, Venlafaxine 37.5-300 mg, Escitalopram 10 mg, Pyridostigmine 2-3 x 10-60 mg, Érythropoïétine 10,000-20,000 UI/semaine par voie sous-cutanée ou intraveineuse, Octréotide 3 x 50-200 µg par voie sous-cutanée, Clonidine 2 x 0,1-0,3 mg per os ou 0,1-0,3 mg patch par semaine, Labétalol 2 x 100-200 mg

- En cas de POTS sévère, 1 litre de NaCl 0,9% par voie intraveineuse pendant 1-2 heures par semaine, titrage à 1 litre toutes les 2-4 semaines jusqu'à 2 litres par semaine

Escalade thérapeutique

- Troubles sensitifs ou dysautonomiques : orientation vers le service de neurologie d'un hôpital universitaire avec la question d'une possible neuropathie des petites fibres
- Naltrexone à faible dose : dissoudre 1 comprimé de naltrexone 50 mg dans 50 ml d'eau (1 mg de naltrexone/ml de solution). Commencer par 0,5 ml le soir, augmenter de 0,5 ml toutes les 1-2 semaines jusqu'à au moins 1,5-2,5 ml, maximum 5 ml. Si insomnie comme effet secondaire, prendre le matin
- Aripiprazole à faible dose : Aripiprazole 1 mg/ml : commencer par 0,1-0,25 ml par jour, augmenter de 0,1-0,25 ml toutes les 1-2 semaines jusqu'à un maximum de 2,0 ml. Prise sur quelques semaines
- Corticostéroïdes systémiques : prednisolone 20 mg pendant 5 jours, suivie de prednisolone 5 mg pendant 23 jours, avec pantoprazole 40 mg
- Si le profil journalier du cortisol est bas, fludrocortisone 0,1-0,2 mg, éventuellement avec 10-37,5 mg de cortisone (équivalent) par jour; envisager une évaluation endocrinologique
- Oxygénothérapie hyperbare
- Immunoglobulines intraveineuses, HELP-aphérèse, immuno-adsorption
- Anticoagulation : aspirine 75 mg, clopidogrel 75 mg et apixaban 2 x 5 mg combiné avec pantoprazole 40 mg. Prudence : Informer sur les risques de saignement, surveillance étroite !

Traitement des symptômes spécifiques

- Anosmie, dysosmie** : entraînement olfactif structuré : sentir des odeurs (rose, citron, eucalyptus et clou de girofle) pendant 30 secondes le matin et le soir, en imaginant l'odeur. Médicaments : zinc 2 x 50 mg, 1 dose de fluticasone en spray nasal ddc ou 32 mg de méthylprednisolone p. o. le matin pendant 10 jours, ou vitamine A en gouttes nasales 10'000 UI/jour pendant 8 semaines
- Fatigue, Brain Fog** : D-Ribose 1-3 x 5-10 g (pas en cas de diabète mellitus)
- Insomnie** : diphenhydramine 3-25 gouttes la nuit (en

Uniquement en cas de test passif en position debout anormal (Nasa Lean Test)

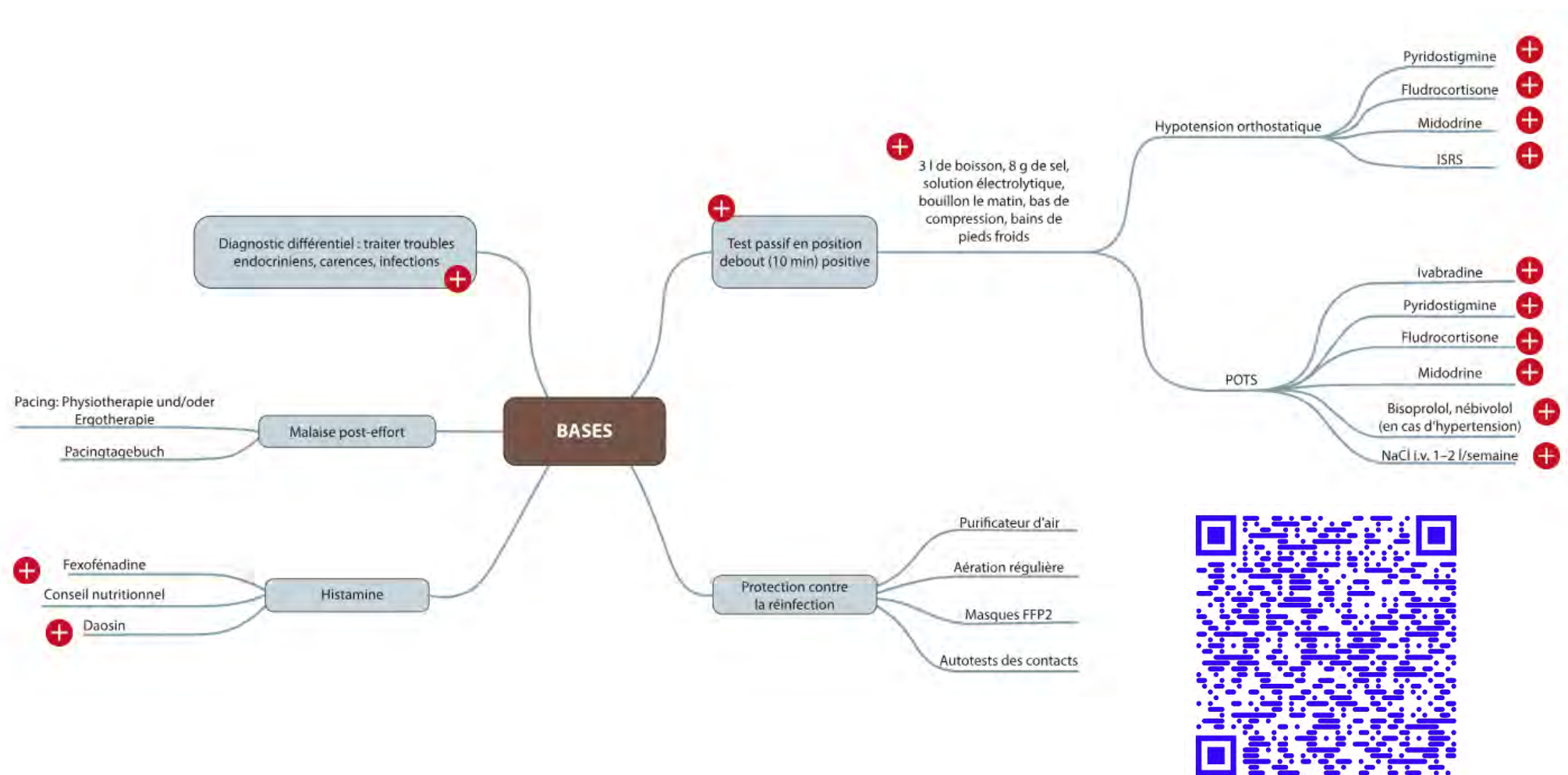
général, une faible dose suffit), mélatonine 3-24 mg la nuit (a souvent un effet bénéfique sur le brain fog), QUUVIQU 25 - 50 mg 30 minutes avant le coucher

- Symptômes cardiaques** : toujours rechercher et traiter le POTS/hypertension posturale. En cas de réponse insatisfaisante sur le plan clinique, éventuellement IRM cardiaque 3T à la recherche d'une myocardiopathie
- Dyspnée** : POTS/hypotension posturale? Physiothérapie respiratoire. Essai de thérapie avec montelukast. Bilan pneumologique, éventuellement V/Q-SPECT/CT à la recherche d'un déficit de ventilation ou de perfusion
- Déficits cognitifs** : POTS/hypotension posturale? Bupropion 150 - 300 mg. Essai thérapeutique avec 1 mg de guanfacine (Intuniv®) et 600 mg de N-acétylcystéine la nuit ; augmenter la guanfacine (Intuniv®) à 2 mg après un mois. IRM cérébrale pour exclure d'autres causes. Bilan neuropsychologique pour objectivation, éventuellement TEP (18F)-FDG pour détecter un hypométabolisme régional. Evt neuro-feedback
- Douleurs** :
 - Duloxétine 30-60 mg, amitriptyline ou trimipramine 10-25 mg la nuit (non disponible en Suisse : milnacipran)
 - Prégabaline 25-50 mg la nuit, si toléré, augmenter la dose jusqu'à max. 300 mg par jour, répartis en trois prises (petites doses pendant la journée).
 - Oxcarbazépine (commencer par 150 mg la nuit, augmenter jusqu'à 2 x 600 mg) ou lamotrigine (commencer par 25 mg le matin, augmenter de 25 mg toutes les deux semaines jusqu'à 3 x 100 mg; attention : rarement un exanthème médicamenteux, surtout si on augmente trop rapidement la dose !), seule ou en association avec la prégabaline
 - Topiramate, surtout en cas de surcharge pondérale (commencer par 25 mg la nuit, augmenter de 25 mg chaque semaine jusqu'à 2 x 50-100 mg)
 - Tizanidine (2 mg la nuit, augmenter jusqu'à 2 x 4 mg), tramadol jusqu'à 4 x 50 mg, en cas de douleurs locales, patch de lidocaïne
 - Chez les patients souffrant de douleurs et présentant un ANA positif, éventuellement Plaquenil (attention : évaluer l'efficacité après plusieurs mois seulement)
 - Méthadone ou MST Continus®
- Troubles de la digestion** : syndrome d'activation des mastocytes ? Fexofénadine 120-180 mg par jour, éventuellement Daosin pendant les repas, conseils diététiques (régime pauvre en histamine). Éventuellement des probiotiques. Lors d'une éventuelle gastroscopie ou coloscopie, faire une histologie avec coloration pour les mastocytes (CD117)

Le auteur déclare toute responsabilité quant à l'exactitude de ces données, l'absence de conflit d'intérêt et l'utilisation de ces recommandations. La Dr. med. M. Strasser n'est pas responsable des dommages qui pourraient résulter de l'utilisation de ces recommandations.



Treatment protocol: MindMaps



Medical history: Always ask about PEM!

During consultations, patients are overestimated because post-exertional malaise only occurs 24–72 hours later (supposed discrepancy, "aggravation," etc.).

Ask explicitly:

- Do you experience deterioration AFTER overexertion? How does it manifest? Duration?
- What level of activity is tolerated without PEM?
- How many hours are you upright?
- How often do you shower and wash your hair?
- How long can you work at the computer or read?

→ PEM limits patients

LC or ME assessments without exploration of PEM are worthless



PEM duration in ME



Article

Assessment of Post-Exertional Malaise (PEM) in Patients with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS): A Patient-Driven Survey

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Abstract: Considerable controversy has existed with efforts to assess post-exertional malaise (PEM), which is one of the defining features of myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS). While a number of self-report questionnaires have been developed to assess this symptom, none have been comprehensive, and a recent federal government report has recommended the development of a new PEM measure. The current study involved a community-based participatory research process in an effort to develop a comprehensive PEM instrument, with critical patient input shaping the item selection and overall design of the tool. A survey was ultimately developed and was subsequently completed by 1534 members of the patient community. The findings of this survey suggest that there are key domains of this symptom, including triggers, symptom onset, and duration, which have often not been comprehensively assessed in a previous PEM instrument. This study indicates that there are unique benefits that can be derived from patients collaborating with researchers in the measurement of key symptoms defining ME and CFS.

Keywords: myalgic encephalomyelitis; chronic fatigue syndrome; post-exertional malaise; assessment; patient-driven questionnaire; participatory research

1. Introduction

Among patients with myalgic encephalomyelitis (ME), post-exertional malaise (PEM) has long been one of the defining features of the condition, which includes more than twenty case definitions regarding defining PEM [2]. For example, discrepant and CFS case definitions, the Fukuda [3] and Casanovi [4] criteria do not define the term beyond requiring a requirement for diagnosis. In contrast, the CDC [5] diagnosis and goes further to describe the symptom as a potential delayed onset [4].

Several activity and self-report measurement tools might result in exacerbation of symptoms: actigraphy, exercise challenges, time logs, and task. Mateo et al. [6] reported a broad spectrum of symptoms including muscle/joint pain, cognitive dysfunction, decreased strength, cardiopulmonary symptoms, lightheadedness, and post-exertional malaise (PEM).



- 58%: PEM duration Ø 3-6 days
- BUT:
- 46.7% PEM 1 week to 1 month
- 30.3% PEM 1 month to 6 months

• 67.1% irreversible PEM
→ Pacing: exertion below PEM threshold



Pacing – Energy management

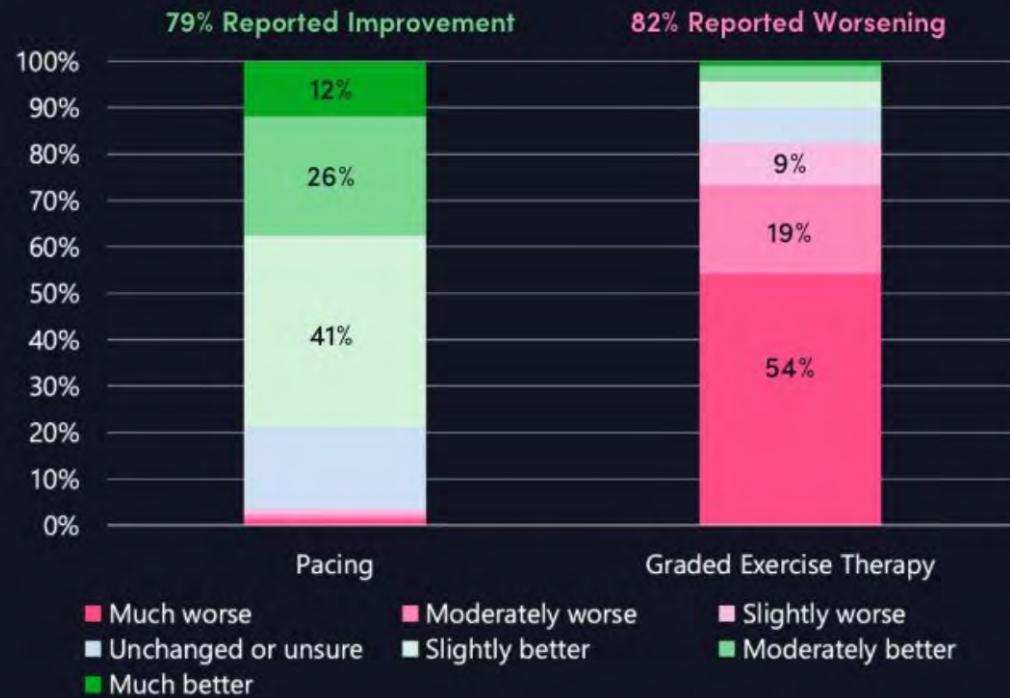
- Any PEM → risk of sustained deterioration and chronicity!
- Energy management **Pacing: Avoid PEM!**
- **Overexertion contraindicated**
(activation in rehabilitation, exercise ECG, etc.)



Pacing

79% of patients reported a beneficial response to pacing, whilst 82% of patients worsened from graded exercise therapy

Results from OMF's TREATME Survey for Patients with ME/CFS or Long COVID



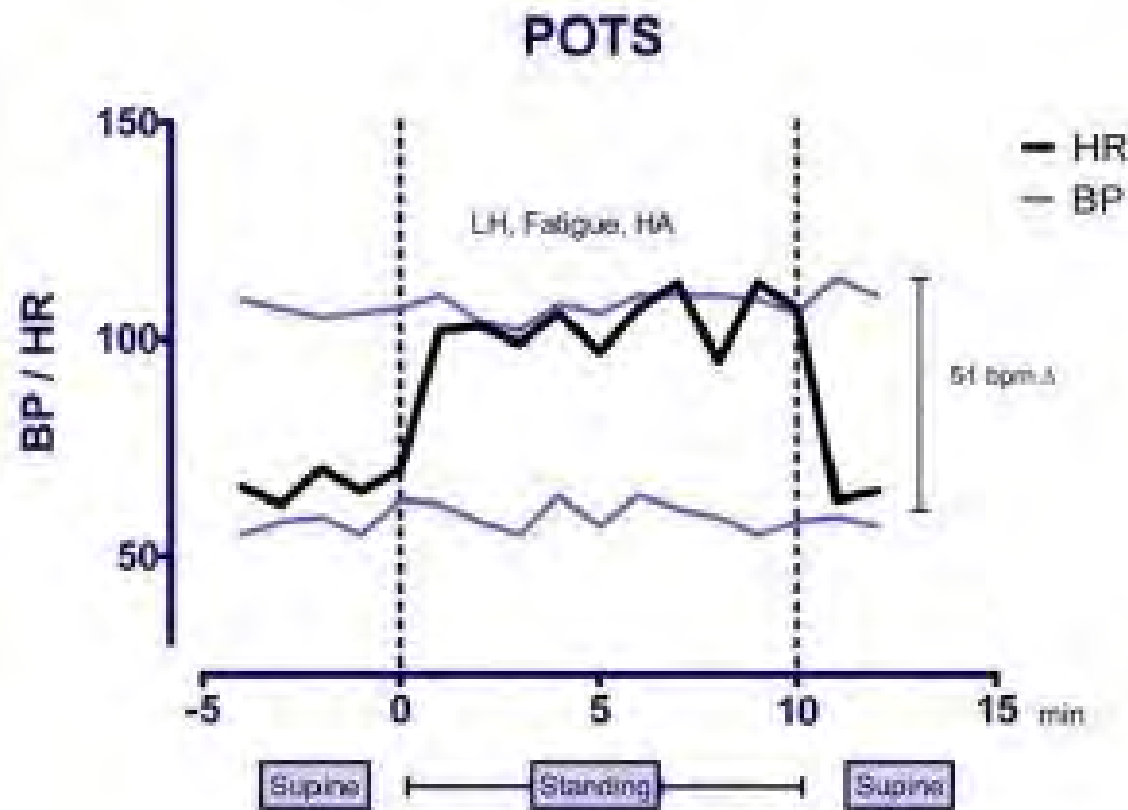
Data Source: OMF's Patient-Reported Treatment Outcomes in ME/CFS and Long COVID (Eckey et al. 2025) | CC BY 4.0



- 79% improved with pacing
- 82% worsened with graded exercise therapy



Orthostatic intolerance



- **Postural orthostatic tachycardia syndrome (POTS)** (pulse increase of >30, below 19 of >40, with stable blood pressure)
- **Orthostatic hypotension** (systolic BP drop >20 mm Hg, diastolic BP drop >10 mm Hg)

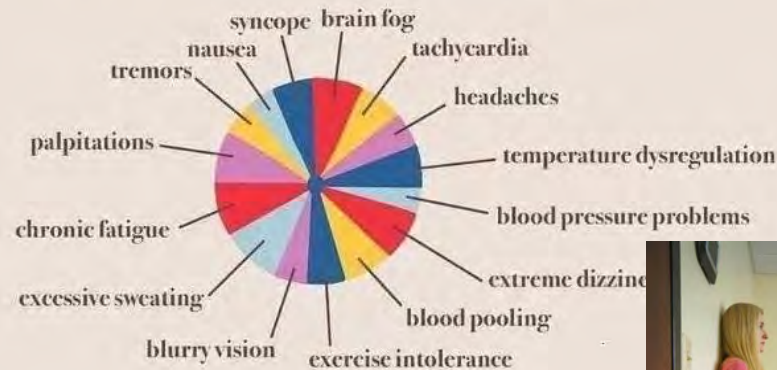


Postural orthostatic tachycardia syndrome

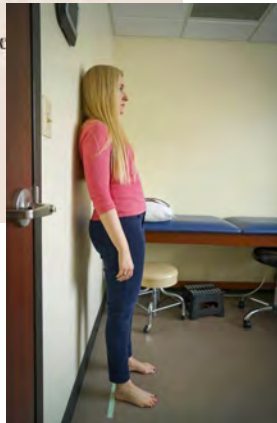
what people think POTS is like:



what POTS is actually like:



@chronically.kelsey



- Entity known since 1871
- 79% of long COVID patients have POTS
- Diffuse symptoms (rarely explicit palpitations in medical history!)
- **ALWAYS** proactively look for and treat POTS or OH:
10-minute passive standing test (NASA lean test)!
- **Drug of choice: ivabradine**

Seeley MC, Gallagher C, Ong E, et al. High Incidence of Autonomic Dysfunction and Postural Orthostatic Tachycardia Syndrome in Patients with Long COVID: Implications for Management and Health Care Planning [published online ahead of print, 2023 Jun 29]. *Am J Med.* 2023;S0002-9343(23)00402-3. doi:10.1016/j.amjmed.2023.06.010

TikTok user: @kelseyybeth



Neurologische Praxis Solothurn
Dr. med. Maja Strasser

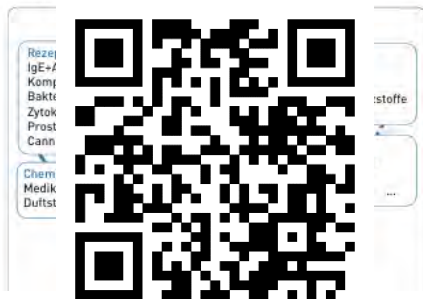


Mast cell hyperactivity

Labordiagnostik bei Verdacht auf Mastzellaktivierungssyndrom

Die Bedeutung der Mastzelle

Die Mastzellen gehören zum unspezifischen Immunsystem und sind Bestandteil fast jeden Gewebes unseres Körpers. Für gewöhnlich zirkulieren sie nicht im Blut und sitzen als Wächter vor allem angereichert an den Kontaktstellen zur Umwelt, wie Haut, Schleimhaut, Luftwege und Magen-Darm-Trakt. Die Mastzellen wurden durch ihren prominenten IgE-Rezeptor (FcεRI) bisher vor allem als primäre Effektorzellen bei Typ-I-allergischen Erkrankungen angesehen. Sie haben jedoch in den letzten Jahren deutlich an Aufmerksamkeit in der Forschung und Medizin gewonnen. Durch ihre einzigartig vorhandene Vielfalt an Oberflächenrezeptoren, weit über den IgE-Rezeptor hinaus, sind sie durch eine Fülle an immunologischen sowie nicht-immunologischen Reizen aktivierbar. Die Mastzellaktivierung führt zur Degranulation und Neusynthese eines ebenfalls breiten Spektrums entzündlicher und immun-modulatorischer Botenstoffe [Abb. 1]. Das erklärt ihre Beteiligung an vielen verschiedenen physiologischen und pathologischen Prozessen, wie z.B. der Blutdruckregulation, Wundheilung Darmmotilität, Angiogenese sowie der Schmerz- und Stressregulation.



Das Mastzellaktivierungssyndrom (MCAS)

Unter dem Begriff Mastzellaktivierungssyndrom (MCAS) wird eine Gruppe von Erkrankungen zusammengefasst, bei der Symptome durch eine übermäßige und unangemessene Freisetzung von zumeist pro-inflammatorischen Mastzellmediatoren ausgelöst werden. In Folge dessen können eine Reihe zum Teil sehr variabler Symptome auftreten, die multiple Organe betreffen können bis hin zur systemischen Anaphylaxie [Abb. 2].

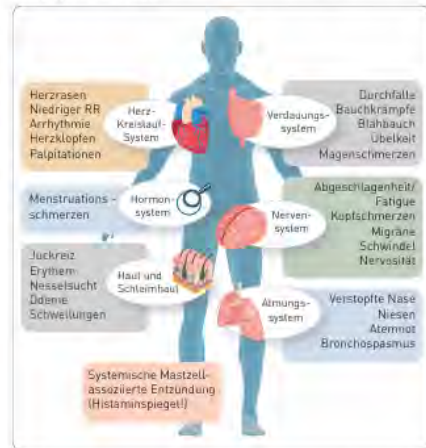


Abb. 2 Übersicht der durch Mastzellmediatoren ausgelösten Symptome (beispielhaft). I.d.R. sollten für die Diagnosestellung MCAS mindestens 2 Organsysteme von den Symptomen betroffen sein.

- MCAS known since the 1980s
- Antihistamine, e.g., fexofenadine 120-180 mg
- Nutritional advice: low histamine, anti-inflammatory
- For postprandial worsening, Daosin[®] with meals

Afrin LW et al. Often seen, rarely recognized: mast cell activation disease – a guide to diagnosis and therapeutic options. Ann Med 2016; 48:190

Sumantri S, Rengganis I. Immunological dysfunction and mast cell activation syndrome in long COVID. Asia Pac Allergy. 2023;13(1):50-53. doi:10.5415/apallergy.0000000000000022



Avoid reinfection

For those who already have long COVID:

- Reinfection: deterioration in 80% (improvement in 10%)

Those who have recovered from long COVID:

- 60% risk of relapse

→ **Aerosols: FFP2 masks, HEPA air filters, frequent ventilation, monitoring of CO₂ (e.g. Aranet 4)**



Treatment protocol M. Strasser

Basics (first consultation!)

- **P**acing for exercise intolerance with post-exertional malaise (physical therapy, occupational therapy, app, diary, brochure, etc.)
- **P**OTS
- **H**istamines (antihistamines, nutritional counseling)
- **R**einfection must be avoided (FFP2, HEPA filters, and ventilation at home and in the classroom!)

→ **Perfect punks honor rebels.**



Psychotherapy for coping



Opinion

The Role of Psychotherapy in the Care of Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

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Abstract: Myalgic encephalomyelitis/chronic fatigue (ME/CFS) is a post-infectious, chronic disease that can lead to severe impairment and, even, total disability. Although the disease has been known for a long time, and has been coded in the ICD since 1969 (C93.3), medical research has not yet been able to reach a consensus regarding its physiological basis and how best to treat it. Against the background of these shortcomings, psychosomatic disease models have been developed and psychotherapeutic treatments have been derived from them, but their empirical testing has led to sobering results. According to the current state of research, psychotherapy and psychosomatic rehabilitation have no curative effect in the treatment of ME/CFS. Nevertheless, we see numerous patients in practices and outpatient clinics who suffer severely as a result of their illness and whose mental well-being and coping strategies would benefit from psychotherapeutic help. In this article, we outline a psychotherapeutic approach that serves this need, taking into account two basic characteristics of ME/CFS: firstly, the fact that ME/CFS is a physical illness and that curative treatment must therefore be physical; and secondly, the fact that post exertional malaise (PEM) is a cardinal symptom of ME/CFS and thus warrants tailored psychotherapeutic attention.

Keywords: chronic fatigue syndrome; cognitive behavioral therapy; exercise; myalgic encephalomyelitis; pacing; psychotherapy; post-exertional malaise

- Very debilitating *organic* disease
- Psychotherapy for long COVID or ME to improve coping and mental well-being (not curative!)
- Post-exertional malaise (PEM) as a cardinal symptom must be given special consideration in psychotherapy



Citation: Grande, T.; Grande, B.; Gerner, P.; Hammer, S.; Stingl, M.; Vink, M.; Hughes, B.M. The Role of Psychotherapy in the Care of Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Medicina* **2023**, *59*, 719. <https://doi.org/10.3390/medicina59040719>



ME or Long COVID and insurance



Long COVID: only a few receive disability benefits

Kassenärztz Espresso > Kassenärztz >

Krank nach Corona

Long-Covid-Betroffene erheben schwere Vorwürfe gegen die IV

Überlange Verfahren, Abdrängen in die Psychoecke und Gutachten, die das Krankheitsbild nicht annähernd erfassen – so schildern Long Covid-Betroffene, Ärzte und Patientenanwälte ihre Erfahrungen mit der Invalidenversicherung

Kathrin Winzenried
Grafen, 18.24 Uhr
Aktualisiert am 18.09.2023

«Mit Long Covid oder dem schweren Verlauf der Krankheit, ME/CFS, haben Betroffene bei den IV-Gutachterstellen eigentlich schon verloren», sagt Neurologin Maja Strasser.

In ihrer Facharztpraxis in Solothurn betreut sie 160 Patientinnen und Patienten mit Long Covid. Es ist eine der wenigen Praxen in der Schweiz, die spezialisiert ist auf Long Covid. Wegen Überlastung nimmt sie keine neuen Patientinnen und Patienten mehr auf.

«IV-Gutachten bilden komplexes Krankheitsbild nicht ab»

Sie behandle sehr viele schwer kranke Patientinnen und Patienten, sagt Neurologin Maja Strasser. Aber keine Patientengruppe sei aufwendiger als diejenige mit Long Covid und ME/CFS, der sogenannten Myalgischen Enzephalomyelitis, einer schweren neuroimmunologischen Erkrankung, die zu einem hohen Grad körperlicher Behinderung führt.

- Disability insurance 01/25: 12% receive benefits
- Expert assessments on long COVID or ME fail to recognize *the* central aspect, PEM



Equal treatment in insurance

– Art. 7⁶¹ Obligations de l'assuré

⁶¹ L'assuré doit entreprendre tout ce qui peut être raisonnablement exigé de lui pour réduire la durée et l'étendue de l'incapacité de travail (art. 6 LPGA⁶²) et pour empêcher la survenance d'une invalidité (art. 8 LPGA).

⁶² L'assuré doit participer activement à la mise en œuvre de toutes les mesures raisonnablement exigibles contribuant soit au maintien de son emploi actuel, soit à sa réadaptation à la vie professionnelle ou à l'exercice d'une activité comparable (travaux habituels). Il s'agit en particulier:

- a. de mesures d'intervention précoce (art. 7d);
- b. de mesures de réinsertion préparant à la réadaptation professionnelle (art. 14a);
- c. de mesures d'ordre professionnel (art. 15 à 18 et 18b);
- d. de traitements médicaux au sens de l'art. 25 LAMal⁶³;
- e.⁶⁴ de mesures en vue d'une nouvelle réadaptation destinées aux bénéficiaires de rente au sens de l'art. 8a, al. 2 (mesures de nouvelle réadaptation).

⁶¹ Nouvelle teneur selon le ch. I de la LF du 6 oct. 2006 (5^e révision AI), en vigueur depuis le 1^{er} janv. 2008 (RO 2007 5129; FF 2005 4215).

⁶² RS 830.1

⁶³ RS 832.10

⁶⁴ Introduite par le ch. I de la LF du 18 mars 2011 (6^e révision AI, 1^{er} volet), en vigueur depuis le 1^{er} janv. 2012 (RO 2011 5659; FF 2010 1647).

– Art. 7a⁶⁵ Mesures raisonnablement exigibles

Est réputée raisonnablement exigible toute mesure servant à la réadaptation de l'assuré, à l'exception des mesures qui ne sont pas adaptées à son état de santé.

⁶⁵ Introduit par le ch. I de la LF du 6 oct. 2006 (5^e révision AI), en vigueur depuis le 1^{er} janv. 2008 (RO 2007 5129; FF 2005 4215).



- **Equal treatment in insurance** → every insured person is assessed **based on current evidence and in accordance with the Federal Law on Disability Insurance** (cooperation with reasonable, adapted measures)

When

- Almost all assessments for ME and Long COVID **do not explore *the* limiting symptom of post-exertional malaise, disregard pathological findings and pre-existing expert opinions, and postulate a psychosomatic illness**
- **39%** of those assessed suffer **irreversible deterioration as a result of the assessment,**
equal treatment is not guaranteed.



Enormous economic costs

Table 1 | Estimated impact of long COVID on national economies in 2024^{a,b}

	Brazil	France	Japan	Saudi Arabia	Spain	Taiwan	United Kingdom	United States
Hours lost for those that exit the workforce (in millions)	509.8	182.8	1,100	442.4	106	230.4	158.9	953.6
Hours lost for those that reduce work hours (in millions)	196.6	72.5	442.4	163.3	41.1	86	61.7	366.3
Hours lost for those that continue working after acute infection (in millions)	97.9	40	222	65	20.7	36.3	31.3	177.5
Total work hours lost (in millions)	803.3	295.1	1,800	670.7	167.8	352.7	251.8	1,500
GDP loss due to long COVID (in billions of US dollars)	11	21	72.2	24.4	7.8	12.2	15.5	152.6
Percentage GDP loss due to long COVID	-0.50%	-0.60%	-1.60%	-2.30%	-0.50%	-1.5%	-0.50%	-0.50%

^aData from ref. 170. ^bThe eight countries were selected on the basis of data availability.



Discussion

Relative to my earlier estimate with Lawrence Summers of the cost of long COVID of \$2.6 trillion, the higher number here is higher: \$3.7 trillion in total. The higher estimate is largely a result of the greater prevalence of long COVID than we had guessed at the time. There are about 10 times the number of people with long COVID as have died of COVID.

Because long COVID is so new, there is uncertainty about all of the numbers involved in the calculations. Still, the costs here are conservative, based on only cases to date.

The enormity of these costs implies that policy to address long COVID are urgently needed. With costs this high, virtually any amount spent on long COVID detection, treatment, and control would result in benefits far above what it costs.



Table 1: The Economic Cost of Long COVID	
Impact	Value (\$ billion)
Reduced quality of life	\$2,195
Reduced earnings	\$997
Increased medical spending	\$528
Total cost	\$3,719
Cost per capita	\$11,189
Percent of 2019 GDP	17%

OECD: Cost of Long COVID 2024: 0.5-2.3% of GDP (up to CHF 16 billion)

CH: Army: 1% of GDP; Education: 5.7%; Healthcare 12.3%

Harvard economist David Cutler: *With costs this high, virtually any amount spent on long COVID detection, treatment, and control would result in benefits far above what it costs.*

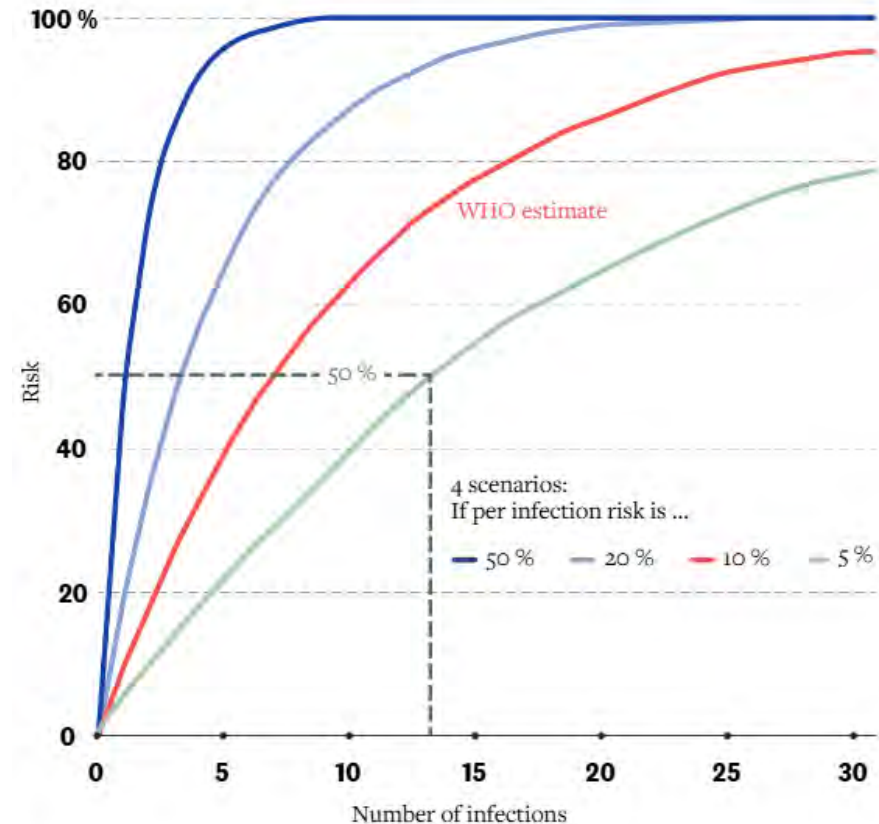


There's money in prevention

- Home office and sickness regulations
- FFP2 masks
- Communication about risks of COVID-19, role modeling
- Air filters, frequent airing
- Vaccinations
- Workplace design, e.g., rapid tests before meetings

There Is Money in Prevention; Britta Domke;
Harvard Business Manager; December 20, 2023

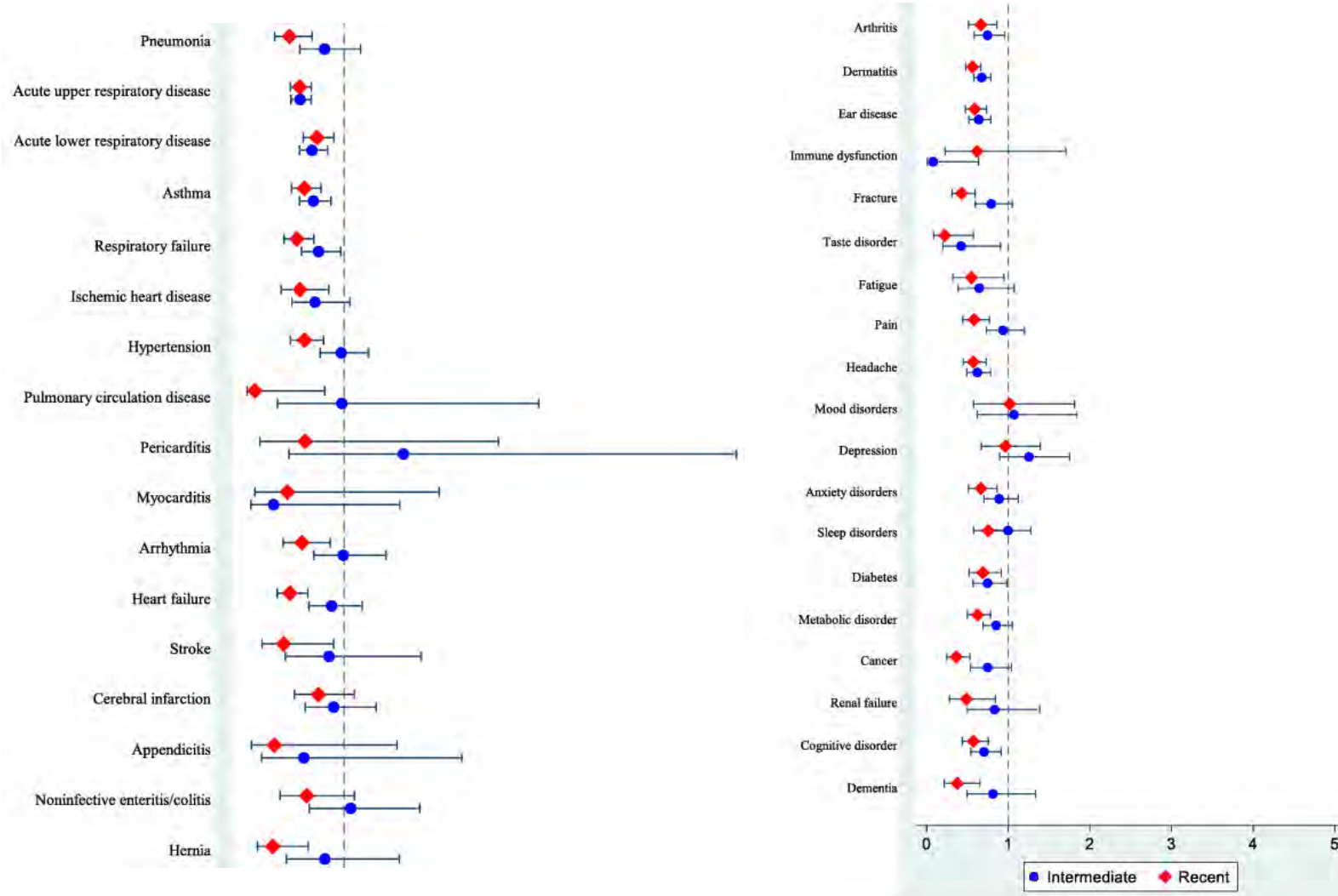
Lifetime cumulative risk of developing long Covid
By per-infection risk and number of infections



Source: David Steadson, International Long Covid Resource Centre, with CDC data



Recent vaccination protects



- 14-149 days since SARS-CoV-2 vaccination: better protection from severe acute infection and long-term sequelae than 150-364 days
- Best prevention: no infection at all



Case presentation

- Healthy adolescent, competitive athlete, born 10/2009
- August 2021: COVID-19 confirmed by PCR, mild acute course
- **Fall 21: severe headaches for days after exercise**



Case study – ChatGPT reply

A 12 year old boy, athlete, has severe headaches for several days after sports. No trauma. He had COVID-19 a couple of weeks ago. Do you have an idea what he could have? What exams should be done?



Has the boy experienced any other symptoms, like nausea or sensitivity to light? It's important to consider post-viral headaches, especially following COVID-19. A thorough neurological exam is essential, along with imaging studies like an MRI or CT scan to rule out any serious conditions. Blood tests might also help to assess for inflammation or other underlying issues.



Case presentation

- Diagnosis: "Tension type headaches"
- Concerned parents are reassured; he should continue training
- MRI brain March 2022: sinusitis, otherwise unremarkable
- 2022: Increasingly debilitating symptoms
- Confined to home since early 2023, unable to attend school, meets diagnostic criteria for ME



Case presentation

- Postural orthostatic tachycardia syndrome
- Extensive investigation inconclusive
- Infectious Diseases February 2023: Initial diagnosis "Post-infectious fatigue syndrome after COVID-19"
- **Early detection and correct management of exercise intolerance with post-exertional malaise → Prevent progression to ME!**



Key takeaways

- Long COVID is common (even in children and adolescents!) – question diagnostic sensitivity („Did you have infection? Are you fully recovered?”)
- Early diagnosis and proper management prevent poor outcomes **(headaches or muscle pain, malaise, gastrointestinal symptoms: exercise 1-3 days ago? → post-exertional malaise!)**



Take Home Messages

- **Chronic pain, “psychosomatic illness”, Münchhausen by proxy:** ask about PEM, fatigue, exercise intolerance, sleep disturbances, cognitive disturbances, orthostatic intolerance, pain, drug intolerances → **ME?**
- Post-exertional malaise must be asked about in detail (especially in assessments for insurance!)
- **Post-exertional malaise must be avoided at all costs**, as it can be irreversible (**pacing**, not graded exercise therapy!)



Take Home Messages

- **P**acing for exercise intolerance with post-exertional malaise (physical therapy, occupational therapy, app, diary, brochure, etc.)
 - **P**OTS (ivabradine)
 - **H**istamines (antihistamines, nutritional counseling)
 - **R**einfection avoidance (FFP2, HEPA filters, and ventilation at home and in the classroom!)
- **Perfect punks honor rebels.**



Protection of vulnerable people

theguardian.com

We are all playing Covid roulette. Without clean air, the next infection could permanently disable you

George Monbiot



As rich people plough money into ventilation to protect themselves, those with long Covid are treated as an embarrassment

Thu 26 Jan 2023 12.26 GMT

- In Switzerland, approximately 1 million people are at greatly increased risk from SARS-CoV-2
 - Human right to life, physical integrity, education, and social participation
- **Optimize indoor air with HEPA filters and ventilation (in all public spaces, but especially in healthcare facilities and education)**
- **FFP2 masks depending on the situation**
- **At least: See a mask, wear a mask**



Austria: PAIS Action Plan

Aktionsplan zu postakuten Infektionssyndromen (PAIS)



Care: PAIS patients require rapid, comprehensive, and low-threshold access to appropriate care which includes direct medical treatment as well as PAIS-qualified nursing, healthcare, and social services professionals. In addition, the expansion of telemedicine services, especially for seriously ill patients, is essential. The comprehensive catalog of measures in the field of care includes primary care, specialist care, tertiary care/inpatient care, rehabilitation, and psychosocial care.

The recommended measures include the establishment of decentralized transdisciplinary and multiprofessional contact points and specialized treatment facilities linked to a research center (national reference center), as well as the creation of a care pathway.

Definition; data situation; prevention and diagnostics; education, training, and awareness raising; social security; research and knowledge; special needs of children and adolescents



National strategy for ME and LC passed

24.4452

MOTION

Nationale Strategie zur Verbesserung der gesundheitlichen Situation von Menschen mit ME/CFS und Long Covid

Eingereicht von:



HESS LORENZ

Die Mitte-Fraktion. Die Mitte. EVP.
Die Mitte

Einreichungsdatum:

18.12.2024

Eingereicht im:

Nationalrat

Stand der Beratungen:

Stellungnahme zum Vorstoss liegt vor



BEGRÜNDUNG

In der Schweiz sind ca. 60'000 Personen an ME/CFS erkrankt, hinzukommen mehr als 300'000 Long Covid Betroffene, von denen ein signifikanter Teil unter die Diagnose ME/CFS fallen dürfte und die Fälle künftig durch Covid-19 zunehmen. Im Gegensatz zum Ausland, das Forschung und Kompetenzzentren finanziert, fällt die Schweiz zurück. Aufgrund der neusten Erkenntnisse und der grossen Auswirkung auf die Bevölkerung fordere ich den Bundesrat auf, eine nationale Strategie und einen Massnahmenplan für ME/CFS und Long Covid zu erarbeiten. Dabei sollen alle relevanten Akteure eingebunden werden. Der Plan soll folgende Massnahmen umfassen:

- Wissenssicherung- und Vermittlung im Bereich der Diagnose, Versorgung und Therapie.
- Unterstützung einer optimalen Zusammenarbeit von Fachpersonen, Personen der gesundheitlichen Grundversorgung, Organisationen Betroffener und den verantwortlichen Instanzen der Gesundheitsversorgung;
- Rechtsgleicher Zugang zu Diagnostik und wirksamen Therapien sowie Unterstützung derer Erforschung;
- Adäquate Unterstützung und Anerkennung durch die Sozialversicherungen und deren Gutachter;
- Förderung von Grundlagen- und klinischer Forschung
- Unterstützung nationaler oder kantonaler Koordinationsstellen für Betroffene;
- Daten zu ME/CFS und Long COVID zentral erfassen;
- Zusammenarbeit mit europäischen/internationalen Referenzzentren und Netzwerken;
- Sicherstellung der Finanzierung durch Bund und Kantone.

- Council of States 09/18/2025 (final hurdle): approved
- Implementation starting 01/2026; Dr. Strasser in expert commission



National Decade Against Post-Infectious Diseases

Chronisches Fatigue Syndrom

Bundesregierung will Erforschung von ME/ CFS stärker fördern

Die Zahl der Long-Covid- und ME/CFS-Erkrankungen hat seit der Pandemie stark zugenommen. Bis 2036 sollen deswegen 500 Millionen Euro in die Forschung investiert werden.

14. November 2025, 0:10 Uhr Quelle: DIE ZEIT, dpa, jsp

▶ 3 Min. 20 Zusammenfassen

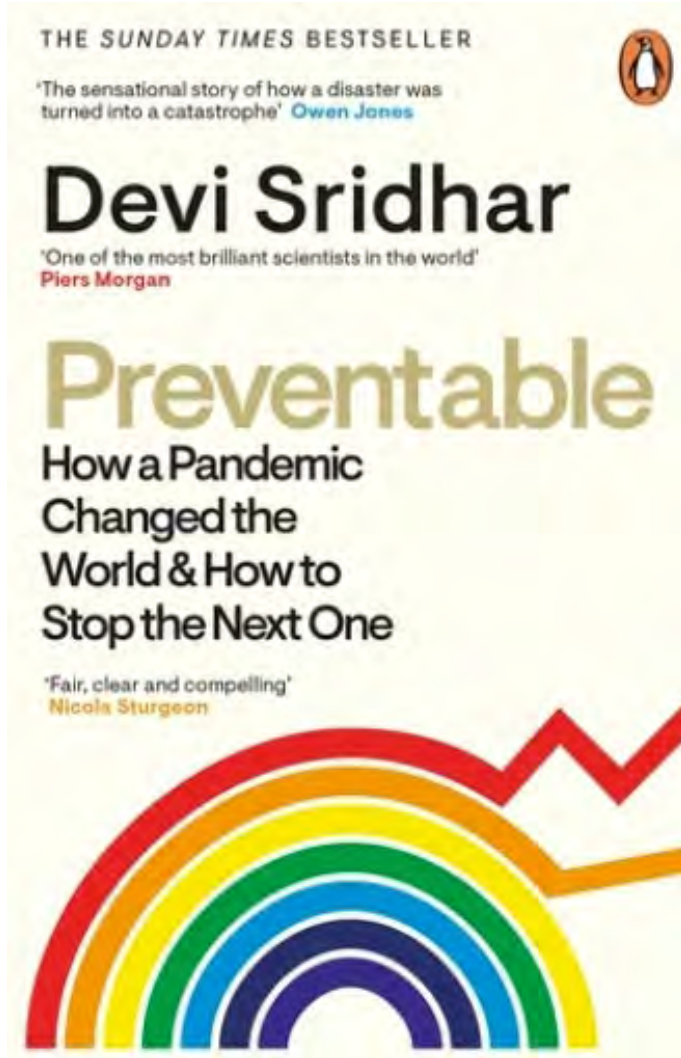


Hunderttausende Menschen in Deutschland sind an ME/CFS erkrankt. Diese Demonstration vor dem Reichstagsgebäude im Januar 2023 erinnerte an sie. © Sean Gallup/Getty Images

- Germany: 2026: 15 million euros for research of Long COVID and ME
- From 2027 to 2036: 50 million euros each year
- Goal: to research diagnosis and treatment to such an extent that these conditions can be cured by the mid-2030s at the latest



Professor Devi Sridhar, Global Public Health



- “**Omicron** has now turned into a disease that challenges how we keep society functioning. And, while some point to its being ‘milder’ – the hospitalization rates are estimated to be half of those of the Delta variant – it **is still hospitalizing and killing people, especially those who are unvaccinated.**”
- “Now is the time to be stepping up to **invest in science** so that when the next pandemic arrives we are ready with the words ‘never again’ burned into our minds. And now is the time to be **mentoring and cultivating the next generation of children to pursue scientific careers.**”



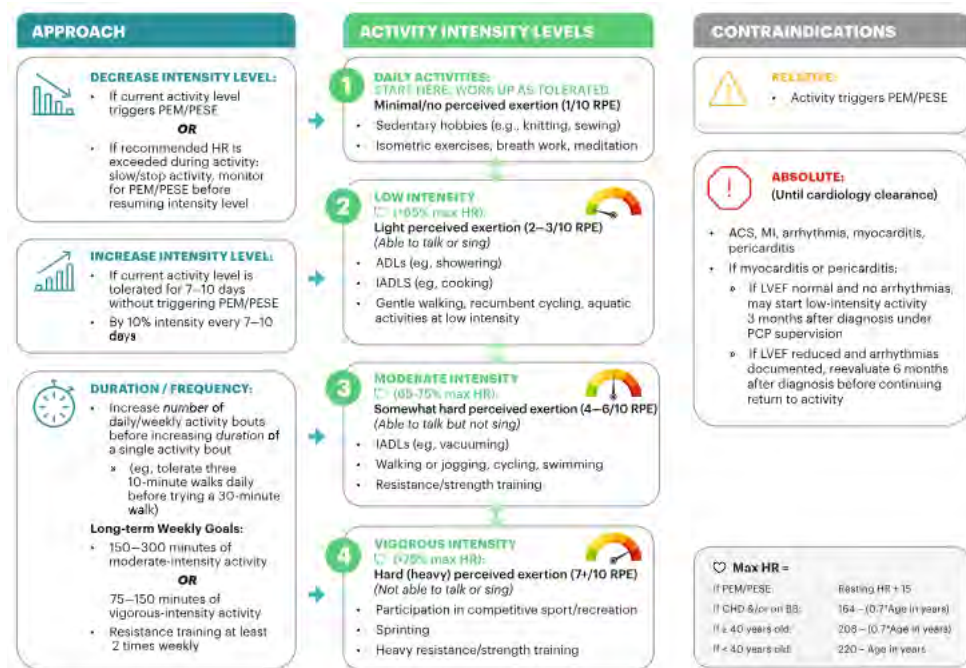


TABLE 5 Commonly used medications for Long COVID symptoms^{a,b,c}

Medication	Dose	Indications	Side effects and other considerations
Propranolol	5–10 mg BID to QID	IST, POTS, OH, NCS, episodic hypertension	Bradycardia, hypotension, fatigue, depression, asthma exacerbation
Midodrine	2.5–10 mg TID to QID	POTS, OH, NCS, hypotension	Supine hypertension, scalp paresthesias, piloerection
Fludrocortisone	Start 0.05 mg QD for 1 week, then increase by 0.05 mg QD every week to a max dose of 0.2 mg QD	POTS, OH, NCS, hypotension	Hypokalemia, edema, headache
Pyridostigmine	30–60 mg BID to TID	POTS, OH, AN, GI dysmotility with constipation	Diarrhea, muscle twitching
H1 and H2 antihistamines in combination (e.g., cetirizine and famotidine)	Sample regimen: Cetirizine 10 mg daily or Levocetirizine 5 mg daily; Famotidine 20 mg daily or bid	MCAS (e.g., itching, flushing, hives, rhinitis, episodic tachycardia, abdominal pain, diarrhea, headache, dyspnea)	Cetirizine: fatigue, headache, abdominal pain, drowsiness, dizziness, dry mucous membranes. Famotidine: headache, dizziness, constipation, diarrhea.
Low-dose naltrexone ^{45–48}	Sample regimen: Start 1 mg QD for 4 weeks, then increase by 1 mg QD every 4 weeks to a max dose of 4.5 mg QD being studied	Fatigue, PEM/PESE, headache	Often requires compounding. Diarrhea and nausea
Meltryphenidate	5–10 mg BID to TID	POTS, OH, NCS, brain fog, fatigue	Headache, tachycardia, insomnia, PEM/PESE exacerbation if over-exerts during drug's duration of action
Amantadine	100 mg QD to BID	Fatigue, brain fog	Contraindicated for ESRD. Abrupt discontinuation can cause withdrawal symptoms. Dry mouth, OH, neuropsychiatric symptoms, livedo reticularis, nausea, abdominal pain
Duloxetine	20–60 mg QD	Depression (especially if coexisting neuropathic pain), OH, NCS	Hypertension, nausea, increased perspiration
Fluoxetine	10–40 mg QD	Anxiety (especially if predominant symptom), depression, NCS	Anxiety, insomnia, nausea
Bupropion	75–150 mg QD to BID	Depression (especially if neurovegetative symptoms), fatigue, hypersomnolence, POTS, NCS	Anxiety, insomnia, nausea, decreased seizure threshold
Gabapentin	100–300 mg QHS to TID, then increase 100–300 mg every week	Neuropathic pain, poor sleep quality	Needs renal dosing. Brain fog, sleepiness, dizziness, nausea
COVID-19 vaccine ^{124–126}	Annual booster	Lower risk of subsequent COVID infection sequelae and reduce the severity and duration of PASC	Vaccine reaction or worsening of symptoms

Cheng AL, Herman E, Abramoff B, et al.

Multidisciplinary collaborative guidance on the assessment and treatment of patients with Long COVID: A compendium statement. PM R.

2025;17(6):684–708.

doi:10.1002/pmrj.13397



Long COVID Network Solothurn

- Detailed treatment protocol (with sources!), cheat sheet, mindmaps (French, English, German)
- Knowledge base
- Invitations as guest speaker: maja.strasser@hin.ch



HEALTH + BEHAVIOR

Scientists confirm COVID tied to wildlife sales at Chinese market

The research, co-authored by UCLA's Marc Suchard, indicates the pandemic started with two separate jumps from animals to humans



Arend Kuester/Flickr

Researchers say all available evidence indicates that live animals sold at the Huanan Seafood Wholesale Market in Wuhan, China, were the source of COVID-19. (Pictured: A seafood and fresh food market in Wuhan.)

- **WHO: One Health** is an integrated, unifying approach that aims to **sustainably balance and optimize the health of people, animals and ecosystems.**
- It recognizes that the **health of humans, domestic and wild animals, plants, and the wider environment (including ecosystems)** are closely linked and interdependent.
- By linking humans, animals and the environment, One Health can help to **address the full spectrum of disease control – from prevention to detection, preparedness, response and management – and contribute to global health security.**





During a pandemic, no one's health is fully in their own hands. ... Infectious diseases are always collective problems because they are infectious.

...

Each person's odds of falling ill depend on the choices of everyone around them – and on societal factors, such as poverty and discrimination, that lie beyond their control. (Ed Yong, The Atlantic)





- Frodo: “I wish it need not have happened in my time.”
- Gandalf: “So do all who live to see such times. But that is not for them to decide. All we have to decide is what to do with the time that is given us.”

