

Information sources and further reading

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Information sheet 1: What is Long COVID?

Physiopedia – Long COVID: https://www.physio-pedia.com/Long_COVID#ppm63722

World Physiotherapy response to COVID-19 briefing paper 9 - Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise
https://world.physio/sites/default/files/2021-06/Briefing_Paper_9_Long_Covid_Final.pdf

Definition and prevalence of Long COVID

NICE guideline [NG188]. [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#). Published: 18 December 2020.

Hannah E Davis, Gina S Assaf, Lisa McCorkell, et al. [Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact](#), *medRxiv* 2020.

Logue JK, Franko NM, McCulloch DJ, et al. [Sequelae in adults at 6 months after COVID-19 infection](#), *JAMA Network Open* 2021;4:e210830.

Munblit D, Bobkova P, Spiridonova E, et al. [Risk factors for long-term consequences of COVID-19 in hospitalised adults in Moscow using the ISARIC Global follow-up protocol: StopCOVID cohort study](#), *medRxiv* 2021.

National Institute for Health Research. [Living with COVID19 - Second Review](#). 2021;2021.

E Perego, F Callard. [Patient-made Long COVID changed COVID-19 \(and the production of science, too\)](#). *SocArXiv* 2021;DOI: 10.31235/osf.io/n8yp6.

1 in 10 of all cases will exhibit symptoms for a period of 12 weeks or longer

S.Rajan KK. [In the wake of the pandemic: preparing for Long COVID](#). World Health Organization regional office for Europe Policy Brief 39. *World Health Organization regional office for Europe* 2021

Office for National Statistics. [The prevalence of long COVID symptoms and COVID-19 complications](#). 2020;2020.

National Institute for Health and Care Excellence. [COVID-19 rapid guideline: managing the long-term effects of COVID-19](#). NICE Guideline [NG188]. Invalid date;2021.

Office for National Statistics. [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK: 4 June 2021](#). 2021;2021.

Many people living with the disease were previously fit and healthy.

Décary S, Gaboury I, Poirier S, Garcia C, Simpson S, Bull M, Brown D, Daigle F. [Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#). *Journal of Orthopaedic & Sports Physical Therapy*. Published Online: 30 April 2021. Volume 51 Issue5 Pages 197-200

Children experience Long COVID symptoms similar to adults and at about the same frequency

Maria Cohut. Long COVID and children: The unseen casualties of COVID-19:

<https://www.medicalnewstoday.com/articles/long-covid-and-children-the-unseen-casualties-of-covid-19#How-many-children-are-long-haulers>

D.Buonsenso, D.Munblit, C.De Rose, D.Sinatti, A.Ricchiuto, A.Carfi, P.Valentini. [Preliminary Evidence on Long COVID in children](#). *MedRxiv*, 2021.

Long COVID affects people who have been hospitalised with acute COVID-19 and those who recovered at home. Individuals who have experienced either mild or severe COVID-19 can go on to have prolonged symptoms or develop Long COVID.

Public Health England. [COVID-19: epidemiology, virology and clinical features](#). February 18, 2021.

L.Townsend, J.Dowds, K.O'Brien, G.Sheill, AH.Dyer, B.O'Kelly, JP.Hynes, A.Mooney, J.Dunne, CN.Cheallaigh, C.O'Farrelly, NM.Bourke, N.Conlon, I.Martin-Loeches, C.Bergin, P.Nadarajan,C.Bannan. [Persistent Poor Health Post-COVID-19 Is Not Associated with Respiratory Complications or Initial Disease Severity](#). *Annals of the American Thoracic Society*, 2021.

EL.Graham, JR.Clark, ZS.Orban, PH.Lim, AL.Szymanski, C.Taylor, RM.DiBiase, DT.Jia, R.Balabanov, SU.Ho, A.Batra, EM.Liotta, IJ.Koralnik. [Persistent neurologic symptoms and cognitive dysfunction in non-hospitalized Covid-19 "long haulers"](#). *Annals of Clinical and Translational Neurology*, 2021.

P.Brodin. [Immune determinants of COVID-19 disease presentation and severity](#). *Nature Medicine*, 2021;27:28–33.

Townsend L, Dyer AH, Jones K, Dunne J, Mooney A, Gaffney F, O'Connor L, Leavy D, O'Brien K, Dowds J, Sugrue JA. [Persistent fatigue following SARS-CoV-2 infection is common and independent of severity of initial infection](#). *Plos one*. 2020 Nov 9;15(11):e0240784.

M.Augustin, P.Schommers, M.Stecher, F.Dewald, L.Gieselmann, H.Gruell, C.Horn, K.Vanshylla, V.Di Cristanziano, L.Osebold, M.Roventa, T.Riaz, N.Tschernoster, J.Altmueller, L.Rose, S.Salomon, V.Priesner, JC.Luers, C.Albus, S.Rosenkranz, B.Gathof, G.Fätkenheuer, M.Hallek, F.Klein, I.Suárez, C.Lehmann. [Recovered not restored: Long-term health consequences after mild COVID-19 in non-hospitalized patients](#). *MedRxiv*, 2021.

JK.Logue, NM.Franko, DJ.McCulloch, D.McDonald, A.Magedson,CR.Wolf, HY.Chu. [Sequelae in Adults at 6 Months After COVID-19 Infection](#). *JAMA Netw Open*. 2021;4(2):e210830.

PHOSP-COVID Collaborative Group. [Physical, cognitive and mental health impacts of COVID-19 following hospitalisation – a multi-centre prospective cohort study](#). *MedRxiv*, 2021.

A.Dennis, M.Wamil, J.Alberts, J.Oben, DJ.Cuthbertson, D.Wootton, M.Crooks, M.Gabbay, M.Brady, L.Hishmeh, E.Attree, M.Heightman, R.Banerjee, A.Banerjee. [Multiorgan impairment in low-risk individuals with post-COVID-19 syndrome: a prospective, community-based study](#). *BMJ Open* 2021;11:e048391.

Long COVID is a multi-system disease; there are over 200 listed symptoms which occur in variable combinations and can fluctuate in both predictable and unpredictable patterns of flares and remissions.

S.Rajan, K.Khunti, N.Alwan, C.Steves, T.Greenhalgh, N.MacDermott, A.Sagan, M.McKee. [In the wake of the pandemic: preparing for Long COVID](#). World Health Organization regional office for Europe, 2021. Policy Brief 39.

National Institute for Health and Care Excellence (NICE). [COVID-19 Rapid Guideline: Managing The Long-term Effects of COVID-19](#). 2020 December 18 [Accessed 7 June 2021]

Davis HE, Assaf GS, McCorkell L, Wei H, Low RJ, Re'em Y, Redfield S, Austin JP, Akrami A. [Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact](#). *medRxiv*. 2020 Jan 1.

Carfi A, Bernabei R, Landi F. [Persistent symptoms in patients after acute COVID-19](#). *Jama*. 2020 Aug 11;324(6):603-5.

Assaf G, Davis H, McCorkell L. [Report: What Does COVID-19 Recovery Actually Look Like? An analysis of the prolonged COVID-19 symptoms survey by Patient-Led Research Team](#). *Patient-Led Research* [online]. Patient-Led Research. 2020.

Salmon-Ceron D, Slama D, Broucker TD. [Clinical, virological and imaging profile in patients with prolonged forms of COVID-19: A cross-sectional study](#). *J Infect*. 2020.

Chaolin Huang, Lixue Huang, Yeming Wang, Xia Li, Lili Ren, Xiaoying Gu, Liang Kang, Li Guo, Min Liu, Xing Zhou, Jianfeng Luo, Zhenghui Huang, Shengjin Tu, Yue Zhao, Li Chen, Decui Xu, Yanping Li, Caihong Li, Lu Peng, Yong Li, Wuxiang Xie, Dan Cui, Lianhan Shang, Guohui Fan, Jiuyang Xu, Geng Wang, Ying Wang, Jingchuan Zhong, Prof Chen Wang, Prof Jianwei Wang, Dingyu Zhang, Prof Bin Cao. [6-month consequences of COVID-19 in patients discharged from hospital: a cohort study](#). *The Lancet*, 2021

Most common symptoms after 6 months: extreme exhaustion (fatigue); post-exertional symptom exacerbation (PESE); problems with memory and concentration (brain fog)

Davis HE, Assaf GS, McCorkell L, Wei H, Low RJ, Re'em Y, Redfield S, Austin JP, Akrami A. [Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact](#). *medRxiv*. 1 Jan 2020.

Carfi A, Bernabei R, Landi F. [Persistent symptoms in patients after acute COVID-19](#). *Jama*. 2020 Aug 11;324(6):603-5.

Tabacof L, Tosto-Mancuso J, Wood J, Cortes M, Kontorovich A, McCarthy D, Rizk D, Nasr L, Breyman E, Mohammadi N, Kellner C. [Post-acute COVID-19 syndrome negatively impacts health and wellbeing despite less severe acute infection](#). *medRxiv*. 1 Jan 2020.

Centers for Disease Control and Prevention. [Late Sequelae of COVID-19](#). 13 November 2020.

A.Dennis, M.Wamil, J.Alberts, J.Oben, DJ.Cuthbertson, D.Wootton, M.Crooks, M.Gabbay, M.Brady, L.Hishmeh, E.Attree, M.Heightman, R.Banerjee, A.Banerjee. [Multiorgan impairment in low-risk individuals with post-COVID-19 syndrome: a prospective, community-based study](#). *BMJ Open* 2021;11:e048391.

Tenforde MW, Kim SS, Lindsell CJ, Rose EB, Shapiro NI, Files DC, Gibbs KW, Erickson HL, Steingrub JS, Smithline HA, Gong MN. [Symptom duration and risk factors for delayed return to usual health among outpatients with COVID-19 in a multistate health care systems network—United States, March–June 2020](#). *Morbidity and Mortality Weekly Report*. 31 July 2020;69(30):993

Nehme M, Braillard O, Alcoba G, Aebischer Perone S, Courvoisier D, Chappuis F, Guessous I. [COVID-19 Symptoms: Longitudinal Evolution and Persistence in Outpatient Settings](#). *Annals of internal medicine*. 8 Dec 2020

Sudre CH, Murray B, Varsavsky T, Graham MS, Penfold RS, Bowyer RC, Pujol JC, Klaser K, Antonelli M, Canas LS, Molteni E. [Attributes and predictors of Long-COVID](#). *Nature Medicine*, 2021

S.Lopez-Leon, T.Wegman-Ostrosky, C.Perelman, R.Sepulveda, P.Rebolledo, A.Cuapio, S.Villapol. [More than 50 Long-term effects of COVID-19: a systematic review and meta-analysis](#). *medRxiv*, 2021

E.Garrigues, P.Janvier, Y.Kherabi, A.Le Bot, A.Hamon, H.Gouze, L.Doucet, S.Berkani, E.Oliosi, E.Mallart, F.Corre, V.Zarrouk, JD.Moyer, A.Galy, V.Honsel, B.Fantin, Y.Nguyen. [Post-discharge persistent symptoms](#)

[and health-related quality of life after hospitalization for COVID-19](#). *Journal of Infection*, 2020; 81(6):E4-E6.

Halpin SJ, McIvor C, Whyatt G, Adams A, Harvey O, McLean L, Walshaw C, Kemp S, Corrado J, Singh R, Collins T. [Postdischarge symptoms and rehabilitation needs in survivors of COVID-19 infection: A cross-sectional evaluation](#). *Journal of medical virology*. 30 Jul 2020.

O.Moreno-Perez, E.Merino, JM.Leon-Ramirez, M.Andres, JM.Ramos, J.Arenas-Jimenez, S.Asensio, R.Sanchez, P.Ruiz-Torregrosa, I.Galan, A.Scholz, A.Amo, P.Gonzalez-delaAleja, V.Boix, J.Gil. [Post-acute COVID-19 Syndrome. Incidence and risk factors: a Mediterranean cohort study](#). *Journal of Infection*, 2021.

D.Munblit, P.Bobkova, E.Spiridonova, A.Shikhaleva, A.Gamirova, O.Blyuss, NA.Nekliudov, P.Bugaeva, M.Andreeva, A.DunnGalvin, P.Comberiati, C.Apfelbacher, J.Genuneit, S.Avdeev, V.Kapustina, A.Guekht, V.Fomin, AA.Svistunov, P.Timashev, TM.Drake, S.Wulf Hanson, L.Merson, P.Horby, L.Sigfrid, JT.Scott, MG.Semple, JO.Warner, T.Vos, P.Olliaro, P.Glybochko, D.Butnaru. [Risk factors for long-term consequences of COVID-19 in hospitalised adults in Moscow using the ISARIC Global follow-up protocol: StopCOVID cohort study](#). *medRxiv*, 2021.

JK.Logue, NM.Franko, DJ.McCulloch, D.McDonald, A.Magedson,CR.Wolf, HY.Chu. [Sequelae in Adults at 6 Months After COVID-19 Infection](#). *JAMA Netw Open*. 2021;4(2):e210830.

D Menges; T.Ballouz; A.Anagnostopoulos; HE.Aschmann; A.Domenghino; JS.Fehr; MA.Puhan. [Estimating the burden of post-COVID-19 syndrome in a population-based cohort study of SARS-CoV-2 infected individuals: Implications for healthcare service planning](#). *MedRxiv*, 2021.

B.Osikomaiya, O.Erinoso, KO.Wright, AO.Odusola, B.Thomas, O.Adeyemi, A.Bowale, O.Adejumo, A.Falana, I.Abdus-salam, O.Ogboye, A.Osibogun, A.Abayomi. [‘Long COVID’: persistent COVID-19 symptoms in survivors managed in Lagos State, Nigeria](#). *BMC Infectious Diseases*, 2021

Other common symptoms for Long COVID

National Institute for Health and Care Excellence (NICE). [COVID-19 Rapid Guideline: Managing The Long-term Effects of COVID-19 - Common symptoms of ongoing symptomatic COVID-19 and post-COVID-19 syndrome](#). 18 Dec 2020.

Davis HE, Assaf GS, McCorkell L, Wei H, Low RJ, Re'em Y, Redfield S, Austin JP, Akrami A. [Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact](#). *medRxiv*. 1Jan 2020.

Consensus has not yet been reached on an internationally agreed Long COVID case definition. However, there is mounting evidence that Long COVID is both common and debilitating. Attempts have been made to characterise Long COVID as prolonged with multi-system involvement and significant disability.

The BMJ. [NICE guideline on long covid](#). 23 Dec 2020.

S.Rajan, K.Khunti, N.Alwan, C.Steves, T.Greenhalgh, N.MacDermott, A.Sagan, M.McKee. [In the wake of the pandemic: preparing for Long COVID](#). World Health Organization regional office for Europe, 2021. Policy Brief 39.

Davis HE, Assaf GS, McCorkell L, Wei H, Low RJ, Re'em Y, Redfield S, Austin JP, Akrami A. [Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact](#). *medRxiv*. 1 Jan 2020.

Michelen M, Manoharan L, Elkheir N, Cheng V, Dagens D, Hastie C, O'Hara M, Suett J, Burls A, Foote C, Carson G. [Characterising long-term covid-19: a rapid living systematic review](#). *medRxiv*. 1 Jan 2020.

N.Ziauddeen, D.Gurdasani, ME.O'Hara, C.Hastie, P.Roderick, G.Yao, NA.Alwan. [Characteristics of Long Covid: findings from a social media survey](#). *medRxiv*, 2021.

Information sheet 2: Rehabilitation and Long COVID

What is rehabilitation? Rehabilitation is defined as a set of interventions to optimise functioning in everyday activities, support individuals to recover or adjust, achieve their full potential, and enable participation in education, work, recreation and meaningful life roles.

World Health Organization. [Rehabilitation Fact Sheet](#). 2020;2021.

World Health Organization. [Rehabilitation in health systems: guide for action](#), 2020.

Krug E, Cieza A. [Strengthening health systems to provide rehabilitation services](#). *Neuropsychological rehabilitation* 2019;29:672-4.

Cieza A. [Rehabilitation the health strategy of the 21st century, really?](#) *Arch Phys Med Rehabil* 2019.

Stucki G, Bickenbach J, Gutenbrunner C, et al. [Rehabilitation: the health strategy of the 21st century](#). *J Rehabil Med* 2018;50:309-16.

Safe and effective rehabilitation is a fundamental part of recovery.

Rehabilitation for Long COVID must be tailored to the individual, depending on their symptoms, goals and preferences.

BMJ Opinion. [We have heard your message about long covid and we will act, says WHO](#). 2020;2021.

Carson G. [Research priorities for Long Covid: refined through an international multi-stakeholder forum](#). *BMC medicine* 2021;19:1-4.

World Health Organization. [Universal Health Coverage \(UHC\) Fact Sheet](#). 2019;2021

World Health Organization. [Rehabilitation Fact Sheet](#). 2020;2021.

Miciak MA. [Bedside matters: a conceptual framework of the therapeutic relationship in physiotherapy](#). 2015.

Ferreira PH, Ferreira ML, Maher CG, et al. [The therapeutic alliance between clinicians and patients predicts outcome in chronic low back pain](#). *Phys Ther* 2013;93:470-8.

Fuentes J, Armijo-Olivo S, Funabashi M, et al. [Enhanced therapeutic alliance modulates pain intensity and muscle pain sensitivity in patients with chronic low back pain: an experimental controlled study](#). *Phys Ther* 2014;94:477-89.

Burns JW, Evon D. [Common and specific process factors in cardiac rehabilitation: Independent and interactive effects of the working alliance and self-efficacy](#). *Health Psychology* 2007;26:684.

The World Health Organization recommends that Long COVID rehabilitation should include educating people about resuming everyday activities conservatively, at an appropriate pace that is safe and manageable for energy levels within the limits of current symptoms, and exertion should not be pushed to the point of fatigue or worsening of symptoms.

World Health Organization. [COVID-19 Clinical Management: Living guidance](#), 25 January 2021, *Clinical management of COVID-19: interim guidance, 27 May 2020* 2021.

Rehabilitation for individuals recovering from COVID-19 is different for everyone. Here are some terms that may best describe your experience: post-intensive care syndrome; post-viral fatigue; permanent organ damage; long-term COVID; relapses

National Institute for Health Research (NIHR). [Living with Covid19 – Second review](#). 16 March 2021

Regardless of which term fits your symptoms best, your physiotherapist will treat you as an individual and get to know the underlying cause of your symptoms before starting treatment.

Miciak MA. Bedside matters: a conceptual framework of the therapeutic relationship in physiotherapy, 2015

Effective rehabilitation interventions to support self-management of symptoms may include: activity pacing; heart rate monitoring

[Long COVID - Physiopedia \(physio-pedia.com\)](#) [includes a list of resources on pacing and heart rate monitoring]

Décary S, Gaboury I, Poirier S, Garcia C, Simpson S, Bull M, Brown D, Daigle F. [Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#). *Journal of Orthopaedic & Sports Physical Therapy*. Published Online: 30 April 2021. Volume 51 Issue5 Pages 197-200

In order to best meet your needs, a physiotherapist will work with other health professionals as part of your assessment and rehabilitation programme. Various tests may be carried out to understand and find the cause of symptoms.

European Society of Cardiology. [ESC Guidance for the Diagnosis and Management of CV Disease during the COVID-19 Pandemic](#). 2020;2021.

Phelan D, Kim JH, Elliott MD, et al. [Screening of Potential Cardiac Involvement in Competitive Athletes Recovering from COVID-19: An Expert Consensus Statement](#). *JACC: Cardiovascular Imaging* 2020.

Nurek M, Rayner C, Freyer A, et al. [Recommendations for the recognition, diagnosis, and management of patients with Post COVID-19 Condition \("Long COVID"\): A Delphi study](#). *SSRN* 2021;2021.

World Health Organization. [COVID-19 Clinical Management: Living guidance](#), 25 January 2021, [Clinical management of COVID-19: interim guidance](#), 27 May 2020 2021

Raj SR, Arnold AC, Barboi A, et al. [Long-COVID postural tachycardia syndrome: an American Autonomic Society statement](#). *Clinical Autonomic Research* 2021:1-4.

Dani M, Dirksen A, Taraborrelli P, et al. [Autonomic dysfunction in 'long COVID': rationale, physiology and management strategies](#). *Clin Med (Lond)* 2021;21:e63-7. Published Online First: 1 January 2021.

Exercise prescription in Long COVID should be approached with care to minimise risk and to ensure exercise programmes are restorative and do not make the individual's symptoms worse. Rehabilitation should aim to prevent oxygen desaturation on exertion. A specialist respiratory physiotherapist may help where there are signs of hyperventilation and breathing pattern disorders.

Davis HE, Assaf GS, McCorkell L, Wei H, Low RJ, Re'em Y, Redfield S, Austin JP, Akrami A. [Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact](#). *medRxiv*. 2020 Jan 1.

N.Ziauddeen, D.Gurdasani, ME.O'Hara, C.Hastie, P.Roderick, G.Yao, NA.Alwan. [Characteristics of Long Covid: findings from a social media survey](#). *medRxiv*, 2021.

Holtzman CS, Bhatia S, Cotler J, Jason LA. [Assessment of post-exertional malaise \(PEM\) in patients with myalgic encephalomyelitis \(ME\) and chronic fatigue syndrome \(CFS\): a patient-driven survey](#). *Diagnostics*. 2019 Mar;9(1):26.

Jason LA, Sunnquist M. [The Development of the DePaul Symptom Questionnaire: Original, Expanded, Brief, and Pediatric Versions](#). *Frontiers in pediatrics*. 2018 Nov 6;6:330.

Phelan D, Kim JH, Elliott MD, Wasfy MM, Cremer P, Johri AM et al. [Screening of Potential Cardiac Involvement in Competitive Athletes Recovering from COVID-19: An Expert Consensus Statement](#). *JACC: Cardiovascular Imaging*. 2020;13(12):2635-2652

A.Dennis, M.Wamil, J.Alberts, J.Oben, DJ.Cuthbertson, D.Wootton, M.Crooks, M.Gabbay, M.Brady, L.Hishmeh, E.Attree, M.Heightman, R.Banerjee, A.Banerjee. [Multiorgan impairment in low-risk individuals with post-COVID-19 syndrome: a prospective, community-based study](#). *BMJ Open* 2021;11:e048391.

Graded exercise therapy should not be used, particularly when post-exertional symptom exacerbation is present.

Davenport TE, Stevens SR, VanNess JM, et al. [Checking our blind spots: current status of research evidence summaries in ME/CFS](#). *Br J Sports Med* 2019;53:1198.

Geraghty K, Hann M, Kurtev S. [Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: Analysis of a primary survey compared with secondary surveys](#). *Journal of health psychology* 2019;24:1318-33.

Van Oosterwijck J, Nijs J, Meeus M, et al. [Pain inhibition and postexertional malaise in myalgic encephalomyelitis/chronic fatigue syndrome: an experimental study](#). *J Intern Med* 2010;268:265-78.

Torjesen I. [NICE advises against using graded exercise therapy for patients recovering from covid-19](#). *BMJ* 2020;370:m2912. Published Online First: July 21.

National Institute for Health and Care Excellence. [Statement about graded exercise therapy in the context of COVID-19](#). 2020;2021.

Information sheet 3: Fatigue and post-exertional symptom exacerbation

Fatigue is a feeling of extreme exhaustion and is the most common symptom of Long COVID. It:

- **is not easily relieved by rest or sleep**
- **is not the result of unusually difficult activity**
- **can limit functioning in day-to-day activities**
- **negatively impacts quality of life**

Brown D, Oller D, Hassell H, et al. [Physical Therapists Living With Long COVID, Part 1: Defining the Indefinable](#). *Journal of Orthopaedic & Sports Physical Therapy*. Published online 3 February 2021.

Post-exertional symptom exacerbation (PESE) is a disabling and often delayed exhaustion disproportionate to the effort made. It is sometimes described as a “crash.” The activity that can trigger this worsening of symptoms can be something that was easily tolerated before, such as:

- **a daily activity (eg a shower)**
- **a social activity**
- **walking (or other exercise)**
- **reading, writing or working at a desk**
- **an emotionally charged conversation**
- **being in a sensory environment (eg loud music or flashing lights)**

Carruthers BM, van de Sande, Marjorie I, De Meirleir KL, et al. [Myalgic encephalomyelitis: international consensus criteria](#). *J Intern Med* 2011;270:327-38.

Chu L, Valencia IJ, Garvert DW, et al. [Deconstructing post-exertional malaise in myalgic encephalomyelitis/chronic fatigue syndrome: A patient-centered, cross-sectional survey](#). *PloS one* 2018;13:e0197811.

Mateo LJ, Chu L, Stevens S, et al. [Post-exertional symptoms distinguish myalgic encephalomyelitis/chronic fatigue syndrome subjects from healthy controls](#), *Work* 2020:1-11.

Brown A, Jason LA. [Meta-analysis investigating post-exertional malaise between patients and controls](#). *Journal of health psychology* 2020;25:2053-71.

Davenport TE, Stevens SR, VanNess JM, et al. [Checking our blind spots: current status of research evidence summaries in ME/CFS](#). *Br J Sports Med* 2019;53:1198.

National Institute for Health and Care Excellence. [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management. In development](#). [GID-NG10091]. 2020;2021.

Many of the symptoms experienced by those living with Long COVID are very similar to those of myalgic encephalomyelitis (ME)/chronic fatigue syndrome (CFS).

Décary S, Gaboury I, Poirier S, Garcia C, Simpson S, Bull M, Brown D, Daigle F. [Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#). *Journal of Orthopaedic & Sports Physical Therapy*. Published Online: 30 April 2021. Volume 51 Issue5 Pages 197-200

The World Health Organization recommends that Long COVID rehabilitation should include educating people about resuming everyday activities conservatively, at an appropriate pace that is safe and manageable for energy levels within the limits of current symptoms, and exertion should not be pushed to the point of fatigue or symptom exacerbation.

World Health Organization. [COVID-19 Clinical Management: Living guidance](#). 25 January 2021, *Clinical management of COVID-19: interim guidance, 27 May 2020* 2021.

PESE is most often triggered by physical activity and exercise. Nearly 75% of people living with Long COVID still experience PESE after 6 months.

Davis HE, Assaf GS, McCorkell L, et al. [Characterizing long COVID in an international cohort: 7 months of symptoms and their impact](#) [preprint]. *medRxiv*. 2020.

The symptoms worsened by exertion can include:

- **disabling fatigue/exhaustion**
- **cognitive dysfunction or “brain fog”**
- **pain**
- **breathlessness**
- **heart palpitations**
- **fever**
- **sleep-disturbance**
- **exercise intolerance**

Hannah E Davis, Gina S Assaf, Lisa McCorkell, et al. [Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact](#), *medRxiv* 2020

Carruthers BM, van de Sande, Marjorie I, De Meirleir KL, et al. [Myalgic encephalomyelitis: international consensus criteria](#). *J Intern Med* 2011;270:327-38.

Chu L, Valencia IJ, Garvert DW, et al. [Deconstructing post-exertional malaise in myalgic encephalomyelitis/chronic fatigue syndrome: A patient-centered, cross-sectional survey](#). *PloS one* 2018;13:e0197811.

Mateo LJ, Chu L, Stevens S, et al. [Post-exertional symptoms distinguish myalgic encephalomyelitis/chronic fatigue syndrome subjects from healthy controls](#). *Work* 2020:1-11.

Brown A, Jason LA. [Meta-analysis investigating post-exertional malaise between patients and controls](#). *Journal of health psychology* 2020;25:2053-71.

Davenport TE, Stevens SR, VanNess JM, et al. [Checking our blind spots: current status of research evidence summaries in ME/CFS](#). *Br J Sports Med* 2019;53:1198.

National Institute for Health and Care Excellence. [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management. In development](#) [GID-NG10091]. 2020;2021.

Symptoms typically worsen 12 to 48 hours after activity and can last for days, weeks or even months.

National Institute for Health and Care Excellence. [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management. In development](#) [GID-NG10091]. 2020;2021.

Stussman B, Williams A, Snow J, et al. [Characterization of Post-exertional Malaise in Patients With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#). *Frontiers in Neurology* 2020;11:1025.

Your physiotherapist can guide you in pacing as an activity management tool that is also used successfully for people with ME/CFS to prevent triggering PESE.

STOP trying to push your limits. Overexertion may harm your recovery.

REST is your most important management strategy. Do not wait until you feel symptoms to rest.

PACE your daily activities and cognitive activities. This is a safe approach to navigate triggers to symptoms.

Décary S, Gaboury I, Poirier S, Garcia C, Simpson S, Bull M, Brown D, Daigle F. [Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#). *Journal of Orthopaedic & Sports Physical Therapy*. Published Online: 30 April 2021. Volume 51 Issue5 Pages 197-200

Davis HE, Assaf GS, McCorkell L, et al. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact [preprint]. *medRxiv*. 2020. <https://doi.org/10.1101/2020.12.24.20248802>Google Scholar

Wormgoor MEA, Rodenburg SC. and The evidence base for physiotherapy in myalgic encephalomyelitis/chronic fatigue syndrome when considering post-exertional malaise: a systematic review and narrative synthesis. *J Transl Med*. 2021; 19: 1. <https://doi.org/10.1186/s12967-020-02683-4>

Physical activity and exercise interventions warrant caution as rehabilitation strategies among people with Long COVID and persistent symptoms of disproportionate breathlessness on exertion, inappropriately high heartbeat (tachycardia), and/or chest pain.

World Physiotherapy Response to COVID-19: Briefing Paper 6 - Safe Rehabilitation Approaches for People Living with Long COVID: Physical Active and Exercise. [\[Insert link\]](#)

Décary S, Gaboury I, Poirier S, Garcia C, Simpson S, Bull M, Brown D, Daigle F. [Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#). *Journal of Orthopaedic & Sports Physical Therapy*. Published Online: 30 April 2021. Volume 51 Issue5 Pages 197-200

Graded exercise therapy should not be used, particularly when post-exertional symptom exacerbation is present.

Davenport TE, Stevens SR, VanNess JM, et al. [Checking our blind spots: current status of research evidence summaries in ME/CFS](#). *Br J Sports Med* 2019;53:1198

Geraghty K, Hann M, Kurtev S. [Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: Analysis of a primary survey compared with secondary surveys](#). *Journal of health psychology* 2019;24:1318-33.

Van Oosterwijck J, Nijs J, Meeus M, et al. [Pain inhibition and postexertional malaise in myalgic encephalomyelitis/chronic fatigue syndrome: an experimental study](#). *J Intern Med* 2010;268:265-78

Torjesen I. [NICE advises against using graded exercise therapy for patients recovering from covid-19](#). *BMJ* 2020;370:m2912 doi:10.1136/bmj.m2912 [doi] [published Online First: July 21].

National Institute for Health and Care Excellence. [Statement about graded exercise therapy in the context of COVID-19](#). 2020;2021

Information sheet 4: How to use pacing with your physiotherapist

Ellen M Goudsmith, Jo Nijs, Leonard A Jason, Karen E Wallman. [Pacing as a strategy to improve energy management in myalgic encephalomyelitis/chronic fatigue syndrome: A consensus document](#), December 2011 *Disability and Rehabilitation* 34(13):1140-7

Décary S, Gaboury I, Poirier S, Garcia C, Simpson S, Bull M, Brown D, Daigle F. [Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome](#). *Journal of Orthopaedic & Sports Physical Therapy*. Published Online: 30 April 2021. Volume 51 Issue5 Pages 197-200

The following resources were additionally used in the production of this information sheet:

Physios for ME:

Pacing: <https://www.physiosforme.com/pacing>

Heart rate monitoring: <https://www.physiosforme.com/heart-rate-monitoring>

Royal College of Occupational Therapists:

How to conserve your energy: <https://www.rcot.co.uk/conserving-energy>

Recovering from COVID-19: Post viral fatigue and energy conservation:

<https://www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-conserving-energy>

Emerge Australia - Pacing: <https://www.emerge.org.au/Handlers/Download.ashx?IDMF=2a2287ee-b84d-428f-b72e-00da812ddd7c>

#ME Action: https://www.meaction.net/wp-content/uploads/2020/10/Pacing-and-Management-Guide-for-ME_CFS-8.pdf

Action for ME – Pacing and energy management: <https://www.actionforme.org.uk/get-information/managing-your-symptoms/pacing-and-energy-management/>

Information sheet 5: Breathing exercises

Physiotherapy for breathing pattern disorders: <https://www.physiotherapyforbpd.org.uk/wp-content/uploads/2017/06/YOUR-Guide-to-Good-Breathing.pdf>

John Hopkins Medicine – Coronavirus recovery: Breathing exercises: <https://www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/coronavirus-recovery-breathing-exercises>

Additional reading and resources

World Physiotherapy response to COVID-19 briefing paper 9 - Safe rehabilitation approaches for people living with Long COVID: physical activity and exercise

https://world.physio/sites/default/files/2021-06/Briefing_Paper_9_Long_Covid_Final.pdf

Long COVID Physio: <https://longcovid.physio/>

Physiopedia – Long COVID: https://www.physio-pedia.com/Long_COVID#ppm63722