A note to my colleagues in medicine and family medicine on the management of patients suffering from Covid Long.

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Dear collegues

Thank you for your letter and for your interest in my work.

Please find enclosed a letter with the questionnaire I ask patients to fill in if they suspect Long covid. At the same time, I study their medical records available on the Hospital network.

The primary objective is to determine the clinical nature of the health problem. Generally, the usual medical examinations are negative, as are the usual biologies.

So we're faced with a set of medically unexplained symptoms that could just as easily be attributable to other problems.

But if you're familiar with your patient, you'll see that the essential thing is a patient who is no longer the same after an acute Covid as he was before.

The profound change in the aftermath of a Covid, including major asthenia, exhaustion on exertion, vertigo or previously unknown allegias, irrepressible headaches and unexplained neurological manifestations, should point to a Long Covid.

Proving it is a different kettle of fish.

In the most severe cases, and when the COOP index (see end of enclosed letter) exceeds 20 out of 30, the patient is no longer able to carry out his usual activities, and in these cases I have been able to demonstrate sometimes severe cerebral perfusion disorders using Technetium scintigraphy (brain SPECT-CT). Even though an 8FDG PET scan was negative. This is the first test I've requested, within the range of a general practitioner's prescription in Belgium.

I'm also requesting a routine clinical blood test to explore certain analyses often described as positive in the Long Covid (a 12% increased risk of diabetes, for example, or a misunderstood elevation of ferritin).

You'll find my form attached. Most of the time, it doesn't show anything, except that the EBV and VZV ACs are surprisingly high.

Then, if the patient is willing and able to travel to Leuven, I put him or her on a list of people who will be contacted by the Rega Institute <u>https://rega.kuleuven.be/</u> for a research blood test that explores DNA, ARNS and proteins. This has been made possible through the Covid Human Genetic Effort network <u>https://www.covidhge.com/</u>

This is experimental research, unlikely to provide individual answers, but collective analysis advances our understanding of the phenomenon.

In terms of therapy, in addition to the nationa insurer sheme for Long Covid pathway, I encourage patients to use the NEURONATION application, which enables them to maintain their intellectual capacity, and I <u>https://www.neuronation.com/</u> encourage them to exercise without ever exceeding their capacity.

Pharmacologically speaking, there's nothing EBM about it. I read a lot and decided to put all my patients on Aspirin 80mg and Piracetam 1200. Both are anticoagulants and the latter may have a beneficial effect on neuronal O2 extraction. Some patients are improved by Cetirizine. Others have benefited from Naltrexone 0.1mg to 0.2mg a day (to be administered magistrally).

I maintain an online ICPC-2 classified bibliography which you can find here <u>https://www.zotero.org/groups/4929325/long_covid_open_library/library</u>

Your questions are welcome bien a vous marc J

PS ; Main publications available

See also https://orbi.uliege.be/simple-search?sort_by=issued_dt&order=desc&query=jamoulle+long+covid

- Jamoulle M. "Ca fait bizarre que quelqu'un m'écoute" (2022) Le long Covid en médecine de famille. "It feels strange that someone is listening to me" The long Covid in family medicine. October 2022. <u>https://orbi.uliege.be/handle/2268/295811</u>.
- 2. Jamoulle M, Kazeneza-Mugisha G, Zayane A. (2022) Follow-Up of a Cohort of Patients with Post-Acute COVID-19 Syndrome in a Belgian Family Practice. Viruses. 2022;14(9):2000. doi:10.3390/v14092000
- Van Weyenbergh, J., Meyts, I., Kazeneza-Mugisha, G., & Jamoulle, M. (08 Décembre 2022). Suivi d'une cohorte de patients Long Covid en médecine de famille . [Poster] 2ème Journée Long Covid, Nancy, France. <u>https://hdl.handle.net/2268/296822</u>
- Jamoulle, M., Soylu, S., Kazenez Mugisha, G., Rimbault, E., Zayane, A., Van Weyenbergh, J., Akturk, Z., & Pizzanelli, M. (29 September 2023). A research journey in Long Covid in General practice. July 2021-Sept 2023. [Poster & présentation] Le Covid long en Belgique : des aspects cliniques aux conséquences de santé publique.ESP/ULB <u>https://hdl.handle.net/2268/307064</u>
- Jamoulle, M., Soylu, S., Kazeneza Mugisha, G., Rimbault, E., Zayane, A., & Van Weyenbergh, J. (07 December 2023). Unraveling the Enigma of Long Covid: A Journey from Clinical Uncertainty to Multi-Omics Research. [Poster presentation]. Demystifying Long Covid.International conference, Madrid, Spain. <u>https://hdl.handle.net/2268/309310</u>
- Jamoulle, M., & Van Weyenbergh, J. (07 December 2023).Single-photon emission computed tomography facilitates the diagnosis of vascular encephalitis in cases of severe Long Covid and correlates with transcriptomic studies [Poster presentation]. Demystifying Long Covid. International conference, Madrid, Spain. <u>https://hdl.handle.net/2268/309271</u>

- Jamoulle, M. (2023). Exploring Long Covid: An Unexpected Research Journey in Family Medicine Leading to Translational Research. Medical Research Archives, 11(11). <u>https://esmed.org/MRA/mra/article/view/4673</u>
- Menezes, S. M., Jamoulle, M., Carletto, M. P., Holm, B. V., Moens, L., Meyts, I., Maes, P., & Weyenbergh, J. V. (2024). Blood transcriptomics reveals persistent SARS-CoV-2 RNA and candidate biomarkers in Long COVID patients. medRxiv. <u>https://doi.org/10.1101/2024.01.14.24301293</u>
- 9. submitted ; 🗉 Porto abstract ; When there is no evidence: the case of Post Acute Covid Syndrome fr...)

download the patient questionnaire here (in French but easy to understand or translate) <u>https://orbi.uliege.be/bitstream/2268/313354/2/CRS-%20Premier%20contact%20-%20instru</u> ctions%20au%20patients%20full.pdf