



A subset of people continues to experience or develop long-lasting symptoms following COVID-19, also known as post-COVID (or long COVID). The Ministry of Health, Welfare and Sport has requested the Health Council of the Netherlands to assess what is known about the definition, prevalence, diagnosis and treatment of post-COVID. The Council was also asked to examine how post-COVID relates to other post-acute infection syndromes (PAIS), and to provide recommendations regarding the organisation of healthcare.

Wide range of symptoms, major impact on daily life

Post-COVID can involve a wide range of symptoms that can vary from person to person. These may include fatigue, shortness of breath, sleep disturbances, or cognitive problems such as difficulties with concentration or memory. In a subset of people with post-COVID, the postural orthostatic tachycardia syndrome (POTS) occurs, which presents with symptoms such as palpitations or dizziness when assuming or maintaining an upright position. Symptoms may also worsen after physical, cognitive or emotional exertion, a phenomenon known as post-exertional malaise (PEM).

Post-COVID can have a major impact on people's wellbeing and daily functioning. In addition, some individuals experience a lack of recognition

and understanding, scepticism, stigma and/or psychologisation of their symptoms, for example in social, healthcare or occupational settings. This can further increase the burden of post-COVID.

Preference for the WHO definition

There is currently no universally accepted definition of post-COVID. The committee compared definitions provided by several international organisations. These definitions differ, for example, in terminology and scope. The committee prefers to use the definitions developed by the World Health Organization (WHO) for adults and for children and adolescents as a starting point. These definitions include the impact on daily functioning and acknowledge the heterogeneous nature of the health problem. However, the committee considers that, as in the definition for adults, the definition for children and adolescents should also explicitly state that the symptoms cannot be explained by another diagnosis.

Underlying mechanisms remain insufficiently understood

It is still not fully understood how post-COVID develops and persists. The scientific literature describes several possible underlying mechanisms, a considerable proportion of which involve changes in the immune system. It is plausible that the mechanisms involved differ between individuals and

that multiple mechanisms may coexist within one person, potentially interacting with one another.

Estimates of the number of people with post-COVID vary

It is unclear how many people in the Netherlands currently have post-COVID. Available estimates vary, partly because of differences in research methods used. Despite this uncertainty, the affected group appears to be substantial.

Diagnosis based on clinical presentation

Post-COVID is diagnosed on the basis of the patient's clinical presentation, because there is no test that can confirm or rule out the presence of post-COVID. Medical history taking, targeted physical examination and, where necessary, additional testing form the basis of diagnosis. Diagnosing post-COVID can be challenging for healthcare professionals due to the wide range of possible symptoms, the absence of a valid diagnostic test, and the fact that many symptoms of post-COVID also occur in other health problems.

Treatment focused on symptom relief, functioning and quality of life

There is no proven curative treatment for post-COVID. Therefore, management and treatment focus on symptom relief and improving functioning and/or quality of life. This can be provided through standard care (in accordance with existing clinical guidelines for specific symptoms), but some medications are also prescribed off-label in practice.

Based on randomised controlled trials of pharmacological treatments for post-COVID, the committee concludes that convincing scientific evidence for the effectiveness of medications is lacking. Research into non-pharmacological treatments is difficult to interpret due to substantial heterogeneity in interventions, patient populations and outcome measures. As a result, no definitive conclusions can currently be drawn regarding the effectiveness of non-pharmacological treatments.

Similarities between post-COVID and other PAIS

Although there are also differences, the committee notes a significant degree of similarity between post-COVID and other PAIS. To assess this, the committee compared post-COVID with post-treatment Lyme disease syndrome, Q fever fatigue syndrome (QFS), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and post-sepsis syndrome. There is considerable overlap in symptom profiles and possible underlying mechanisms.

Other important similarities include the lack of valid diagnostic tests and curative treatment, the potentially major impact on daily life, and the fact that some individuals experience a lack of recognition and understanding, scepticism or disbelief regarding the legitimacy of their symptoms.



Recommendations

Recognise post-COVID as an important health problem

The committee considers post-COVID and other PAIS to be important health problems that should be broadly recognised in society. According to the committee, recognition means that symptoms and their consequences for daily life are taken seriously.

Provide personalised care and evaluate care provided

As with any health problem, and especially given the heterogeneity of symptoms, diagnosis and treatment of post-COVID should involve an integrated approach with personalised care. Given the uncertainty surrounding the effectiveness of (combinations of) treatments, evaluation of care is essential.

Organise care through regional networks

The committee considers it essential that care for people with post-COVID and other PAIS is adequately embedded within regular healthcare. Because uncertainties remain both regarding the medical aspects and the number of people affected, it is difficult to make statements about the optimal organisation of healthcare. The committee has therefore decided, for the time being, to align with current developments in the healthcare sector and to advocate for the formation of regional networks of primary, secondary, and tertiary care providers. This could facilitate and strengthen collaboration between healthcare professionals and support the further development and optimal use of expertise.

To gain a better understanding of the number of people with post-COVID and other PAIS in the Netherlands for the purpose of organising healthcare, the committee advocates for improved registration of PAIS in clinical practice.

Invest in a long-term research programme and effective knowledge exchange

Further scientific research is needed into at least the underlying mechanisms, diagnosis and treatment of post-COVID and other PAIS. The committee therefore recommends investing in a long-term research programme on PAIS.

Finally, the committee stresses the importance of effective knowledge exchange on post-COVID and other PAIS. Education and continuing training for healthcare professionals, as well as the development of multidisciplinary, evidence-based guidelines for diagnosis, management and treatment, are essential in this regard.

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