

A message from EUROMENE to people with ME/CFS during the COVID-19 pandemic

The current pandemic may give many people with ME/CFS new concerns about their health and wellbeing.

It is well known that many infections can trigger ME/CFS. Fatigue, malaise and muscle-type pain are often reported by people with acute infection by COVID-19, and there may be prolonged fatigue in those who recover from the infection. People with ME/CFS also often report a temporary worsening of their ME symptoms when they experience even mild acute infections. More severe infections as well as concurrent diseases may take a significant toll on people with ME/CFS.

For those with ME and chronic fatigue syndrome, we cannot emphasise enough the importance of preventative measures to minimise the risk of infection with COVID-19. Countries and regions within countries will adopt different measures at different stages of the pandemic, from strict and enforceable isolation measures to more relaxed approaches. We strongly recommend that if you have not had COVID-19, you follow your local and national public health recommendations and protect yourself and others from infection. This may include strict social distancing from others; thorough hygiene measures, e.g. careful and regular hand-hygiene; and remaining in quarantine or self-isolation if and when appropriate.

ME/CFS patients have to most scrupulously and rigorously respect recommendations from health professionals using barrier actions to avoid as much as possible to be infected.

Prolonged periods of social isolation and stress can affect psychological wellbeing, so we recommend that people with ME/CFS keep a daily schedule planning each day to include work/housework, leisure and so on at specified times (even if these are not strictly adhered to). It is essential to maintain a balanced and healthy diet and good sleep hygiene with healthy day/night schedules. Remember that strict physical isolation does not necessarily mean social isolation; regular audio or video calls with friends and family can help maintain psychological wellbeing. Try not to wear your pyjamas all day, every day and remember the importance of keeping as active as possible within your limits – which in many cases is already much lower than the general public. Many with ME/CFS, and particularly those with more severe disease, are already accustomed to some degree of social isolation, and they may actually be in a position to share advice on how to cope in such circumstances.

For those with flu-like symptoms, please follow the local recommendations about who to contact and when. Where possible, testing for COVID-19 infection is desirable for those with symptoms such as fever and cough, although we know that tests are not yet widely available in many countries. Measures like paracetamol for fever and home-remedies for cough, such as honey and lemon tea are appropriate for most. If you are a smoker, as smoking increases vulnerability to covid-19, we can only recommend that you take this opportunity to stop. Other symptoms such as loss of smell and of taste,

gastrointestinal upset, body pains and increasing fatigue and other ME-type symptoms may also occur. If symptoms are more severe, and, in particular, if you experience shortness of breath or other symptoms of severe disease such as confusion, seek urgent medical help according to local protocols.

Despite some evidence that people with ME/CFS may react differently in terms of immunity to others in full health, the recommended treatment of a person with ME/CFS and COVID-19 infection is the same. Patients with severe forms of COVID-19 may require intensive care admission or assisted mechanical ventilation. Doctors must be informed of the diagnosis of ME/CFS when anyone is admitted to hospital.

Treatment will be similar as for those without ME/CFS, but the burden to those with already a debilitating illness such as ME may be more significant. It is important that health professionals caring for people with ME/CFS, and particular when in intensive care are aware of the additional needs of people with ME/CFS experiencing critical illness.

USEFUL LINKS:

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public>

For professionals:

<https://www.who.int/emergencies/diseases/novel-coronavirus-2019/events-as-they-happen>

<https://www.thelancet.com/coronavirus>

<https://jamanetwork.com/journals/jama/pages/coronavirus-alert>

https://coronavirus.frontiersin.org/?utm_campaign=sub-cov-cco&utm_medium=fhpc&utm_source=fweb