

Advice for people with neuromuscular diseases associated with coronavirus

Many patients have contacted the hospital units in the NMK collaboration, the Muscle Clinic Haukeland University Hospital and the Association for Patients with Muscular Disease with questions about the new coronavirus. Since neuromuscular diseases covers a wide range of different diagnoses, and the level of disability seen in people with the same diagnosis can vary widely, it is difficult to make specific recommendations.

Nevertheless, we consider that patients with neuromuscular disease and breathing impairment and/heart disease are a vulnerable group, and we would strongly advise these to adhere to the Public Health Institute's advice to people at risk:

- Stay home as much as possible
- Make sure you have all your necessary medication available
- Keep away from others and avoid crowds
- Limit your use of public transport, if possible
- Arrange with others to help you do shopping (food etc.)
- Avoid caring for smaller children, as they may have no or only mild symptoms of a covid-19 infection
- If the person you are living with is not feeling well (and especially if you suspect covid-19 infection), limit your contact.

In addition, we would urge you and your carers/assistants to follow the Public Health Institute's general advice to reduce infection:

- Wash your hands frequently and thoroughly with soap and lukewarm water, especially when you have been in contact with other people. Alcohol-based hand disinfection is a good alternative if hand washing is not possible
- Make sure that those you live with wash their hands frequently. This also applies to visitors/carers/assistants
- Avoid hand greeting and close contact (hugging etc.)
- As far as possible, keep your home clean especially surfaces that are often touched
- Avoid contact with people with symptoms of respiratory disease. Ask before you meet friends/family and ask carers/assistants regularly etc.
- Stay up to date on the situation by following local media, the National Institute of Public Health's website / or [helsenorge.no](https://www.fhi.no/helsenorge.no)
<https://www.fhi.no/nettpub/coronavirus/fakta/risikogrupper/>
- Updated information for patients already using home ventilation or BiPAP:
<https://helse-bergen.no/avdelinger/lungeavdelinga/nasjonal-kompetansetjeneste-for-hjemmerespiratorbehandling/pasientinformasjon#3-for-deg-som-bruker-livsoppretholdende-behandling-bipap-eller-hjemmerespirator-hele-dognet-og-er-avhengig-av-hjelp-fra-hjemmesykepleie-eller-brukerstyrt-personlig-assistanse-bpa-hele-dognet>

We recommend everyone to take the regular flu vaccine. Unfortunately, there is no coronavirus vaccine yet. We would encourage people with neuromuscular diseases and respiratory problems and/or heart involvement to ask their GP about the need for pneumococcal vaccine. This only protects against pneumococcal infection (a bacterial

infection of the lung) and has no protection against the coronavirus. If you are one in the high risk group (have breathing difficulties or heart problems) you should also ask your GP if you should be tested for coronavirus if you develop symptoms