

COVID-19 and people with neuromuscular disorders:

World Muscle Society position and advice

Update 10-05-2020

This advice is regularly updated. The recommendations, dated April 19th 2020, detailing aspects of risk assessment, definition of high-risk groups among people with neuromuscular disorders, measures to avoid infection, medical management, care provisions, and on support through neuromuscular specialists and centres, essentially remain following current review.

A new discussion emerging however is that of ensuring safe de-escalation of some aspects of shielding and self-isolation to allow people with neuromuscular disorders to resume social interactions and education, work, or attend scheduled medical appointments.

There is at the moment considerable variation in the way national restrictions are evolving, and this impacts on people with neuromuscular conditions, their families and carers, who seek advice from their neuromuscular services.

Despite the range of national approaches to this issue, our Society agrees on the following considerations regarding risk stratification:

1. For people with neuromuscular disorders who are considered at low risk (see paragraph 1 of the Advice and Position document), i.e. no cardiorespiratory impairment, no immunosuppression, and no significant risk-elevating factors and comorbidities, we suggest cautiously following local and national guidance. In doubt, consultation with the neuromuscular specialist is recommended.
2. For patients with medium risk, for instance with mild respiratory involvement, we advise a detailed discussion with their neuromuscular specialist, or with the physician responsible for their neuromuscular care. Controlled relaxation of restrictions, strictly in a secure environment, may be considered with appropriate caution and taking into account local and national recommendations.
3. Special considerations must remain for people considered at “high” or “very high” risk (see paragraph 1 of the original document), in particular people with severe or unstable respiratory compromise (FVC < 60% predicted); reliance on home ventilation; clinically relevant impairment of heart function; immunosuppression; or severe weakness requiring multiple carers or complex ongoing support. For these, measures of self-isolation to avoid infection should remain in place. Carers and family members who are no longer in self-isolation must continue to use masks and barriers when in contact with the person at risk.

For children and adolescents with neuromuscular disorders, and their parents, the leading question is whether a return to school and child care centres is acceptable; conversely, schools and childcare centres may be concerned whether children with neuromuscular disorders can be safely accepted back to education. This decision depends on individual factors, and must include specifics of the school/childcare centre regarding staffing levels and whether they can ensure hygiene protection along national guidelines. Some recommendations are already available (see References); internationally there is significant variation.

Patients need to be reassured that they can safely attend for important procedures such as sleep studies, cardiac tests, and initiation of non-invasive ventilation. Neuromuscular specialists need to monitor their patient cohort, to detect what medical procedures or monitoring may have been postponed during “lockdown”, and begin to arrange for services to be safely resumed. Neuromuscular services should ensure that their hospital is making adequate provisions for the safety of people with neuromuscular disorders attending, including staff adequately equipped with personal protection, designated “green” areas in hospitals for non-COVID-19 related treatments, and safe waiting areas and consulting rooms with appropriate distancing between patients and staff.

References and links:

http://www.filnemus.fr/menu-filiere/evenements/actualites/article/news/les-recommandations-de-filnemus-dans-la-periode-du-deconfinement/?tx_news_pi1%5Bcontroller%5D=News&tx_news_pi1%5Baction%5D=detail&cHash=56f89313ee508b50526c7dbfb952dd7a

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Authors of this document:

Collated by Maxwell S. Damian, PhD, FNCS, FEAN and the members of the Executive Board of the WMS (www.worldmusclesociety.org) in cooperation with members of the Editorial Board of Neuromuscular Disorders, official journal of the WMS