

## **Introduction**

The Covid-19 pandemic is a major concern for patients with neuromuscular disorders using home ventilation. This group of people are critically dependent on a complex chain of support with specialised equipment involving highly trained personnel and carers. Challenges apply to day to day function of ventilation in the home, where they are often in self-isolation as a very high-risk group, as well as to use of their ventilation system on admission to hospital.

This document from the World Muscle Society has been prepared by an expert group of Neurologists and Respiratory Physicians caring for such patients, in order to inform patients and their carers about the main problems arising in the pandemic, and to advise on strategies and point to resources available, in order to minimise risk to neuromuscular patients.

**Note: Patients and carers are strongly advised to contact their local Home Ventilation Centre in order to obtain national and locally specific advice adapted to their exact situation.**

**Specific questions around the use of home ventilation include the following**

**1. What should patients on home ventilation consider in terms of equipment to ensure their ventilation at home can be continued in the Covid-19 pandemic?**

Home ventilation devices can increase the risk of infectious particle being dispersed into the environment. Most modern home ventilation devices are equipped with bacterial/viral (HEPA) filters, but some are not. However, we do **not** advise patients or their carers to attempt to modify their systems at home, due to the risk of incorrect modifications.

If there are any queries about specifics of the device, we advise contact with the local Home Ventilation Centre.

Filters and disposables (i.e. tubing, suction devices) need regular replacement and/or cleaning and adequate supplies of disposables should be held. Shortages of supplies must be anticipated, and there is currently no central mechanism of sourcing supplies.

Advice should be sought from the local home ventilation service. There may be shortages of staff in home ventilation centres due to staff sickness, or redeployment in intensive care.

## **2. What equipment is needed for carers and ventilation outreach service personnel when they are support patients at home?**

Patients with known or suspected Covid-19: Carers and support personnel should be equipped with full protective clothing when entering the room of a patient with known or suspected Covid-19, and as a minimum requirement they should use an FFP2 or N95 standard face mask, gloves and use hand cleaning gel as well as a protective gown when entering the room. Eye protection (visor or protective glasses) is advised. Protective clothing must be changed on leaving the room. [Note: The supply of protective clothing can be very limited due to demand.]

In patients who are not infected with Covid-19: The priority is for carers and persons coming in to the home, who may be unknowingly infected, not to pass the infection on to the patient. In such cases, use of surgical masks, gloves, and observance of hand washing guidelines are minimum requirements.

## **3. What modifications should be made when patients are admitted to hospital to allow patients' ventilators to continue be used after admission to hospital?**

Patients' ventilators can continue to be used in hospital if a non-vented mask is used with a bacterial/viral filter at the device outlet, and a filter between the mask and the device tubing. These modifications provide adequate protection from dispersion of infectious particles into the environment, but they need to be made by trained personnel, ideally through the home ventilation service. The supply of disposables and trained personnel may be limited in local hospitals without a home ventilation service on site. In case of admission to a hospital without home ventilation service, we advise patients and medical providers to urgently contact the regional home ventilation service.

Many, but not all ventilators can be adapted to provide high flow oxygen. However, high flow oxygen cannot be used as an alternative to Bilevel Positive Pressure ventilation (BiPAP) used for neuromuscular disorders.

Masks should be placed before starting a new or adapted ventilator, and the ventilator should be stopped, before the mask is taken off.

### **Resources:**

Canadian Neuromuscular Network advice on home ventilation

<https://neuromuscularnetwork.ca/news/covid-19-resources-care-recommendations-for-home-based-ventilation-patients/>

International Ventilation Users Network, “Take charge not chances program”

<http://www.ventusers.org/vume/intro.html>

Twitter feed from the British Home ventilation group:

[https://twitter.com/SiLVaH\\_UK](https://twitter.com/SiLVaH_UK)

Advice for hospital staff fitting filtered systems:

[https://www.youtube.com/watch?v=Ed\\_-UowEScU&feature=youtu.be](https://www.youtube.com/watch?v=Ed_-UowEScU&feature=youtu.be)

Authors: Covid-19 and Home Ventilation Group for the WMS (in alphabetical order)

Peter van den Bergh, Belgium; R. van den Biggelaar, Netherlands; Maxwell Damian, UK; James Dowling, Canada; Teresinha Evangelista, France; Reghan Foley, USA; Michael A. Gaytant, Netherlands; A. J. Kooi, Netherlands; Dirk Koschel, Germany; Susana Quijano-Roy, France; Benedikt Schoser, Germany; Volker Straub, UK; Haluk Topaloglu, Turkey; Antonio Toscano, Italy; Marianne de Visser, Netherlands; Thomas Voit, UK; Carlos Vrins, Netherlands.

Corresponding author: Maxwell S. Damian, [msdd2@cam.ac.uk](mailto:msdd2@cam.ac.uk), April 11<sup>th</sup> 2020.