

COVID-19 & DUCHENNE CARE IMPERATIVES



This fact sheet provides high-level takeaways for the care of persons with Duchenne and Becker muscular dystrophy during the COVID-19 pandemic, based on information from a recently published article accepted to *Muscle & Nerve*. This article is the result of a group of expert clinicians in our community, many representing Certified Duchenne Care Centers. The publication outlines consensus recommendations if a person with Duchenne or Becker were to be diagnosed with or suspected of infection with COVID-19, and guides physicians and caregivers on best practices for management and treatment. For more information, visit PPMD's COVID-19 (Coronavirus) Information Center at parentprojectmd.org/covid19.

C COUGH ASSIST

Cough assist use should continue regardless of infection with COVID-19 to support airway clearance. Use at whatever frequency necessary to provide support with coughing; you cannot overuse a cough assist device.

V VENTILATOR SUPPORT

Consider transitioning to full face masks with ventilation systems and cuffed tracheostomies with closed tubing systems to decrease potential spread of COVID-19.

O OT & PT

Occupational and physical therapy may be available through telehealth. Continue home stretching routines, use of splints, and appropriate physical activity within the home. Consult with your therapists for creative solutions while unable to access physical or occupational therapy services.

I INTUBATION

If intubation is required, advocate for consultation with pulmonary and anesthesiology experts, and avoid succinylcholine, which is not safe to use in Duchenne. Safe anesthesia can be found at parentprojectmd.org/surgery

R RENEW PRESCRIPTIONS

Renew prescription medications in advance when possible to ensure adequate supply at home and minimize need for going to the pharmacy.

R RESEARCH YOUR COMMUNITY

Research local, state, and federal policies about social distancing, closures in your community, and other policies that may affect you.

O ONLINE TELEMEDICINE VISITS

Connect with your providers via telemedicine visits instead of in-person visits when possible and appropriate to minimize exposure to potential infection.

U URGENT EVALUATION

Urgent evaluation is necessary when: fever is $>103^{\circ}$ despite use of fever-reducing medications; signs of decreased oxygen saturation; difficulty breathing/shortness of breath; or decreased urinary output.

N NECESSARY PERSONAL PROTECTION

Necessary personal protective equipment should be used when in public or when in contact with anyone from outside your home.

S STRESS DOSING

Discuss stress dosing with your neuromuscular specialist or endocrinologist, and consider having a dose available at home. Intramuscular injection of steroids may be necessary if unable to take steroids orally; discuss this with your physician. parentprojectmd.org/pj

A ACETAMINOPHEN

Acetaminophen should be used for fever reduction. Avoid use of ibuprofen, as it can be harmful when combined with steroids.

Veerapandiyan, A., Wagner, K.R., Apkon, S., McDonald, C.M., Mathews, K.D., Parsons, J.A., Wong, B.L., Eichinger, K., Shieh, P.B., Butterfield, R.J., Rao, V.K., Smith, E.C., Proud, C.M., Connolly, A.M. and Ciafaloni, E. (2020), The care of patients with Duchenne, Becker and other muscular dystrophies in the COVID-19 pandemic. *Muscle Nerve*. Accepted Author Manuscript. doi:10.1002/mus.26902

Care for Duchenne
parentprojectmd.org/care

Emergency Care Considerations
parentprojectmd.org/emergencycare

Center for Disease Control and
Prevention Care Considerations
parentprojectmd.org/careguidelines

Parent Project Muscular Dystrophy
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