
Muscular
Dystrophy

DUCHENNE MUSCULAR DYSTROPHY EMERGENCY CARE INFORMATION FOR FAMILIES

RESPIRATORY CARE

Follow your child's pulmonary action plan! If trouble breathing, or Oxygen saturation low, use cough assist or Ambu bag or BiPAP to clear the airway. If breathing does not improve in 5-10 minutes, go to ER. **Bring all equipment and medications with you to the Emergency Room (ER) if possible.**

LEG FRACTURE TREATMENT

If your child has leg pain following a fall, go to Urgent Care or ER to get an X-ray. **If your child has difficulty breathing, seems confused, or is less alert after a fall/fracture, this is an emergency; go immediately to the ER and alert staff that symptoms could be due to Fat Embolism Syndrome (FES).**

STEROIDS

Remember to tell your doctor if your child is on steroids. If severe trauma or unable to take daily corticosteroids for 48 hours, go to the ER and ask that IV corticosteroids are given until pills by mouth are tolerated **(6 mg of deflazacort equals 5 mg of Prednisone).** Bring the PJ Nicholoff Steroid Protocol (parentprojectmd.org/pj). Stress doses may be needed for moderate/severe stress on the body.

ANESTHESIA PRECAUTIONS

If possible, inhaled anesthesia should be avoided. IV anesthesia is considered safe with close monitoring. **Succinylcholine should NEVER be used.** Local anesthesia and nitrous oxide are generally safe for minor dental procedures.

GENERAL RECOMMENDATIONS

- Keep immunization up to date & get influenza (flu) vaccine annually. Always wear seat belts in the car AND in chairs/wheelchair/scooter/shower chairs.
- Call your neuromuscular team and tell them you are going to the ER/hospital (do not depend on the ER staff to do this).

FOR FAMILIES

NEUROMUSCULAR CENTER/DOCTOR:

NEUROMUSCULAR CENTER EMERGENCY NUMBER:

DUCHENNE MUSCULAR DYSTROPHY EMERGENCY CARE INFORMATION FOR HEALTHCARE PROVIDERS

RESPIRATORY CARE

Risk of respiratory failure. **Do not give Oxygen** without close monitoring of CO2 levels. Breathing may need to be supported (non-invasive ventilation). Use cough assist machine if needed and available.

LEG FRACTURE TREATMENT

Risk of pain, loss of ambulation, FES. If ambulatory before leg fracture, surgery is preferred over casting to preserve ambulation (i.e., internal fixation with rapid weight bearing). Following a fracture or body trauma, **watch for signs of Fat Embolism Syndrome (FES)** including fast breathing and/or confusion.

STEROIDS

Risk of adrenal crisis. Please refer to the PJ Nicholoff Steroid Protocol (parentprojectmd.org/pj) for stress dosing. Watch for signs of adrenal crisis during times of severe illness or injury, or surgery.

ANESTHESIA PRECAUTIONS

Risk of rhabdomyolysis. Inhaled anesthesia can cause rhabdomyolysis among other serious complications (i.e., cardiac arrest) in patients with Duchenne. When possible, inhaled anesthesia should be avoided. IV anesthesia is considered safe. Use all anesthesia with extreme caution after discussing with the anesthesiologist. **Succinylcholine should never be used.** Local anesthesia and nitrous oxide are generally safe for minor dental procedures.

GENERAL RECOMMENDATIONS

- Consider long term steroid therapy when administering live vaccinations.
- AST/ALT are normally elevated in patients with Duchenne and need no further evaluation.

FOR HEALTHCARE PROVIDERS

Parent Project Muscular Dystrophy