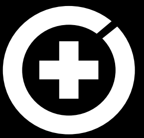
ADULT IMPERATIVES FOR DUCHENNE MD

A Guide for Providers



D — DISCUSS GOALS

■ Provider should spend time alone with patient at every visit ■ Monitor transition to adult care ■ Assess independence at every visit ■ Discuss educational and/or employment goals at every visit ■ Facilitate discussions around advanced care planning including advanced directives and having an emergency care plan in place

U — UNDERSTAND BREATHING PROBLEMS

■ Pulmonary function evaluation every 6 months or as recommended by a pulmonologist ■ Discuss cough assist when cough peak flow is < 270 liters per minute or if cough becomes weaker ■ Discuss sleep study and nighttime non-invasive ventilation (Bi-PAP) when forced vital capacity (FVC) < 50% or with symptoms of hypoventilation (frequent awakenings, morning headaches, and behavioral changes) ■ Discuss daytime non-invasive ventilation when exhaled CO_2 > 45 mmHg ■ Keep immunizations (including pneumonia and annual flu) up to date ■ Treat respiratory infections promptly and aggressively ■ Do NOT give supplemental oxygen without monitoring CO_2

C — CORTICOSTEROIDS

■ Discuss the rationale for lifelong steroid management ■ Evaluate efficacy and manage side effects of corticosteroids at each neuromuscular visit ■ Never stop taking steroids abruptly ■ Discuss the need for stress dosing of steroids for illnesses or surgeries

H — HEART

■ Cardiology visit with imaging (cardiac MRI preferred; echocardiogram if cardiac MRI not available) every 6 months or as recommended by a cardiologist ■ Prescribe first line cardiac medications (ACEi or ARB) as tolerated ■ Standard heart failure medications should be initiated with evidence of heart failure (SF or shortening fraction <28% or ejection fraction <55%)

E — ENDOCRINE

■ If taking steroids, check 25-OH vitamin D annually ■ Supplement vitamin D as needed ■ Nutrition discussions of adequate calcium and vitamin D intake ■ Discuss measurement of bone density and use of bisphosphonates ■ Assess for back pain or signs of vertebral compression fractures ■ Evaluate sexual maturity at each clinic visit until progression through puberty is established for need for testosterone therapy

N — NEVER FORGET PHYSICAL & OCCUPATIONAL THERAPY

■ Specialized PT evaluations every 4-6 months using standardized strength and function measures ■ Stretching every day if comfortable ■ Discuss and encourage contracture prevention (splints, stretches), appropriate exercise, assistive mobility devices (strollers, scooters, wheelchairs) and other assistive devices (beds, arm assistance, lifts, etc.) ■ Assess positioning and posture and the need for supports at each visit to prevent scoliosis

N — NUTRITION & GASTROINTESTINAL

■ Monitor weight ■ Assess/discuss diet (healthy eating, calcium, vitamin D) ■ Evaluate swallowing/need for intervention ■ Treat GERD, constipation and gastroparesis as necessary ■ See your dentist every 6 months

E — EMERGENCY

■ Have patients, parents and/or caregivers carry a copy of their last visit/note summary (including medications and neuromuscular contact information) and a Duchenne emergency card with them at all times ■ Use caution with all anesthesia; avoid inhaled anesthesia ■ Never use succinylcholine

M — MENTAL HEALTH

■ Assess adjustment, coping, behavioral and emotional disorder and social isolation for the patient and family at each visit ■ Discuss the need for individualized personal care/support ■ Assess relationships, friendships, activities and community engagement at each visit

D — DON'T DO IT ALONE

■ Direct to trustworthy, reliable online resources ■ Organize follow up via a comprehensive neuromuscular center with expertise in caring for people living with Duchenne ■ Offer contact with organizations (**ParentProjectMD.org, WorldDuchenne.org**) ■ Encourage connection to other adults living with Duchenne locally or through social media

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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

World Duchenne Organization UPPMD