# Adult Imperatives for Duchenne MD

## 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

## 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 CO2 > 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 CO2

## 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

## 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%)

## 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

## 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

## 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

## 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

## 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

## 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
Careguidelines

Parent Project Muscular Dystrophy
WorldDuchenne.org