



Accredited Duchenne Centers Program

Screening criteria – adults (aged ≥ 18 years)

Centers that apply for accreditation for adults and meet the screening criteria can be scheduled for a visitation with a group of experienced professionals and a patient representative. Criteria for adults are in agreement with the latest care considerations, consensus guidelines and/or expert opinions.^{1,2,3,4,5}

Screening criteria for adults are¹:

Organization of health care

- The number of adults with DMD treated is in relation to the care region
- Adult DMD care is provided by a multidisciplinary team (patients have access to: neuromuscular specialist (rehabilitation physician and/or neurologist), cardiologist, respiratory physician, physiotherapist, occupational therapist, speech and language therapist, dietitian, gastroenterologist, (clinical neuro)psychologist)
- Multidisciplinary adult DMD care may be delivered either by one center, or shared with other locations; however, the applying center is responsible for the care plan, communication and collaboration

Neuromuscular management

- Continuation of corticosteroids is advised if evidence for benefit outweighs risk in adult DMD patients
- Regular assessment of side effects of corticosteroids

Rehabilitation management

- Comprehensive multidisciplinary rehabilitation assessments are done at least once every 6 months in line with the disease stage (can be in shared care; assessments are done at least once per year in the main center)

Endocrine management

- Education about adrenal crisis and stress dose steroid prescription if adults are on glucocorticoids

¹ Criteria described are the minimum criteria. The multidisciplinary team can recommend more frequent follow-ups if needed.

Gastrointestinal and nutritional management

- Assessment by a dietitian at least annually
- Assessment of body weight at least annually
- Preventing both overweight and cachexia
- Annual assessment of the level of vitamin D
- Annual assessment of dietary calcium intake
- Gastrointestinal complications (including constipation, bloating, reflux, gastroparesis and swallowing dysfunction) are actively treated and prevented

Renal and bladder management

- Annual assessment of renal function

Respiratory management

- Respiratory assessments are performed every 6-12 months in adult DMD patients
- Adult DMD patients are referred to a home ventilation team if needed
- Adult DMD patients are recommended to initiate lung volume recruitment (LVR) techniques with an LVR bag or Mechanical Insufflation-Exsufflation (MI-E) device

Cardiac management

- Annual cardiologist follow-up with assessment of cardiac function
- Annual assessment of cardiac function with echocardiography and/or electrocardiogram(ECG)
- Adult DMD patients are treated with ACEi (and a beta-blocker if needed) and/or ARBs

Bone health management

- Adult DMD patients on long term steroid treatment are assessed annually for symptoms and signs of steroid induced osteoporosis with a lateral spine x-ray and DXA scan (lateral spine x-rays should be prioritized, and DXA scans require individualized plans with adjustments for height)

Orthopedic management

- Joint range of motion is assessed at least once every six months by one of the members of the multidisciplinary team (such as the physiotherapist)
- Visual monitoring for scoliosis at least once every six months in non-ambulatory adults with DMD

Participation, psychosocial and palliative care

- A mental health clinician (such as a psychologist or social worker) is part of the multidisciplinary team
- Mental health and quality of life of adults with DMD and their families are assessed at every clinic
- Adults with DMD and their families receive ongoing mental support
- A clinical neuropsychologist is part of the multidisciplinary team, or is available to the team
- Neuropsychological evaluations and interventions for learning, emotional and behavioral problems are provided
- A psychiatrist is available to the team

Perioperative and anesthetic care

- There is always a pre-anesthetic assessment which includes assessments of 1) airway (mouth opening), 2) cardiac status (echo/cMRI) and 3) respiratory status

References

- 1) Birnkrant et al. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *Lancet Neurology*; 17(3):251-267.
- 2) Birnkrant et al. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 2: respiratory, cardiac, bone health, and orthopaedic management. *Lancet Neurology*; 17(4):347-361.
- 3) Birnkrant et al. (2018). Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across lifespan. *Lancet Neurology*; 17(5): 445-455.
- 4) Narayan S et al. (2022). Adult North Star Network (ANSN): Consensus Document for Therapists Working with Adults with Duchenne Muscular Dystrophy (DMD) – Therapy guidelines. *Journal of Neuromuscular Diseases*; 9:365-381.
- 5) Quinlivan R et al. (2021). Adult North Star Network (ANSN): Consensus Guideline For The Standard Of Care Of Adults With Duchenne Muscular Dystrophy. *Journal of Neuromuscular Diseases*; 8:899-926.