

Adult North Star Network (ANSN): Consensus Guideline for the Standard of Care of Adults With Duchenne Muscular Dystrophy

Quinlivan R, Messer B, Murphy P; ANSN, et al. J Neuromuscul Dis. 2021;8(6):899–926.

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AIM OF GUIDELINE

This guideline was designed to provide a framework to improve clinical services and multidisciplinary care for adults living with Duchenne muscular dystrophy (DMD).

METHODOLOGY

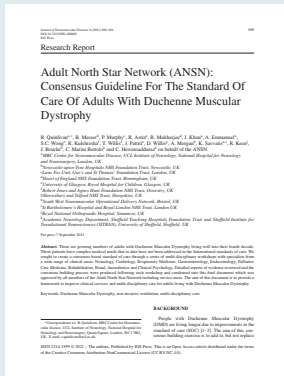
Working subgroups of the ANSN reviewed the literature and current practices in key areas, including respiratory, anaesthesia, cardiology, renal, psychology, endocrinology, and palliative care. Where published evidence was lacking, the subgroups developed a consensus-based opinion of the best practice of care. ANSN members reached unanimous agreement on the final published document.

“ *Most adults with DMD are frail and highly vulnerable, as their condition progresses they experience increasingly complex health issues including cardiac failure, cachexia, pain, renal dysfunction and bowel dysmotility that do not generally occur in childhood. Thus, for adult patients the emphasis of care shifts from a preventative approach to a treatment approach.* **”**

Please see the reverse for an overview of the ANSN Consensus Care Guideline.

SUMMARY OF ANSN CONSENSUS GUIDELINE FOR THE STANDARD OF CARE OF ADULTS WITH DUCHENNE MUSCULAR DYSTROPHY

The ANSN Guideline includes the following selected recommendations for the management of adults with DMD:



- **Respiratory care:** Routine monitoring should include measurement of FVC and PCF every 6 to 12 months. Services caring for adults with DMD must have access to a skilled respiratory team, with joint clinics or a clear referral pathway to a complex ventilation service
- **Anaesthetic care:** Patients requiring general anaesthesia should be managed in centres with expertise in the care of adults with DMD; if this is not possible, advice should be sought from a specialist centre
- **Cardiac management:** Adults with DMD should be seen at least annually by a cardiologist with experience in the management of neuromuscular cardiomyopathy. All patients should have annual cardiologist follow-up with assessment of cardiac function by echocardiography or cMRI
- **Renal care:** Renal function monitoring for adults with DMD is recommended at least annually. Abnormal results should prompt a GFR test and urgent referral to a nephrologist
- **Nutrition and gastrointestinal care:** Constipation should be actively prevented or treated, and weight and nutrition should be assessed every 6 to 12 months
- **Corticosteroid management:** Corticosteroid use should be monitored regularly to ensure that evidence for benefit exceeds risk
- **Bone health:** Active management of bone health by a metabolic bone specialist is important for all patients with DMD. Steroid-induced osteoporosis and presence of vertebral fractures should be assessed annually

The guideline notes that comprehensive multidisciplinary care should also include access to services such as physical therapy, speech and language therapy, occupational therapy, clinical psychology, and social work or care coordination.

cMRI=cardiac magnetic resonance imaging; FVC=forced vital capacity; GFR=glomerular filtration rate; PCF=peak cough flow.

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