

# Independence for patients living with DMD continues beyond ambulation

Loss of functional independence impacts quality of life for patients and their families<sup>1,2</sup>

Of responses from patients/caregivers who reported quality of life impairment,

**dependence (58%)**

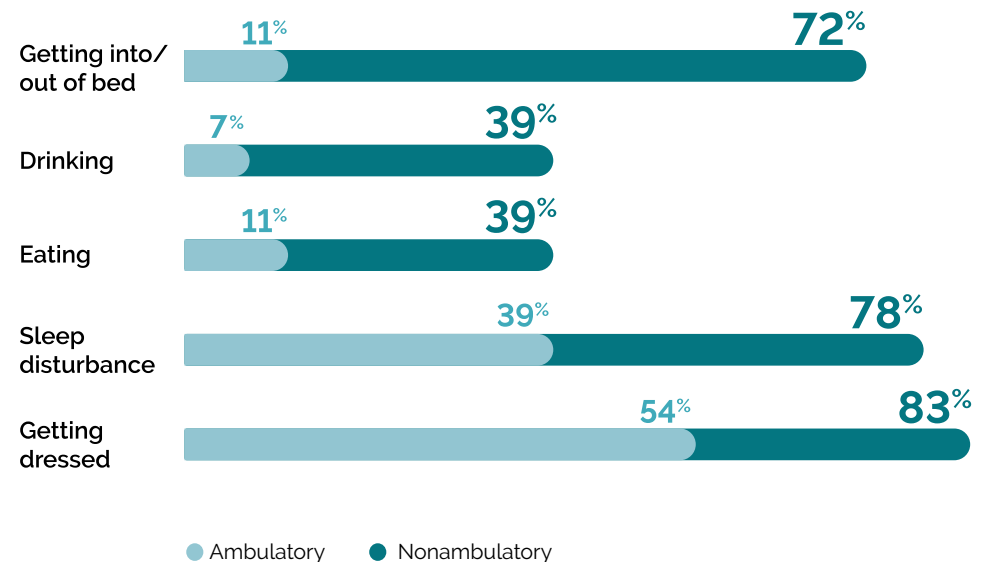
was reported as having the biggest impact.<sup>1,a</sup>

These responses associated dependency as **being reliant on other people** for activities of daily living, such as eating, dressing, showering, and using the bathroom.<sup>1</sup>

"I cannot reach for a lot of things that I would like to reach. It can get frustrating to have somebody help me every time I need to get something."

– Patient living with DMD<sup>3</sup>

Frequency of Symptoms and Impacts Reported by Patients and Caregivers<sup>2,b</sup>



<sup>a</sup>Of the 275 patients/caregivers in the analytic sample, 231 answered the question about the symptoms that have the biggest impact on day-to-day life. Out of a total of 603 unique responses, 403 responses were from early-stage nonambulatory patients and 200 were from late-stage nonambulatory patients.<sup>1</sup>

DMD=Duchenne muscular dystrophy.

<sup>b</sup>In a 2022 qualitative survey among caregivers and patients aged 4 to 22 years, including 28 ambulant patients (mean age: 8.7 years) and 18 nonambulant patients (mean age: 11.3 years).<sup>2</sup>

Make functional status a priority in DMD care<sup>1-3</sup>

For your patients living with DMD

# Upper limb function is key to independence

The Brooke Upper Extremity Scale is a clinically reliable and meaningful assessment of an individual's level of upper limb function.<sup>4</sup>

Other measures are available, including the PUL 2.0, a clinical measure of disease progression as assessed through upper limb function among ambulatory and nonambulatory patients.<sup>1</sup>

## It is important to evaluate upper limb assessments at all stages of DMD<sup>3,5,6</sup>

PUL=Performance of the Upper Limb.







**References:** **1.** Schuster ALR, Crossnohere NL, Fischer R, et al. Unmet therapeutic needs of non-ambulatory patients with Duchenne muscular dystrophy: a mixed-method analysis. *Ther Innov Regul Sci.* 2022;56(4):572-586. **2.** Brown V, Merikle E, Johnston K, et al. A qualitative study to understand the Duchenne muscular dystrophy experience from the caregiver/patient perspective. Poster presented at: Muscular Dystrophy Association (MDA) Conference; March 13-16, 2022. Nashville, Tennessee. **3.** Mazzone ES, Vasco G, Palermo C, et al. A critical review of functional assessment tools for upper limbs in Duchenne muscular dystrophy. *Devel Med Child Neurol.* 2012;54(10):879-885. **4.** Connolly AM, Malkus EC, Mendell JR, et al. Outcome reliability in non-ambulatory boys/men with Duchenne muscular dystrophy. *Muscle Nerve.* 2015;51(4):522-532. **5.** Wojnicz W, Sobierajska-Rek A, Zagrodny B, et al. A new approach to assess quality of motion in functional task of upper limb in Duchenne muscular dystrophy. *Appl Sci.* 2022;12(23):12247. **6.** Birnkrant DJ, Bushby K, Bann CM, et al. Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *Lancet Neurol.* 2018;17(3):251-267. **7.** Brooke MH, Griggs RC, Mendell JR, et al. Clinical trial in Duchenne dystrophy. I. The design of the protocol. *Muscle Nerve.* 1981;4(3):186-197.

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## The Brooke Upper Extremity Scale<sup>3,7</sup>

Highest Score	Description	Example of daily skill
1	Starting with arms at the sides, patient can abduct arms in a full circle until they touch above the head	 Reach above the head
2	Can raise arms above head, only by flexing the elbow or using accessory muscles	 Comb hair
3	Cannot raise hands above head, but can raise 8 oz glass of water to mouth, using both hands if necessary	 Drink 8 oz from glass
4	Can raise hands to mouth, but cannot raise 8 oz glass of water to mouth	 Brush teeth
5	Cannot raise hand to mouth, but can use hand to hold a pen or pick up pennies from table	 Use joystick
6	Cannot raise hands to mouth and has no useful function of hands	 No hand use
Lowest Score		