REFERENCIAS

Arora, K., Uppal, K., Kumar, S., Polipalli, S. K., & Kapoor, S. (2025). Counselling for Duchenne muscular dystrophy (DMD): Integrating psychosocial perspective. *The International Journal of Indian Psychology, 13*(3), 2541–2548. DOI: 10.25215/1303.233

Baldini, V., Varallo, G., Nuredini, A., Tupler, R., Plazzi, G., De Ronchi, D., Pera, M.C., Liguori, R., Rubichi, S., Scorza, M. (2025). The Psychological Burden of Neuromuscular Diseases: A Narrative Review of Anxiety, Depression, Coping, and Quality of Life. *Muscles, 4*(4):59. doi: 10.3390/muscles4040059. PMID: 41441446; PMCID: PMC12736145.

Birnkrant, D. J., Bushby, K., Bann, C. M., Apkon, S. D., Blackwell, A., Brumbaugh, D., et al.; DMD Care Considerations Working Group. (2018a). Diagnosis and management of Duchenne muscular dystrophy, Part 1: Diagnosis, and neuromuscular, rehabilitation, endocrine, and gastrointestinal and nutritional management. *The Lancet Neurology, 17*(3), 251–267. https://doi.org/10.1016/S1474-4422(18)30024-3

Birnkrant, D. J., Bushby, K., Bann, C. M., Apkon, S. D., Blackwell, A., Colvin, M. K., et al.; DMD Care Considerations Working Group. (2018b). Diagnosis and management of Duchenne muscular dystrophy, Part 3: Primary care, emergency management, psychosocial care, and transitions of care across the lifespan. *The Lancet Neurology, 17*(5), 445–455. https://doi.org/10.1016/S1474-4422(18)30026-7

Brogna, C., Moriconi, F., Capasso, A., et al. (2025). Identification and treatment of neurodevelopmental and mental disorders in boys and adults with Duchenne muscular dystrophy: A cohort study. *Archives of Disease in Childhood, 110*(11), 913–920. https://doi.org/10.1136/archdischild-2024-328344

Conn, R., Geagan, C., Bouquillon, L., Bonney-Murrell, C., Bindman, D., Eilon, T., Hoskin, J., Johnson, A., Kerr, A., Rodney, S., Turner, C., Quinlivan, R., Guglieri, M., & Straub, V. (2026). *Duchenne Care UK: Psychosocial standards of care guideline recommendations. Volume 2: For mental health professionals in the UK working with people of all ages living with Duchenne muscular dystrophy (DMD)* (Version 1.0). Duchenne Care UK.

Díaz-Pinto, A., Osuna Macho, S., Montolio Del Olmo, M. (2022*). Guía educativa: Aspectos cognitivos y emocionales de DMD/DMB*. Parent Project Duchenne España. https://www.infocoponline.es/pdf/011-Guia-Educativa-en-DMD-DMB-WEB.pdf

DMD Companion. (2025, 12 de diciembre). *Someone to talk to: Finding mental health support for DMD*. https://www.dmdcompanion.com/features/finding-mental-health-support-dmd/

DMD Warrior. (2026, 27 de marzo). *How does Duchenne muscular dystrophy affect the brain?* https://dmdwarrior.com/duchenne-muscular-dystrophy-brain-effects/

DMD Warrior. (2026, 1 de mayo). *Psychological support in Duchenne muscular dystrophy: 16 powerful strategies*. https://dmdwarrior.com/psychological-support-in-duchenne-muscular-dystrophy/

DMD Warrior. (2026, 31 de marzo). *Stress and anxiety in Duchenne muscular dystrophy*. https://dmdwarrior.com/stress-and-anxiety-in-duchenne-muscular-dystrophy/

DMD Warrior. (2026, 26 de marzo). *Esperanza de vida en la distrofia muscular de Duchenne: El impacto de la atención y el tratamiento en los resultados*. https://dmdwarrior.com/es/life-expectancy-in-duchenne-muscular-dystrophy/

Geagan, C., Conn, R., Bouquillon, L., Bonney-Murrell, C., Bindman, D., Eilon, T., Hoskin, J., Johnson, A., Kerr, A., Rodney, S., Turner, C., Quinlivan, R., Guglieri, M., & Straub, V. (2026). *Duchenne Care UK: Psychosocial standards of care guideline recommendations. Volume 1: For neuromuscular specialist teams working with people of all ages living with Duchenne muscular dystrophy (DMD)* (Version 1.0). Duchenne Care UK.

Hoskin, J., Geagan, C., Conn, R., Alhashwani, Z., Catlin, N., Catlin, S., Cornelius-Light, S., Ebanks, J., Fawcett, A., Fitzpatrick, L., Kerr, A., James, B., Johnson, A., Mayhew, A., Rodney, S., Velleman, F., Turner, C., Vers, L., Guglieri, M., & Straub, V. (2026). *Supporting people with Duchenne muscular dystrophy in school, college and university: A guide for professionals working in education. Volume 3 of the psychosocial standard of care guideline recommendations*. Duchenne Care UK.

Katsomiti E, Kastanioti C, Chroni E, Mavridoglou G, Pavlou E. (2025). Quality of Life and Financial Burden in Duchenne Muscular Dystrophy in Greece: Insights into Health System Performance in the Post-Pandemic Context. *Healthcare (Basel), 8*;13(22):2835. doi: 10.3390/healthcare13222835. PMID: 41302223; PMCID: PMC12652078.

Miranda, R., Weerkamp, P. M., Kolesnik, A., Geagan, C., Chieffo, D., Suárez-Bagnasco, M., ... & Zanetti, C. (2026). Screening for brain-related comorbidities in Duchenne muscular dystrophy: Construction, reliability, and validity of the BIND screener. *Developmental Medicine & Child Neurology, 68:*1080–1096. DOI: 10.1111/dmcn.70145

Orozco, M., Kestler, E., Ramirez, G., Silva, G., Cabrera, J., De la Vega, S., & Al Khleifat, A. (2025). Genetic and clinical landscape of Duchenne muscular dystrophy in Guatemala: Insights from a national study. *Frontiers in Genetics, 16*, 1595423. https://doi.org/10.3389/fgene.2025.1595423

Read, J., Kinali, M., Muntoni, F., & Garralda, M.E. (2010). *Psychosocial adjustment in siblings of young people with Duchenne muscular dystrophy*. *European Journal of Paediatric Neurology, 14*(4), 340-348. https://doi.org/10.1016/j.ejpn.2009.09.011

Read, J., Kinali, M., Muntoni, F., Weaver, T., & Garralda, M.E. (2011). *Siblings of young people with Duchenne muscular dystrophy: A qualitative study of impact and coping*. *European Journal of Paediatric Neurology, 15*(1), 21-28. https://doi.org/10.1016/j.ejpn.2010.07.006

United Nations. (s.f.). *World Duchenne Awareness Day, 7 September*. https://www.un.org/en/observances/duchenne-awareness-day