

Improving allied health and nursing outcomes through best practice guidelines for Duchenne muscular dystrophy

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Background: The fundamental principal of care for people with Duchenne muscular dystrophy (DMD) is anticipatory and preventative management, much of which is delivered by allied health and nursing professionals. Within the multidisciplinary context, allied health and nursing interventions aim to improve function, quality of life, and health outcomes. Although allied health and nursing care is considered within current practice guidelines, there is inadequate detail regarding what constitutes best practice.

The aim of this project is to:

1. Provide evidence-based guidance specific to allied health and nursing practice for the assessment and management of those with DMD.
2. Where appropriate evidence does not exist, obtain consensus for allied health and nursing practice for assessment and management of those with DMD.
3. Disseminate the guidelines widely across Australia and New Zealand.

Methods: The methodology for the guidelines will be conducted in accordance with the requirements of National Health and Medical Research Council of Australia (NHMRC). In brief, a series of systematic literature reviews will be conducted to identify assessment and management strategies for key allied health and nursing focus areas encompassing physical, cognitive and psychosocial wellbeing. The review process will result in the development of preliminary recommendations. Consensus on these preliminary recommendations will be obtained using a modified Delphi methodology. Allied health and nursing professionals from Australia and New Zealand will be engaged throughout process culminating in an expert workshop to confirm consensus.

Results: This presentation will provide an update on the outcomes of the guideline process to date, as well as discussion of the methodology employed.

Discussion: Through their development and subsequent adoption, our vision is for these best practice guidelines to improve and standardise allied health and nursing practice. This will enable better health outcomes and improved quality of life for those living with DMD in Australia and New Zealand.