

DMD Care UK's guideline on respiratory care: NICE review

NICE review

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Overview

NICE has reviewed [DMD Care UK's guideline on respiratory care for Duchenne muscular dystrophy](#). We think the guideline from [DMD Care UK](#) is a useful resource that will help healthcare professionals improve care in this area.

NICE has carried out this review to support improved care and outcomes for people with DMD, and to assist healthcare professionals in their decision making. However, NICE has not developed its own recommendations for this topic.

NICE has chosen to present this guideline on the basis that:

- it covers a condition that NICE does not have an existing guideline on
- it was developed using an appropriate process and methods.

Disclaimer

NICE does not assume responsibility for the content of the guideline, including its clinical recommendations, accuracy, or relevance to specific patient circumstances. Healthcare professionals should exercise their own clinical judgment and consider local policies, individual patient needs, and other relevant guidance before applying any information from the linked material in practice.

NICE commentary

NICE has reviewed [DMD Care UK's guideline on respiratory care](#) for Duchenne muscular dystrophy.

We think the guideline from [DMD Care UK](#) is a useful resource that will help healthcare professionals improve care in this area.

Summary of the review

The recommendations in the guideline are specific and clearly described. The guideline's development process was editorially independent, and relevant stakeholders were involved throughout. Although the evidence used to develop this guideline was not identified through a systematic review, the recommendations were informed by a large number of clinical experts and by patient representatives.

The applicability limitations could be addressed in future updates by analysing data from an audit of DMD care centres, to identify remaining barriers to implementing the recommendations.

Review process

NICE has reviewed the guideline using AGREE II assessments. This is a structured approach to evaluating the quality of clinical guidelines.

Strengths of the guideline

- DMD Care UK's guideline was developed by an expert working group made up of specialists and patient representatives from across the UK. It was reviewed and endorsed by the British Thoracic Society. Additionally, the recommendations were reviewed by patients and by over 100 clinical experts which gives confidence in the acceptability of the recommendations to services and healthcare professionals. This is particularly important when developing recommendations for rare diseases such as DMD that have the inherent challenge of a lack of published evidence.

- The guideline clearly describes the objectives, health questions and the population covered by the recommendations.
- The management pathway is well presented, and the key recommendations are easy to identify. The guideline includes helpful summary flow charts which will aid implementation.
- The expert working group was editorially independent, as the guideline clearly states who funded it and group members had no competing interests.

Limitations of the guideline

- There are inherent challenges in developing guidance for rare diseases, such as a lack of published evidence. The guideline does however explain why and how it used an alternative, informed approach to develop the recommendations.
- No information on the strengths and weaknesses of the evidence used to develop the guideline is reported. However, because of the lack of evidence on DMD, many of the recommendations are based on the consensus of the expert working group and on internationally agreed standards of care rather than evidence identified from a systematic literature review.
- There is a lack of information on the applicability of the recommendations. No information is provided on implementation advice, facilitators and barriers, or resource implications. No cost and resource analysis was carried out.

Users should be aware that this is not NICE guidance and that the development does not follow NICE's published methods and processes.

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