

The management of myalgic
encephalomyelitis / chronic fatigue
syndrome

English summary

Une production de l'Institut national
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SUMMARY

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Introduction

Myalgic encephalomyelitis / chronic fatigue syndrome (ME / CFS) is a chronic disease involving various multisystem clinical manifestations. The diagnostic process is complicated by the existence of different diagnostic criteria and the lack of confirmatory testing. In addition, management is an issue as some clinical manifestations are unfamiliar to primary care clinicians and others require adaptation of standard clinical practice. Therefore, the Ministère de la Santé et des Services sociaux has asked the Institut national d'excellence en santé et en services sociaux to develop clinical tools to support front-line health and social services professionals in the diagnosis and management of ME / CFS.

Methodology

A systematic review of documents presenting clinical information or recommendations was conducted in collaboration with a scientific information consultant (librarian). The literature was searched in the MEDLINE, Embase and EBM Reviews databases. A manual search of the literature was also carried out by consulting, among others, the websites of learned societies specialized in the field under study. Two scientific professionals independently selected the documents, extracted them and assessed their methodological quality. The clinical recommendations developed are the result of an assessment of information, positions and recommendations from the literature, the perspective of stakeholders, and contextual elements specific to Québec. An advisory committee made up of clinicians with different specialties and expertise, as well as people with ME / CFS, provided stakeholder perspectives and contextual input. Finally, the overall quality of the work, its acceptability and applicability were assessed by external readers who were specialists in the field of interest as well as future users who had not participated in the work.

Results

As a result of the analysis of the information gathered and the iterative process conducted with the members of the advisory committee, the following findings and key messages were identified as having the potential to improve practice and ultimately the experience of care and service for people with ME / CFS.

Assessment of health condition

ME / CFS may be suspected in a person who has an atypical constellation of multisystem clinical manifestations lasting at least 6 weeks. The diagnostic process is based on standard practice, but adherence to the energy envelope (i.e., the amount of energy available) should be considered in the choice of investigations.

Diagnostic criteria

ME / CFS is the condition of a person who meets the following conditions : 1- presence of asthenia, post-exertional malaise, cognitive difficulties and non-restorative sleep or sleep disturbances, 2- existence of clinical manifestations for at least 24 weeks on a continuous basis, or not, and 3- no other condition can explain the entire clinical picture.

Management

Management of the individual should be initiated as soon as ME / CFS is suspected, even if the diagnosis is not confirmed, to promote stabilization of the condition and help prevent deterioration. The therapeutic approach should be flexible and personalized. Respect for the energy envelope and the increased sensitivity of people with ME / CFS to medications and drug interactions should be considered in all interventions.

Support

Various health and social service professionals may be involved in supporting people with ME / CFS with the burden of illness. They should adapt their practice to support the adherence to the energy envelope.

Follow-up

Regular follow-up of affected individuals is necessary since the condition and needs vary over time. Furthermore, the effect of the strategies and interventions implemented should be assessed by characterizing post-exertional malaise and not by the intensity of fatigue.

Recommendations and clinical tools

Following the iterative process with the advisory committee members, where clinical information and recommendations from the literature, contextual elements and the perspective of various stakeholders consulted were triangulated, a series of findings and recommendations were developed. These recommendations are at the heart of this report and are also incorporated into the clinical tools that emerged from the work, primarily intended for front-line clinicians, namely, a management tool for ME / CFS and an aide-mémoire on support for those affected.

Conclusions

The development of the ME / CFS clinical tools is based on clinical practice recommendations that have been enhanced by the perspective of the various stakeholders as well as by contextual aspects. Without being a substitute for clinical judgment, the clinical information presented and the recommendations developed should contribute to better management of people with ME / CFS.

Update

The relevance of updating the recommendations will be evaluated in 4 years from the date of publication according to the progress of scientific data on ME / CFS, the evolution of clinical practices and the needs of the health and social services network.

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