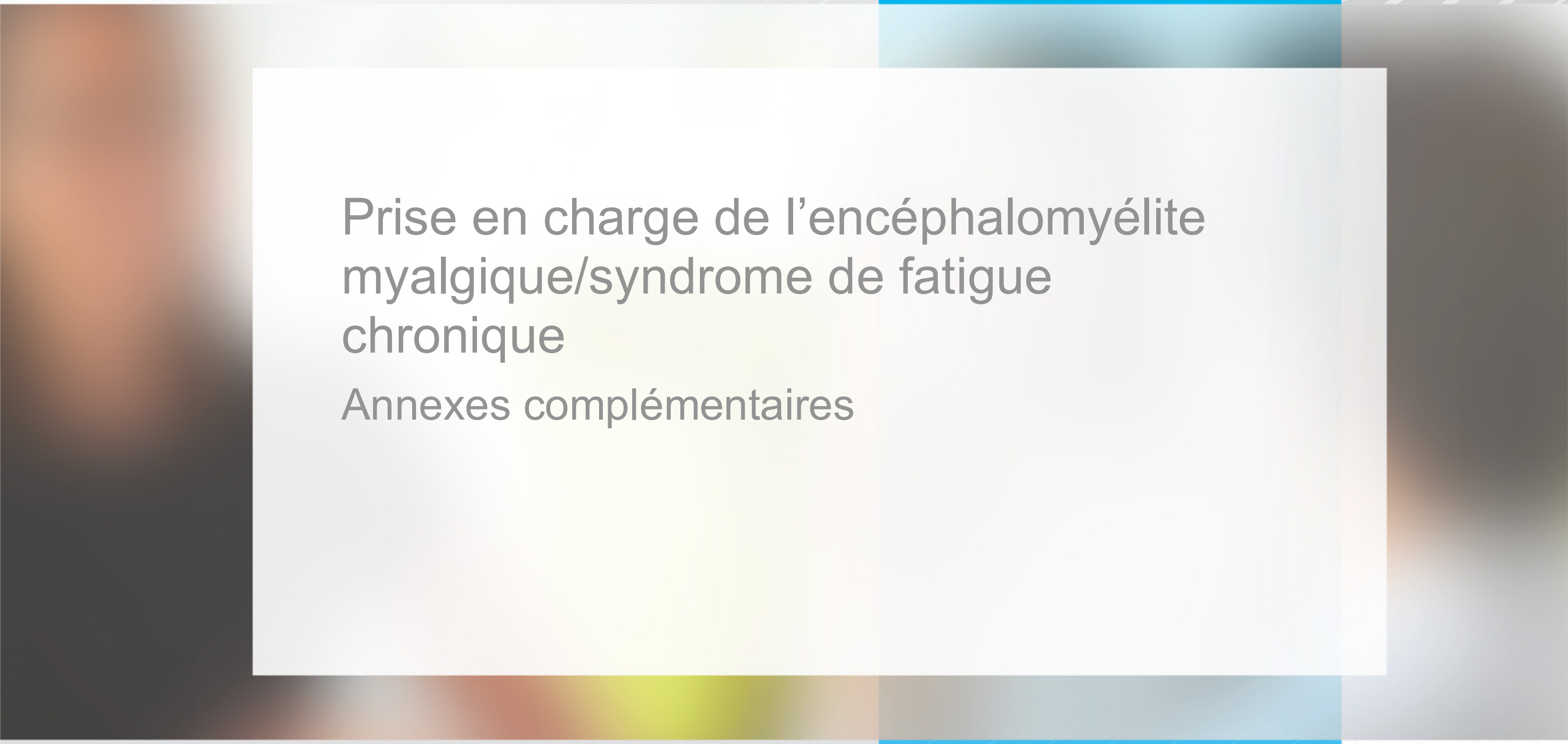
AVRIL 2023

GUIDES ET NORMES



Prise en charge de l’encéphalomyélite myalgique/syndrome de fatigue chronique

Annexes complémentaires

Une production de l’Institut national
d’excellence en santé
et en services sociaux (INESSS)

Direction de l’évaluation et de la pertinence
des modes d’intervention en santé

Le présent document contient les annexes complémentaires au rapport *Prise en charge de l'encéphalomyélite myalgique/syndrome de fatigue chronique*.

Le contenu de cette publication a été rédigé et édité par l'INESSS.

Ces annexes et le rapport final sont accessibles en ligne dans la section *Publications* de notre site *Web*.

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Responsabilité

L'Institut rend accessibles les principales informations qui ont servi à la préparation du rapport *Prise en charge de l'encéphalomyélite myalgique/syndrome de fatigue chronique* aux lecteurs qui désirent plus de détails sur sa démarche scientifique.

Ce document n'a pas fait l'objet d'une révision linguistique. Il ne reflète pas forcément les opinions des autres personnes consultées aux fins du présent dossier.

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ANNEXE A

Méthodologie

QUESTIONS D'ÉVALUATION

Les questions d'évaluation ont été déterminées selon les aspects à documenter dans les outils cliniques à produire. Elles ont été formulées, de manière générale, en tenant compte des éléments du modèle PIPOH : population, interventions d'intérêt, professionnels à qui s'adressent les travaux, paramètres d'intérêt (*outcomes*) et le milieu et contexte clinique où s'appliquent les interventions (*health care setting*).

1. Quels sont les aspects épidémiologique, étiologique et pronostic ainsi que les facteurs de risque de l'EM/SFC?
2. Quels sont les signes et symptômes de l'EM/SFC?
3. Quelles sont les modalités de bonnes pratiques cliniques pour :
    a) apprécier la condition de santé de la personne en ce qui concerne :
        - les signes et symptômes?
        - les éléments de l'histoire de santé?
        - les autres conditions possibles?
        - les examens à réaliser?
        - les analyses et investigations à effectuer?
        - les critères diagnostiques à privilégier?

    b) effectuer la prise en charge des signes et symptômes?
    c) soutenir les personnes atteintes?
    d) effectuer le suivi?

MÉTHODES DE SYNTHÈSE DE L'INFORMATION ET DES RECOMMANDATIONS ISSUES DE LA LITTÉRATURE

Type de revue de la littérature

Une revue systématique des documents qui présentent de l'information ou des recommandations cliniques pour répondre à l'ensemble des questions d'évaluation a été réalisée.

Stratégies de repérage de la littérature

Le repérage de la littérature a été réalisé par un conseiller en information scientifique (bibliothécaire) en collaboration avec un professionnel scientifique. Les bases de données bibliographiques MEDLINE, Embase et EBM Reviews (Cochrane Database of Systematic Reviews, Health Technology Assessment, NHS Economic Evaluation

Database) ont été interrogées. La recherche documentaire a ciblé les documents publiés entre janvier 2015 et juin 2022, afin de se limiter aux synthèses récentes d'informations cliniques et aux recommandations les plus actuelles. Le choix d'une période de 6 ans et demi visait à reculer jusqu'au moment de la publication d'un document charnière de l'Institute of Medicine [IOM, 2015]. Les principaux concepts ci-après ont été utilisés et combinés pour la recherche d'information : « chronic fatigue », « fatigue syndrome », « myalgic encephalomyelitis », « systemic exertion intolerance disease ».

Une recherche manuelle de la littérature a également été réalisée par un professionnel scientifique. Les sites Web des agences et des organismes d'évaluation des technologies de la santé, ainsi que ceux d'organismes gouvernementaux et paragouvernementaux, d'associations ou d'ordres professionnels associés au thème des travaux, ont aussi été consultés. Les documents des pays inclus dans l'Organisation de coopération et de développement économique (OCDE) ont été consultés.
Les documents publiés par l'INESSS ont également été consultés. Le moteur de recherche Google a aussi été utilisé afin de répertorier des documents qui n'auraient pas été publiés dans les bases de données consultées. Par ailleurs, les références bibliographiques des publications retenues ont été vérifiées pour répertorier d'autres documents pertinents. Seules les publications en français et en anglais ont été retenues.

La stratégie de repérage d'information ainsi que les mots clés utilisés sont détaillés à l'annexe B.

Critères et processus de sélection des documents

La sélection a été effectuée de façon indépendante par deux professionnels scientifiques à partir des critères d'inclusion et d'exclusion établis (tableau A-1). Les deux professionnels scientifiques ont testé un échantillon aléatoire de citations pour s'assurer de la compréhension commune des critères de sélection des études. La sélection a ensuite été effectuée par lecture des titres et résumés puis des textes intégraux. Les divergences d'opinions ont été réglées en prenant en considération l'avis d'une troisième personne. Dans le cas de publications multiples, seule la version la plus récente a été retenue pour analyse. Les raisons d'une inclusion ou d'une exclusion ont été inscrites dans un fichier. Un diagramme de flux selon le modèle PRISMA illustrant le processus de sélection des documents, de même que les raisons d'exclusion détaillées sont présentés à l'annexe C.

Tableau A-1 Critères d'inclusion et d'exclusion des documents qui présentent de l'information et des recommandations cliniques

ÉLÉMENTS	CRITÈRES D'INCLUSION
POPULATION	Enfants et adultes qui ont des signes et symptômes compatibles avec l'encéphalomyélite myalgique/syndrome de fatigue chronique
INTERVENTION	Diagnostic et prise en charge de l'encéphalomyélite myalgique/syndrome de fatigue chronique
PROFESSIONNELS VISÉS	Professionnels de la santé et des services sociaux de première ligne (médecins, pharmaciens, personnel infirmier, professionnels de la réadaptation, travailleurs sociaux, professionnels de la santé mentale, etc.)

ÉLÉMENTS	CRITÈRES D'INCLUSION
PARAMÈTRES D'INTÉRÊT (ASPECTS À DOCUMENTER)	▪ Épidémiologie ▪ Étiologie ▪ Pronostic ▪ Facteurs de risque ▪ Paramètres de l'appréciation de la condition de santé : – signes et symptômes, histoire de santé, examens, analyses et investigations, critères diagnostiques ▪ Modalité de prise en charge clinique, y compris le soutien à la gestion des symptômes et la réadaptation ▪ Éléments de suivi
CONTEXTE CLINIQUE	Ambulatoire
TYPE DE PUBLICATION	Guides de bonne pratique clinique, consensus d'experts, lignes directrices ou tout autre document qui présente de l'information et des recommandations cliniques
ANNÉES DE PUBLICATION	2015 à 2022
	CRITÈRES D'EXCLUSION
MILIEU OU CONTEXTE D'INTERVENTION	Guides de pratique et lignes directrices dont les recommandations sont ciblées pour des pays exclus de l'Organisation de coopération et de développement économique.
TYPE DE PUBLICATION	▪ Documents dont l'objectif principal n'inclut pas l'élaboration de recommandations cliniques. ▪ Documents qui reprennent sans adaptations les recommandations et l'information clinique d'un autre document

Évaluation de la qualité méthodologique

L'évaluation de la qualité des documents sélectionnés a été effectuée de façon indépendante par deux professionnels scientifiques. En présence d'une divergence importante relativement à l'évaluation, un consensus a été recherché. L'intervention d'un troisième évaluateur n'a pas été nécessaire.

Les outils et les grilles d'évaluation de la qualité méthodologique suivants ont été utilisés :

- AGREE II (*Appraisal of guidelines for research and evaluation*) pour évaluer la qualité des documents qui comportent des recommandations [Brouwers *et al.*, 2010];
- la liste de vérification AACODS (*Authority, accuracy, coverage, objectivity, date and significance*) pour l'information clinique provenant des CDC [Tyndall, 2010].

Certains auteurs ont été contactés afin d'obtenir davantage d'information sur la méthodologie utilisée pour l'élaboration des documents afin d'assurer une évaluation adéquate de ceux-ci. Les résultats de l'évaluation de la qualité sont présentés à l'annexe D.

Extraction

L’extraction de l’information et des recommandations cliniques (section « paramètre d’intérêt » du tableau A-1) a été effectuée par un professionnel scientifique à l’aide de tableaux d’extraction préétablis et préalablement testés sur quelques documents pour en assurer la validité. L‘information extraite a été validée par un deuxième professionnel scientifique. Les tableaux d’extractions sont présentés à l’annexe E.

Analyse et synthèse

Une analyse a été effectuée pour repérer les similarités et les différences entre l'information clinique et les recommandations recensées. Celles-ci ont ensuite été résumées dans une synthèse narrative textuelle.

MÉTHODES DE SYNTHÈSE DE L’INFORMATION CONTEXTUELLE ET DE LA PERSPECTIVE DES PARTIES PRENANTES

Les recommandations cliniques élaborées par l’INESSS sont le fruit de l’appréciation de l’information et des recommandations issues de la littérature, de la perspective de parties prenantes québécoises ainsi que d’éléments contextuels propres au Québec. L’information contextuelle et les différentes perspectives ont été obtenues principalement par la consultation des personnes qui ont participé au comité consultatif mis en place dans le cadre des travaux. Ces échanges ont permis de comparer l’information recensée dans la littérature à celles issues de la pratique clinique québécoise.

Stratégies de collecte, processus et approche pour garantir la qualité et l’intégrité des informations recueillies

Afin de documenter la perspective des cliniciens et de préciser les enjeux professionnels et organisationnels, un comité consultatif a été mis sur pied au commencement du projet. Le comité était composé de cliniciens et chercheurs avec différentes expertises, dont notamment de médecins de famille, d’un neurologue et d’un interniste. Par ailleurs, deux patients partenaires faisaient aussi partie de ce comité. Le comité consultatif avait pour mandat d’assurer la crédibilité scientifique, la pertinence clinique et de pratique et l’acceptabilité des produits livrés, et ce, en fournissant de l’information, de l’expertise, des opinions ou des perspectives essentielles à la réalisation des travaux.

Les rencontres ont été enregistrées avec l’accord des participants. Les comptes rendus de ces rencontres ont été rédigés par un professionnel scientifique. Ils indiquent la date, le lieu, la synthèse des points saillants de la rencontre et les précisions sur le suivi à effectuer. Une fois les comptes rendus validés par un autre membre de l’équipe et par les membres présents aux rencontres, les enregistrements ont été effacés.

Analyse et synthèse

L’information issue des consultations avec les parties prenantes a été extraite des comptes rendus par un professionnel scientifique en fonction des questions d’évaluation. L’information ainsi extraite a été validée par un autre membre de l’équipe ayant assisté aux échanges. Ces documents ont servi de base pour étayer la perspective des parties prenantes dans les documents produits. Une synthèse narrative a été réalisée afin de comparer entre eux les renseignements tirés des différentes perspectives recueillies.

PROCESSUS ET MÉTHODE D’ÉLABORATION DES RECOMMANDATIONS CLINIQUES ET DE L’OUTIL

Le choix du contenu et l’élaboration des outils cliniques ont été faits avec le comité consultatif.

Pour chaque question d’évaluation, des propositions de recommandations et l’information clinique ont d’abord été formulées et choisies par l’équipe projet en tenant compte 1) de l’information clinique ou des recommandations de bonnes pratiques cliniques issues de la littérature 2) de l’information contextuelle et 3) de la perspective des parties prenantes. L’ensemble de la preuve a été analysé selon les dimensions populationnelles, cliniques, professionnelles et organisationnelles. Les critères présentés au tableau A-2 ont été utilisés pour associer le choix du temps du verbe avec le niveau de confiance que les bénéfices d’adopter une recommandation excèdent les inconvénients et le degré attendu d’adoption de celle-ci. Ensuite, les membres du comité consultatif ont été invités à échanger dans un processus informel, sur l’ensemble de la preuve et à réagir aux propositions préliminaires en vue d’élaborer l’outil d’aide à la prise en charge et l’aide-mémoire sur le soutien à offrir aux personnes atteintes. Deux rencontres ainsi que des échanges par courriel ont été nécessaires pour compléter les premières propositions. Finalement, les membres du comité se sont prononcés sur les documents par courriel. Les recommandations et l’information clinique retenues ont obtenu l’approbation l’ensemble des membres du comité consultatif.

Le contenu a été élaboré en considérant l’équilibre entre les avantages et les inconvénients, les valeurs et les préférences des professionnels et des usagers et l’applicabilité de l’intervention dans le contexte de la pratique au Québec. La portée de l’application de l’outil et de l’aide-mémoire sur la population cible et les répercussions possibles sur les pratiques et sur les ressources humaines, matérielles et organisationnelles ont également été examinées, avec le comité consultatif, durant le processus d’élaboration.

Tableau A-2 Formulation des recommandations

Niveau de consensus basé sur l’ensemble de la preuve	Interprétation des recommandations	Directive pour la formulation de la recommandation
Le groupe de travail est certain que l’intervention ou la décision est : ✓ associée à une obligation légale ✓ peut avoir des conséquences sérieuses sur la santé ou le bien-être de la population si elle n’est pas appliquée.	L’intervention **doit ou ne doit pas être appliquée** à l’ensemble des patients, usagers ou proches aidants.	La recommandation est formulée comme une norme ou une obligation, en utilisant le verbe « devoir ».
Le groupe de travail estime, avec un niveau de confiance élevé, que pour la grande majorité des situations, des patients, usagers ou proches aidants, les bénéfices l’emportent sur les inconvénients ou l’inverse.	L’intervention **devrait ou ne devrait pas être appliquée** à la grande majorité des patients, usagers ou proches aidants, dans la majorité des situations.	La recommandation est formulée comme une instruction directe, en utilisant le verbe « devoir » à la forme conditionnelle, suivi d’un verbe d’action. *Exemples : « l’intervention X devrait être offerte … », « …devrait être proposée… »*
Le groupe de travail estime, avec un niveau de confiance élevé que pour la grande majorité des situations, des patients, usagers ou proches aidants, les bénéfices l’emportent sur les inconvénients ou l’inverse.	L’intervention **pourrait** ou ne pourrait pas **être appliquée** selon les circonstances cliniques, les valeurs ou les préférences des patients, usagers ou proches aidants.	La recommandation est formulée comme une instruction directe; en utilisant un verbe « pouvoir » à la forme conditionnelle, *Exemple : « …. l’intervention X pourrait considérer … »; « l’usage de …pourrait être considérée … »*
Le groupe de travail estime, avec un niveau de confiance élevé qu’en absence de données probantes, les données expérientielles sont suffisantes pour l’élaboration d’une recommandation applicable à la plupart des patients, usagers ou proches aidants ; ou à certains choix décisionnels.	L’intervention **pourrait être considérée au cas par cas** selon les circonstances cliniques, les préférences et les valeurs des patients, usagers ou proches aidants.	Le verbe « considérer » est utilisé.

PROCESSUS DE VALIDATION EXTERNE

Les outils cliniques et le rapport en soutien ont été envoyés à quatre lecteurs externes pour qu'ils évaluent la pertinence du contenu et la qualité scientifique globale de ces documents. Ces personnes ont été choisies en fonction de leur expertise ou de leur implication dans le domaine concerné et de manière à pouvoir représenter différentes régions du Québec.

De plus, afin de s'assurer de la qualité globale des outils cliniques, de leur clarté et de la complétude de l'information présentée ainsi que de leur applicabilité, une consultation de futurs utilisateurs potentiels de différentes régions du Québec a été effectuée par le biais d'un sondage en ligne afin de recueillir leurs commentaires.

Le nom et l'affiliation des lecteurs externes et des futurs utilisateurs sont présentés dans les pages liminaires du rapport en soutien. Les commentaires recueillis ont été analysés par l'équipe de projet et intégrés aux documents finaux, le cas échéant. Un retour par courriel vers les membres du comité consultatif n'a pas été nécessaire.

CONFIDENTIALITÉ ET CONSIDÉRATIONS ÉTHIQUES

Toute information de nature personnelle ou médicale fournie par les parties prenantes consultées a été anonymisée afin de protéger l'identité des participants. Les membres de l'équipe de projet ainsi que toutes les parties prenantes consultées étaient tenus de respecter le devoir de réserve, de confidentialité, d'intégrité et de respect dicté par l'INESSS. Chaque membre de l'INESSS et chaque collaborateur participant aux travaux a pris connaissance du code d'éthique et s'est engagé à le respecter.

PRÉVENTION, DÉCLARATION ET GESTION DES CONFLITS D'INTÉRÊTS ET DE RÔLES

Toute personne appelée à collaborer sur ce dossier, à l'exception des informateurs clés et des futurs utilisateurs qui ont été interrogés de façon ponctuelle et de manière spécifique sur les aspects précités, a dû déclarer les intérêts personnels qui la placent dans une situation propice au développement de conflits d'intérêts, qu'ils soient commerciaux, financiers, relatifs à la carrière, relationnel ou autre. Elle était également invitée à déclarer les différentes activités professionnelles ou les rôles qui la placent dans une situation propice au développement de conflits de rôles. Une telle déclaration était faite sur la base du formulaire standardisé applicable à l'INESSS. Les déclarations complétées par les collaborateurs au dossier ont été évaluées par l'équipe de projet afin de déterminer les modalités de gestion à appliquer selon les situations déclarées. L'ensemble des conflits d'intérêts et de rôles sont divulgués publiquement dans les pages liminaires du rapport par souci de transparence.

GESTION DES RÉFÉRENCES

Les références ont été gérées par le logiciel bibliographique EndNote. Le fichier EndNote est enregistré dans un répertoire électronique dédié au projet et géré par les membres de l'équipe de projet.

MISE À JOUR

Vers la fin du processus de réalisation des travaux, l'équipe de projet a discuté avec le comité consultatif des éléments qui guideront l'évaluation de la pertinence de mettre à jour le produit, le mécanisme proposé ainsi que les échéanciers :

- le type de recherche documentaire prévue (recherche exploratoire, mise à jour de la stratégie de recherche;
- la consultation des parties prenantes, si besoin et lesquelles (p. ex. expert du comité consultatif, membres du comité de suivi, utilisateurs, représentants des ordres professionnels, patients et proches, informateur-clé), afin d'assurer que les aspects influençant la nécessité et la fréquence de la mise à jour soient pris en considération;
- les échéanciers prévus (p. ex. la veille en continu de la littérature, la veille ponctuelle répétée ou la recherche de littérature après une période fixe);
- les critères spécifiques au projet qui déterminent la nécessité de la mise à jour.

Les modalités d'évaluation de la pertinence de mettre à jour les outils cliniques sont présentées narrativement à la section *Mise à jour* du rapport.

ANNEXE B

Stratégie de repérage de l'information scientifique

Bases de données bibliographiques

MEDLINE (Ovid) **Date du repérage : 3 juin 2022** **Limites : 2015- ; anglais, français**	
1	Fatigue Syndrome, Chronic/
2	(chronic fatigue OR fatigue syndrome*).ti
3	((chronic fatigue ADJ2 (disorder* OR immune dysfunction OR syndrome*)) OR chronic infectious mononucleosis-like syndrome OR (fatigue syndrome* ADJ2 (postviral OR post-viral)) OR myalgic encephalomyelitis OR systemic exertion intolerance disease).ti,ab
4	1 OR 2 OR 3
5	Animals/ NOT (Humans/ AND Animals/)
6	4 NOT 5

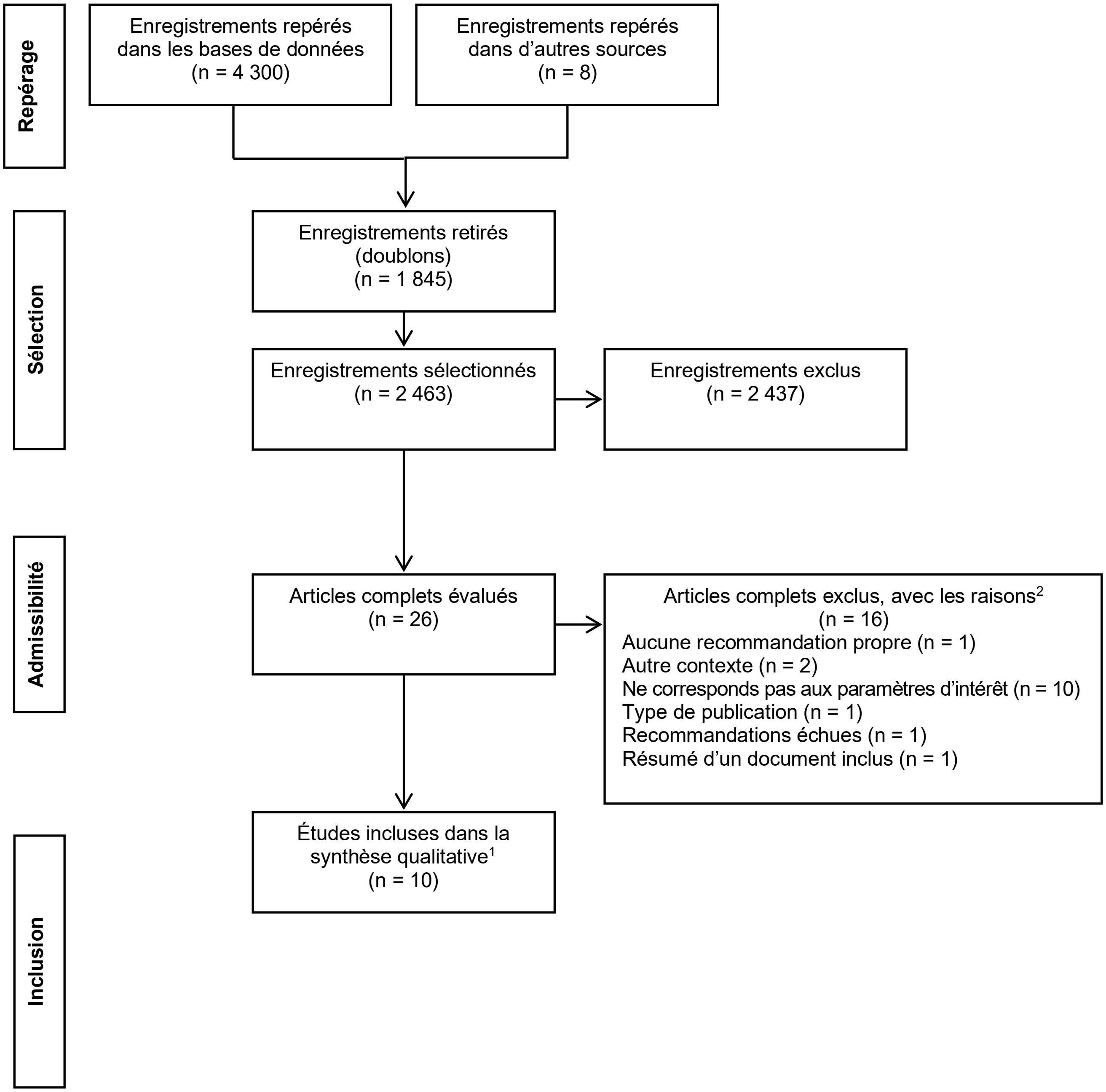
Embase (Ovid) **Date du repérage : 3 juin 2022** **Limites : 2015- ; anglais, français**	
1	*Chronic Fatigue Syndrome/
2	(chronic fatigue OR fatigue syndrome*).ti
3	((chronic fatigue ADJ2 (disorder* OR immune dysfunction OR syndrome*)) OR chronic infectious mononucleosis-like syndrome OR (fatigue syndrome* ADJ2 (postviral OR post-viral)) OR myalgic encephalomyelitis OR systemic exertion intolerance disease).ti,ab
4	1 OR 2 OR 3
5	Nonhuman/ NOT (Human/ AND Nonhuman/)
6	4 NOT 5
7	Conference Abstract.pt
8	6 NOT 7

EBM Reviews (Ovid) : Cochrane Database of Systematic Reviews; Health Technology Assessment; NHS Economic Evaluation Database **Date du repérage : 3 juin 2022** **Limites : 2015- ; anglais, français**	
1	((chronic fatigue ADJ2 (disorder* OR immune dysfunction OR syndrome*)) OR chronic infectious mononucleosis-like syndrome OR (fatigue syndrome* ADJ2 (postviral OR post-viral)) OR myalgic encephalomyelitis OR systemic exertion intolerance disease).ti,ab,kw

ANNEXE C

Sélection des documents

Figure C-1 Diagramme de flux



[1] Voir le tableau C-1 pour la liste des documents inclus.

[2] Voir le tableau C-2 pour la liste des documents exclus et les raisons de leur exclusion.

Tableau C-1 Liste des documents inclus

Identification	Référence	Caractéristiques			
		Pays	Année	Population d'intérêt	Professionnels ciblés
Guides de pratique clinique					
NICE	NICE (2021). "Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management " National Institute for Health and Care Excellence 10: 29	Angleterre	2021	Enfants et adultes	Professionnels de soins de santé, y compris ceux qui travaillent ou qui interviennent dans les services de santé scolaires et professionnels
TOP	TOP ME/CFS Working Group (2016). Identification and symptom management of myalgic encephalomyelitis/chronic fatigue syndrome clinical practice guideline. Edmonton, AB, Toward Optimized Practice: 34 p.	Canada	2016	Enfants et adultes	Professionnels de la santé
Autre source d'information					
CDC	CDC (2022). "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." Retrieved 31 octobre 2022, from https://www.cdc.gov/me-cfs/healthcare-providers/index.html.	États-Unis	2018-2022 selon les sections	Enfants et adultes	Professionnels de la santé
EUROMENE	Nacul, L., F. J. Authier, et al. (2021). "European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE): Expert Consensus on the Diagnosis, Service Provision, and Care of People with ME/CFS in Europe." Medicina 57(5): 19.DOI: https://dx.doi.org/10.3390/medicina57050510	International	2021	Enfants et adultes	Médecins de première ligne
Montoya et coll.	Montoya, J. G., T. G. Dowell, et al. (2021). "Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." Healthcare 9(10): 06.DOI: https://dx.doi.org/10.3390/healthcare9101331	États-Unis	2021	Adultes atteints d'une forme sévère	Professionnels de la santé et autres
Rowe et coll.	Rowe, P. C., R. A. Underhill, et al. (2017). "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer." Frontiers in Pediatrics 5: 121.DOI: https://dx.doi.org/10.3389/fped.2017.00121	International	2017	Enfants	Professionnels de la santé

Identification	Référence	Caractéristiques			
		Pays	Année	Population d'intérêt	Professionnels ciblés
US ME/CFS CC	Bateman, L., A. C. Bested, et al. (2021). "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management." Mayo Clinic Proceedings 96(11): 2861-2878.DOI: https://dx.doi.org/10.1016/j.mayocp.2021.07.004	États-Unis	2021	Adultes	Professionnels de la santé de première ligne ou spécialisés
	US ME/CFS CC (2020). Diagnosing and treating myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), United States Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinician Coalition.	États-Unis	2020	Adultes	Professionnels de la santé de première ligne ou spécialisés
	US ME/CFS CC (2021). Testing recommandations for suspected ME/CFS, United States Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinician Coalition.	États-Unis	2021	Adultes	Professionnels de la santé de première ligne ou spécialisés
	US ME/CFS CC (2021). ME/CFS treatment recommandations, United States Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Clinician Coalition.	États-Unis	2021	Adultes	Professionnels de la santé de première ligne ou spécialisés

Tableau C-2 Liste des documents exclus et raisons d'exclusion

Références	Raisons d'exclusion
Bhatti, S. and Q. A. Bhatti (2019). "Prescribing for patients with chronic fatigue syndrome." Prescriber 30(2): 29-33.DOI: http://dx.doi.org/10.1002/psb.1741	Aucune recommandation propre
Castro-Marrero, J., N. Saez-Francas, et al. (2017). "Treatment and management of chronic fatigue syndrome/myalgic encephalomyelitis: all roads lead to Rome." British Journal of Pharmacology 174(5): 345-369.DOI: https://dx.doi.org/10.1111/bph.13702	Ne corresponds pas aux paramètres d'intérêt
Chand SP, Kuckel DP, Huecker MR. Cognitive Behavior Therapy. 2022 May 8. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022.Jan–.	Ne corresponds pas aux paramètres d'intérêt
Committee on the Diagnostic Criteria for Myalgic Encephalomyelitis/Chronic Fatigue, S., P. Board on the Health of Select, et al. (2015). "Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness." National Academies Press 02: 10.DOI: https://dx.doi.org/10.17226/19012	Recommandations échues
Dukes, J. C., M. Chakan, et al. (2021). "Approach to Fatigue: Best Practice." Medical Clinics of North America 105(1): 137-148.DOI: https://dx.doi.org/10.1016/j.mcna.2020.09.007	Ne corresponds pas aux paramètres d'intérêt
Fennell, P. A., N. Dorr, et al. (2021). "Elements of Suffering in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: The Experience of Loss, Grief, Stigma, and Trauma in the Severely and Very Severely Affected." Healthcare 9(5): 09.DOI: https://dx.doi.org/10.3390/healthcare9050553	Ne corresponds pas aux paramètres d'intérêt
Kluck, B. N., A. N. Junghans-Rutelonis, et al. (2017). "Adolescent Chronic Fatigue and Orthostatic Intolerance." Clinical Pediatrics 56(1): 85-89.DOI: http://dx.doi.org/10.1177/0009922816644730	Type de publication
O'Boyle, S., L. Nacul, et al. (2021). "A Natural History of Disease Framework for Improving the Prevention, Management, and Research on Post-viral Fatigue Syndrome and Other Forms of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." Frontiers in Medicine 8: 688159.DOI: https://dx.doi.org/10.3389/fmed.2021.688159	Ne corresponds pas aux paramètres d'intérêt
Pavlik, D., D. Agnew, et al. (2016). "Recognizing postural orthostatic tachycardia syndrome." JAAPA 29(4): 17-23.DOI: https://dx.doi.org/10.1097/01.JAA.0000481398.76099.09	Ne corresponds pas aux paramètres d'intérêt
Sandler, C. X. and A. R. Lloyd (2020). "Chronic fatigue syndrome: progress and possibilities." Medical Journal of Australia 212(9): 428-433.DOI: https://dx.doi.org/10.5694/mja2.50553	Ne corresponds pas aux paramètres d'intérêt
Scheibenbogen, C., H. Freitag, et al. (2017). "The European ME/CFS Biomarker Landscape project: an initiative of the European network EUROMENE." Journal of Translational Medicine 15(1): 162.DOI: https://dx.doi.org/10.1186/s12967-017-1263-z	Ne corresponds pas aux paramètres d'intérêt
Sharpe, M., T. Chalder, et al. (2022). "Evidence-Based Care for People with Chronic Fatigue Syndrome and Myalgic Encephalomyelitis." Journal of General Internal Medicine 37(2): 449-452.DOI: https://dx.doi.org/10.1007/s11606-021-07188-4	Ne corresponds pas aux paramètres d'intérêt

Références	Raisons d'exclusion
Strassheim, V., J. Welford, et al. (2018). "Managing fatigue in postural tachycardia syndrome (PoTS): The Newcastle approach." Autonomic Neuroscience-Basic & Clinical 215: 56-61.DOI: https://dx.doi.org/10.1016/j.autneu.2018.02.003	Autre contexte
TOP ME/CFS Working Group (2016). Identification and symptom management of myalgic encephalomyelitis/chronic fatigue syndrome clinical practice guideline. Edmonton, AB, Toward Optimized Practice**:** 4 p.	Résumé d'un document inclu
Twisk, F. (2018). "Myalgic Encephalomyelitis or What? The International Consensus Criteria." Diagnostics 9(1): 20.DOI: https://dx.doi.org/10.3390/diagnostics9010001	Ne corresponds pas aux paramètres d'intérêt
Zadourian, A., T. A. Doherty, et al. (2018). "Postural Orthostatic Tachycardia Syndrome: Prevalence, Pathophysiology, and Management." Drugs 78(10): 983-994.DOI: https://dx.doi.org/10.1007/s40265-018-0931-5	Autre contexte

ANNEXE D

Évaluation de la qualité méthodologique des documents

Tableau D-1 Critères d’évaluation de la grille AGREE II

Domaine 1. Champ et objectifs (score 1 à 7)
1. Le ou les objectifs de la RPC sont décrits explicitement.
2. La ou les questions de santé couvertes par la RPC sont décrites explicitement.
3. La population à laquelle la RPC doit s'appliquer est décrite explicitement.
Domaine 2. Participation des groupes concernés (score 1 à 7)
4. Le groupe de travail ayant élaboré la RPC inclut des représentants de tous les groupes professionnels concernés.
5. Les opinions et leurs préférences de la population cible ont été identifiées.
6. Les utilisateurs cibles de la RPC sont clairement définis.
Domaine 3. Rigueur d’élaboration de la RPC (score 1 à 7)
7. Des méthodes systématiques ont été utilisées pour rechercher les preuves scientifiques.
8. Les critères de sélection des preuves sont clairement décrits.
9. Les forces et les limites des preuves scientifiques sont clairement définies.
10. Les méthodes utilisées pour formuler les recommandations sont clairement décrites.
11. Les bénéfices, les effets secondaires et les risques en termes de santé ont été pris en considération dans la formulation des recommandations.
12. Il y a un lien explicite entre les recommandations et les preuves scientifiques sur lesquelles elles reposent.
13. La RPC a été revue par des experts externes avant sa publication.
14. Une procédure d'actualisation de la RPC est décrite.
Domaine 4. Clarté et présentation (score 1 à 7)
15. Les recommandations sont précises et sans ambiguïté.
16. Les différentes options de prise en charge de l'état ou du problème de santé sont clairement présentées.
17. Les recommandations clés sont facilement identifiables.
Domaine 5. Applicabilité (score 1 à 7)
18. La RPC décrit les éléments facilitant son application et les obstacles
19. La RPC offre des conseils et/ou des outils sur les façons de mettre les recommandations en pratique.
20. Les répercussions potentielles sur les ressources de l'application des recommandations ont été examinées.
21. La RPC propose des critères de suivi et de vérification.
Domaine 6. Indépendance éditoriale (score 1 à 7)
22. Le point de vue des organismes de financement n'a pas influencé le contenu de la RPC.
23. Les intérêts divergents des membres du groupe ayant élaboré la RPC ont été pris en charge et documentés.
Appréciation générale de la qualité du guide (score de 1 à 7)
Recommandation de l'utilisation du guide (oui ou non)

Tableau D-2 Qualité globale des documents selon la grille AGREE II

	NICE, 2021				TOP, 2016				EUROMENE, 2021			
Évaluateurs	**1**	**2**			**1**	**2**			**1**	**2**		
Domaines			T*	%†			T*	%†			T*	%†
Champ d’application et objectifs	19	21	40	94,4	17	16	33	75,0	18	13	31	69,4
Participation des groupes concernés	21	18	39	91,7	11	9	20	38,9	14	10	24	50,0
Rigueur du processus d’élaboration du guide	47	47	94	81,3	30	22	52	37,5	14	16	30	14,6
Clarté et présentation	20	14	34	77,8	19	21	40	94,4	14	10	24	50,0
Applicabilité	16	20	36	58,3	4	11	15	14,6	4	4	8	0,0
Indépendance éditoriale	11	10	21	70,8	9	9	18	58,3	11	10	21	70,8
Total	134	130	264		90	88	178		75	63	138	
Score global**	-	-	-	79,0	-	-	-	47,8	-	-	-	33,3

	Bateman, 2021				Montoya, 2021				Rowe, 2018			
Évaluateurs	**1**	**2**			**1**	**2**			**1**	**2**		
Domaines			T*	%†			T*	%†			T*	%†
Champ d’application et objectifs	17	11	28	61,1	13	10	23	47,2	16	13	29	63,9
Participation des groupes concernés	14	9	23	47,2	12	9	21	41,7	9	7	16	27,8
Rigueur du processus d’élaboration du guide	13	12	25	9,4	10	11	21	5,2	12	11	23	7,3
Clarté et présentation	14	12	26	55,6	15	15	30	66,7	14	12	26	55,6
Applicabilité	4	5	9	2,1	4	5	9	2,1	7	7	14	12,5
Indépendance éditoriale	6	8	14	41,7	8	10	18	58,3	11	8	19	62,5
Total	68	57	125		62	60	122		69	58	127	
Score global**	-	-	-	28,6	-	-	-	27,5	-	-	-	29,3

*Somme des scores obtenus par domaine pour chaque évaluateur.

† Pourcentage des scores par domaine = [(Total – score minimal possible / (score maximal possible -score minimal possible)] x 100.

** Score global = [(Total des scores pour l’ensemble des domaines – score minimal possible (46))/ (score maximal possible (322) - score minimal possible(46))] x 100.

Tableau D-3 Liste de vérification AACODS des documents retenus

DOMAINES	Document	CDC, 2022	
	Évaluateurs	1	2
	Questions		
Compétence	Déterminer qui est responsable du contenu intellectuel. **Un seul auteur**		
	Associé à une organisation réputée?	s.o.	s.o.
	Détenant des compétences professionnelles ou une expérience considérable?	s.o.	s.o.
	Ayant produit ou publié d'autres travaux (littérature grise / noire) dans le domaine?	s.o.	s.o.
	Étant un expert reconnu, nommé dans d'autres sources?	s.o.	s.o.
	Étant cité par d'autres (utiliser Google Scholar pour une vérification rapide)?	s.o.	s.o.
	Étant étudiant à un cycle supérieur, sous la supervision d'« experts »?	s.o.	s.o.
	Déterminer qui est responsable du contenu intellectuel. **Une organisation ou un groupe**		
	L'organisation est-elle réputée (p. ex., l'Organisation mondiale de la Santé)?	Oui	Oui
	L'organisation est-elle une autorité dans le domaine?	Oui	Oui
	Dans tous les cas :		
	Le document présente-t-il une liste de références détaillée ou une bibliographie?	Non	Non
Exactitude	L'objectif ou le résumé du document est-il clairement énoncé?	Oui	Oui
	Le cas échéant, le document répond-il à l'objectif ou le résumé correspond-il au contenu du document?	Oui	Oui
	La méthodologie est-elle précisée?	Non	Non
	Le cas échéant, est-elle respectée?	s.o.	s.o.
	Le document a-t-il fait l'objet d'une revue par les pairs?	Non	Non
	A-t-il été édité par une autorité réputée?	Oui	Oui
	A-t-il été soutenu par des références documentées et faisant autorité ou des sources fiables?	Oui	Oui
	Est-il représentatif des travaux dans le domaine?	Oui	Oui
	Si ce n'est pas le cas, le document constitue-t-il une contrepartie valide?	s.o.	s.o.
	Toutes les collectes de données sont-elles explicites et répondent-elles aux besoins de la recherche?	Non	Non
	Si le document est de source secondaire (p. ex., orientation en matière de politiques d'un rapport technique), se reporter à l'original.	s.o.	s.o.
	L'interprétation ou l'analyse est-elle exacte et objective?	Oui	Oui
Étendue	Les limites sont-elles clairement énoncées?	Oui	Oui
Objectivité	Il est important de déceler les biais, en particulier s'ils ne sont pas énoncés ou reconnus. Une opinion, qu'elle vienne d'un expert ou non, demeure une opinion : la perspective de l'auteur est-elle claire?	Non	Non
	La présentation du travail semble-t-elle équilibrée?	Oui	Oui
Date	Pour que l'étude éclaire votre recherche, elle doit être datée afin de confirmer sa pertinence. Le document indique-t-il précisément une date relativement à son contenu? L'absence de date (qui devrait pouvoir être trouvée facilement) est fortement préoccupante.	Oui	Oui
	Si le document n'est pas daté, mais que sa date peut être vérifiée avec précision, existe-t-il une raison valide qui justifie l'absence de date?	s.o.	s.o.
	Vérification de la bibliographie : des références contemporaines clés ont-elles été incluses?	Oui	Oui
Portée	C'est une évaluation de la valeur du document, dans le domaine de recherche pertinent. Le document est-il significatif (ce qui comprend la faisabilité, l'utilité et la pertinence)?	Oui	Oui
	Met-il la recherche en contexte?	Non	Non
	Enrichit-il la recherche ou y ajoute-t-il quelque chose d'unique?	Non	Oui
	Renforce-t-il ou réfute-t-il une position actuelle?	Oui	Oui
	Le domaine de recherche serait-il moins riche sans ce document?	Non	Non
	Est-il intégral, représentatif, caractéristique?	Oui	Oui
	A-t-il une incidence (dans le sens d'influence sur le travail ou le comportement d'autrui)?	Oui	Oui

ANNEXE E

Tableaux d’extractions des recommandations et de l’information clinique issues des documents retenus

Tableau E-1 Recommandations et information clinique concernant les aspects épidémiologique, étiologique, pronostic et les facteurs de risque de l’encéphalomyélite myalgique (Question 1)

Guides de pratique clinique retenus		Sources d’information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
Description de la maladie et de ses conséquences						
There is no […] universally accepted definition for ME/CFS. Be aware that ME/CFS: • is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is still being investigated; • is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity over a day, week or longer; • affects everyone differently and its impact varies widely – for some people symptoms still allow them to carry out some activities, whereas for others they cause substantial incapacity • can affect different aspects of the lives of	**Recommendations** ***Practice point*** Illness severity in ME/CFS ranges from mild (still able to work with effort) to extreme (bedbound needing 24 hour care). Pathological fatigue and post exertional malaise – out of proportion to exertion and taking more than 24 hours to recover – is the key to considering a diagnosis of ME/CFS. Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is the current terminology used to describe a physical condition most commonly associated with post-exertional malaise, debilitating fatigue, pain, cognitive problems, sleep dysfunction as well as many other neurologic, immune and autonomic symptoms. Rest and sleep can provide some relief from the fatigue	The composite term ME/CFS thus carries the disadvantages and shortcomings of both contributary terms. We use it and recommend its use, on purely pragmatic grounds despite these problems, since most clinicians and researchers working in the field use the term and understand its shortcomings. Patients with ME/CFS tend to be multi-symptomatic […]. There is significant intolerance to efforts, both physical and mental, with post-exertional aggravation of symptoms or PEM. Importantly, the symptoms of ME/CFS lead to substantial reductions in previous levels of activity and function. Some individuals will still manage full-time work or education, at least for some time. However, very often	Pediatric myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex disease characterized by overwhelming fatigue and a substantial loss of physical and cognitive function. While all patients experience a substantial loss of physical and cognitive functioning, there is a wide spectrum of severity. • Mildly affected young people might be able to attend school full-time or part-time, but they might have to limit sport and after-school activities and have frequent school absences. • More severely affected young people can be wheelchair dependent, housebound, or bedbound. The more impaired might even	Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex, chronic, debilitating disease with systemic effects. ME/CFS is characterized by reduced ability to perform pre-illness activities that lasts for more than 6 months and is accompanied by profound fatigue, which is not improved by rest. Patients frequently experience a substantial impairment in both physical and mental function at some point in their illnesses. Some patients may be wheelchair- or bed-bound for variable periods during the course of their illnesses. They may require significant assistance with activities of daily living, as well as adjustments to or interruption of their employment or education.	Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic, multi-system disease […]. --- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex, chronic, debilitating disease […]. --- Myalgic encephalomyelitis/chronic fatigue syndrome substantially impairs occupational, educational, social, and personal activities. There is a wide spectrum of severity ranging from mild to very severe: • Mild: mobile and self-caring; may continue working but will have reduced other activities • Moderate: reduced mobility, restricted in instrumental activities of	Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic, multisystem, debilitating disease […]. The severity of specific symptoms and the level of functional impairment seen in ME/CFS can vary widely from person to person and over time. **Spectrum of severity in ME/CFS** • Mild : Mobile and able to self-care. May be working or attending school, but often with accommodations and by reducing other domestic and social activities. • Moderate: Reduced mobility and restricted activities of daily living. Requires frequent rest periods and typically not working or attending school.

Guides de pratique clinique retenus		Sources d’information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
both people with ME/CFS and their families and carers, including activities of daily living, family life, social life, emotional wellbeing, work and education. Definition of severity are not clean cut because individual symptoms vary widely in severity and people may have some symptoms more severely than others. • **Mild ME/CFS** People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and use the weekend to cope with the rest of the week. • **Moderate ME/CFS** People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level	and the other symptoms but often not enough to cope with activities of daily living. In addition, reduced physical and/or cognitive functioning is common.	patients are unable to take up or continue full-time work or education, or any at all, with a significant minority (often quoted as corresponding to 25% of all patients) virtually home- or bedbound. Educational, social, and economic consequences take their toll, with a resulting compromise in emotional wellbeing. People who have severe ME/CFS may be unable to carry out activities of daily living and may spend a significant proportion, or all, of the day in bed. The symptoms experienced by patients with severe ME/CFS are diverse and debilitating, and these may fluctuate and change, both in type and in severity.	have difficulty participating in home tutoring sessions. Myalgic encephalomyelitis/chronic fatigue syndrome is characterized by numerous symptoms in multiple body systems […]. Myalgic encephalomyelitis/chronic fatigue syndrome preceding puberty can impact the development of both the physical, pubertal changes, and the young person’s emotional state and self-image. There can be delay or acceleration of pubertal changes or alteration of physiological processes including hypo-function or, less commonly, hyper-function of the neuroendocrine system. The development of ME/CFS following puberty can be associated with a delay in normal, psychological development fostered by social isolation. Cessation of menstruation can also occur and this can be of great concern to the patient. Emotional responses to the difficulties of ME/CFS are common. These responses are similar to the responses	The spectrum of ME/CFS can range from mild to severe. For example, patients mildly impaired by ME/CFS may be able—with careful planning and activity management—to keep a job or continue their education, participate in social and family activities, and attend to daily life. Those patients who are moderately impaired might, for example, have trouble maintaining a regular work schedule or standing and sitting for prolonged periods. Patients who are severely or very severely affected by ME/CFS include those who are completely wheelchair-dependent and house- or bed-bound for months or even years. Some primarily house-bound patients have increased symptoms after trips for healthcare or after performing daily tasks that healthy people take for granted, such as bathing, showering, and cooking meals. Those who are bed-bound might need assistance performing even these basic tasks.	daily living, needs frequent periods of rest; usually not working • Severe: mostly housebound; limited to minimal activities of daily living (eg, face washing, showering); severe cognitive difficulties; may be wheelchair dependent • Very severe: mostly bedridden; unable to independently carry out most activities of daily living; often experience extreme sensitivity to light, sound, and other sensory input.	• Severe: Mostly homebound. Limited activities of daily living (e.g., self-care, showering, dressing). Severe cognitive difficulties. May be wheelchair dependent. • Very Severe: Bedbound. Unable to carry out most activities of daily living for themselves. Often extreme sensory sensitivity to light, sound, touch, etc. May need total care. These are general categories intended to convey the wide spectrum of disease severity and functional impairment seen in ME/CFS. The assessment of a given patient should be based on their particular level of disease severity and functional impairment.

<table>
<tr><th colspan="2">Guides de pratique clinique retenus</th><th colspan="5">Sources d'information clinique retenues</th></tr>
<tr><th>NICE 2021
Angleterre</th><th>TOP 2016
Canada</th><th>EUROMENE 2021 - Nacul et al. 2021
International</th><th>Rowe et al. 2017
International</th><th>CDC[1] 2018 à 2022 selon les sections
États-Unis</th><th>US ME/CFS CC – Bateman et al. 2021 et documents du site Web
États-Unis</th><th>Montoya et al. 2021
États-Unis</th></tr>
<tr><td>of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.
• Severe ME/CFS People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.
• Very severe ME/CFS People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating, and are very sensitive to sensory stimuli. Some people may not be able to</td><td></td><td></td><td>of young patients with other chronic illnesses.
• Grief and anger
• Apprehension
• Frustration
• Outbursts of weeping
• Emotional distress
These emotional responses to the illness do not ordinarily rise to the level of a psychiatric disorder, but occasionally, psychiatric symptoms are more severe, and a clinically diagnosable, psychiatric disorder can co-exist with ME/CFS.</td><td></td><td></td><td></td></tr>
</table>

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
swallow and may need to be tube fed.						
Épidémiologie						
Recent data from the UK Biobank suggest that there are over 250,000 people in England and Wales with ME/CFS,[…]. ME/CFS can affect people of all ages.	Onset […] may occur at almost any age. The prevalence in adolescents and children is uncertain, but appears to be lower than in adults […]. There is no high quality epidemiological data for Canada. The Statistics Canada Community Health Survey (2014) estimates Canadian prevalence at 407,789, or 1.4% of Canadians 12 years and older.	Prevalence rates have been estimated as between 0.1 and 0.7%, and the incidence rate as 0.015 new cases/1000-year. However, ME/CFS has been reported in all age groups.	Myalgic encephalomyelitis/chronic fatigue syndrome is globally endemic. Most cases are sporadic, but cluster outbreaks have occurred worldwide. In several outbreaks the illness has been prominent in schoolchildren. In sporadic cases the disease is not thought to be transmitted by casual contact. ME/CFS affects all ages, races and socioeconomic groups. Estimates of the prevalence of pediatric ME/CFS vary in different studies from 0.1 to 0.5%.	Estimates about the prevalence and incidence of ME/CFS vary depending on the populations studied and methods used. Between 836,000 and 2.5 million Americans have been estimated to have ME/CFS, as noted in the 2015 IOM report. […] anyone can get ME/CFS […]. ME/CFS occurs in all ethnic and racial groups and in countries around the world. It is at least as common among African Americans and Hispanics as it is among whites. People of all income levels can develop ME/CFS. Most cases are sporadic, but some cluster outbreaks have been reported. Scientists estimate that up to 2 in 1,000 children suffer from ME/CFS. ME/CFS is more common in adolescents than in younger	Myalgic encephalomyelitis/chronic fatigue syndrome affects between 836,000 and 2.5 million Americans of all ages, ethnicities, genders, and socioeconomic backgrounds.	Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) […] affects a million or more Americans of all ages, ethnicities, nationalities, genders, and socioeconomic backgrounds The US prevalence estimate of 1–2.5 M is less than 1% of its population. Prevalence estimates for ME/CFS vary considerably because of factors such as the case definition used, how cases were assessed and whether the study was community based or not.

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
				children		
Étiologie						
Be aware that ME/CFS: - is a complex, chronic medical condition affecting multiple body systems and its pathophysiology is still being investigated. It is not clear what causes ME/CFS. In many cases, symptoms are thought to have been triggered by an infection but it is not simple post-illness fatigue. It lasts longer and even minimal mental or physical activity can make symptoms worse.	Most agree that ME/CFS is a heterogeneous condition with multiple triggers and clinical courses. Both predisposing and precipitating factors are thought to contribute to the developing condition. Precipitating and causal factors: ME/CFS is thought to occur following: - Environmental toxin exposure - A recent vaccination - A significant physical or emotional trauma - Occasionally no identifiable trigger - Acute or chronic infections	Aucune information présentée	Significant pathophysiological changes found in ME/CFS show that it is an organic/physical illness. The underlying etiology of ME/CFS has not been established. Well-documented pathophysiological changes demonstrate that ME/CFS is a multisystem physical disease, not a psychological disorder. The wide variety of pathophysiological findings has led to multiple hypotheses for etiology. These include: infectious agents, immune dysfunction, autoimmune disorders, circulatory abnormalities, neuroendocrine disorders, metabolic disturbances, brain dysfunction, toxins, genetic susceptibility, abnormal gene expression, or a combination of any of these mechanisms. **Precipitating Factors** Sporadic cases of ME/CFS	Scientists have not yet identified what causes myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). It is possible that ME/CFS has more than one cause, meaning that patients with ME/CFS could have illness resulting from different causes (see below). In addition, it is possible that two or more triggers might work together to cause the illness. While the cause or causes of ME/CFS are still unknown, evidence supports a combination of factors that are thought to contribute to the development of this illness. These may include: - Infection – some, but not all, patients develop ME/CFS following an acute viral-like illness. It is possible that in some people an infection may lead to changes in the immune system that contribute to the development of ME/CFS. […] However, in ME/CFS, no causal	Moreover, ME/CFS itself often follows an infectious-like illness. On occasion, the infectious illness preceding ME/CFS […] has been well documented, but often, no attempt has been made to diagnose the infectious agent. While the exact etiology of ME/CFS is uncertain, studies show neurologic, immunologic, autonomic, and energy metabolism impairments.	[…] few published studies have focused specifically on server or very severe ME/CFS patients because they are often unable to travel outside their home to participate in research studies.

Guides de pratique clinique retenus		Sources d'information clinique retenues				
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			can be preceded (triggered) by: a viral, bacterial, or parasitic infection, an immunization, significant physical or emotional trauma, overexertion, ("overtraining") chronic sleep deprivation, exposure to a toxin, or an atypical adverse reaction to a medication. In some patients no precipitating factor can be identified.	role has been established for a specific infectious agent. • Physical or emotional trauma – some patients report experiencing an accident, trauma, immobilization, surgery, or significant emotional stress prior to onset of symptoms. • Genetics – ME/CFS has been observed within some families. This suggests either a possible genetic link or a common environmental exposure (infectious or toxic). […] However, specific genetic associations have not been established. • Environmental factors – exposure to mold or toxins has been suspected as a trigger for ME/CFS. However, associations of specific environmental factors with ME/CFS have not been established. ME/CFS is a biological illness, not a psychologic disorder. These patients have		

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				multiple pathophysiological changes that affect multiple systems. It is not known whether these changes occur prior to the onset of the illness or as its consequence. These changes include: • Immune system abnormalities • Cellular metabolism abnormalities • Neuroendocrine disturbances • Blood pressure or heart rate regulation abnormalities		
Pronostic						
Explain that ME/CFS: • is a fluctuating medical condition that affects everyone differently, in which symptoms and their severity can change over a day, week or longer • varies in long-term outlook from person to person – although a proportion of people recover or have a long period of remission, many will need to adapt to living with ME/CFS Explain to children and young people with ME/CFS and their parents or carers (as appropriate) that the	Despite the increased severity, children tend to have better outcomes than adults as long as they are treated respectfully and not forced to do things they cannot do.	There is little evidence on long term prognosis. However, full recovery is not the norm, particularly in adults […]	The course of ME/CFS is very unpredictable but must often be measured in years, not weeks or months. Remissions and relapses are common. Relapses can be caused by overexertion, infectious illnesses or failure to recover from a "crash". Dramatic improvement sometimes occurs in the first 4 years, but slow improvement over time is more likely. It is generally accepted that young people with ME/CFS have a more favorable prognosis than adults. Symptoms of ME/CFS wax	For some patients, symptoms may diminish or even go into complete remission. However, symptoms can recur. The percentage of ME/CFS patients who recover is not well-studied […]. Some patients return to full function. Some who improve continue to experience symptoms and do not achieve pre-illness levels of function, and many who improve continue to modify their activities to remain improved or symptom-free. Some do not improve or, in fact, worsen over time.	Although it is known that patients can be ill for years or even decades, no definitive study of prognosis exists. A systematic review concluded that the chance of full recovery is only 5%. Temporary remission is reported, but relapses often occur. Patients most commonly report a fluctuating illness pattern in which symptoms wax and wane but are always present. Myalgic encephalomyelitis/chronic	As with ME/CFS in general, recovery is not common and patients with severe and very severe ME/CFS can remain ill for years or decades.

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outlook is better in children and young people than in adults.			and wane over time. […] factors such as severity of symptoms or age at onset have not been shown to be reliable predictors of long-term outcomes. Aggravating factors include: failure to diagnose the illness promptly, resulting in poor management in the early stages of the illness, overexertion resulting in "crashes," stress, inadequate sleep, and co-morbid conditions, such as OI. The course of the severe form of the illness is unpredictable. Many severely affected young patients do show varying degrees of improvement with time and some manage to return to full activities. A few remain severely affected. There is no published literature on prognosis in very severely affected young patients with ME/CFS.	Even though more studies are needed, most experts agree that children, including teenagers, with ME/CFS have a better chance of full or partial recovery than adults	fatigue syndrome is also seen in pediatric patients and appears to have a better prognosis than in adults.	
Facteurs de risque						
[…] about 2.4 times as many women affected as	Onset usually occurs between the ages of 30 and	At least 2/3 of the cases are in women, with young people	[…] adolescents are more likely than younger children	Although anyone can get ME/CFS, among persons	Some groups are disproportionately affected:	aucune information fournie

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men.	50 years […]. The prevalence in adolescents and children is uncertain, but appears to be lower than in adults, with equal numbers of boys and girls affected. Predisposing factors: • Mostly occurs among female gender adults. • Can be familial or inheritad.	in their most productive phases of life being preferentially affected.	to have ME/CFS […]. Being female is a predisposing factor in post-pubertal adolescents. In adolescents, approximately 3–4 times as many girls as boys have ME/CFS. There are less data on the sex ratio in younger children. Genetic factors may produce a susceptibility to the illness in some families.	diagnosed with ME/CFS, the ratio of women to men can be as high as 4 to 1. ME/CFS is less common in children than in adults, and it is more prevalent in adolescents than in younger children. ME/CFS is most common in people between 40 and 60 years old. ME/CFS is sometimes seen in members of the same family.	• Women are affected at a rate 3 times that of men. • Onset often occurs between the ages of 10 to 19 years and 30 to 39 years. • Blacks and Latinxs may be affected at a higher rate and with greater severity than other groups. • An infectious episode near the onset of ME/CFS is recounted by 80% or more of patients.	

Sources : [CDC, 2022; Bateman *et al.*, 2021; Montoya *et al.*, 2021; Nacul *et al.*, 2021; NICE, 2021; US ME/CFS CC, 2021a; US ME/CFS CC, 2021b; US ME/CFS CC, 2020; Rowe *et al.*, 2017; TOP ME/CFS Working Group, 2016]

[1] Site Web consulté le 23 août 2022.

Tableau E-2 Recommandations et information clinique concernant les signes et symptômes de l'encéphalomyélite myalgique (Question 2)

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
Signes et symptômes						
All of these symptoms should be present: • Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and is not significantly relieved by rest.	Pathological fatigue and post exertional malaise – out of proportion to exertion and taking more than 24 hours to recover – is the key to considering a diagnosis of ME/CFS. ME/CFS symptom checklist • pathological fatigue **-** a significant degree of	**Key symptoms** • Persistent, debilitating symptoms that include extreme fatigue or lack of energy, assessed by the impairment in the ability to work, study, or undertake domestic tasks, leisure activities, and social interactions. • Persistent exhaustion	The cardinal feature is a sensation of feeling ill (malaise) and worsening of symptoms following minimal physical or mental exertion. This post-exertional worsening can persist for hours, days, or weeks, and is not relieved by rest or sleep. Other symptoms include unrefreshing or	A hallmark of ME/CFS is that symptoms can worsen after physical, mental, or emotional effort, a manifestation known as post-exertional malaise (PEM). Patients with ME/CFS also have unrefreshing sleep. Other common manifestations	Notably, although postexercise fatigue and musculoskeletal pain are common in healthy people and other medical conditions (eg, osteoarthritis), the postexertional worsening of function and the constellation of symptoms (such as sleep, memory,	ME/CFS causes profound fatigue, unrefreshing sleep, cognitive impairment, orthostatic intolerance, pain, sensory sensitivities, gastrointestinal issues, and other bodily symptoms leading to substantial impairment in function. The hallmark symptom is post-exertional malaise (PEM),

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• Post-exertional malaise after activity in which the worsening of symptoms: o is often delayed in onset by hours or days o is disproportionate to the activity o has a prolonged recovery time that may last hours, days, weeks or longer. • Unrefreshing sleep or sleep disturbance (or both), which may include: o feeling exhausted, feeling flu-like and stiff on waking o broken or shallow sleep, altered sleep pattern or hypersomnia. • Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.	new onset, unexplained, persistent or recurrent physical and/or mental fatigue that substantially reduces activity levels and which is not the result of ongoing exertion and is not relieved by rest. • post-exertional malaise & worsening of symptoms **- m**ild exertion or even normal activity is followed by malaise: the loss of physical and mental stamina and/or worsening of other symptoms. Recovery is delayed, taking more than 24 hours. • sleep problems **-** sleep is un-refreshing: disturbed quantity – daytime hypersomnia or nighttime insomnia and/or disturbed rhythm – day/night reversal. Rarely there is no sleep problem • pain **-** pain is widespread, migratory or localized: myalgia; arthralgia (without signs of inflammation); and/or headache – a new type, pattern or severity. Rarely there is no pain • neurocognitive	or unusually high levels of fatigue, aggravated by low levels of exertion, still, upright position, and stress (physical or emotional, such as infections or raised anxiety levels). • Post-exertional malaise, or post-exertional exacerbation of symptoms: any or all symptoms can get worse following physical or mental efforts and stress—this can happen immediately or more typically delayed after a period following the exertion, e.g., which may be longer than 24 h; recovery to previous levels of functioning and symptom severity may last long (typically from a day to weeks). • Sleep dysfunction with unrefreshing sleep, i.e., waking up not feeling rested as one would expect following a good night's sleep. • Complaints of cognitive impairment, such as poor memory, attention, and concentration, slow thinking, reasoning	disturbed sleep, cognitive impairment, and a multitude of immune, neurological, and autonomic symptoms. Orthostatic intolerance (OI) is a common co-morbid condition. […] all patients experience a substantial loss of physical and cognitive functioning […]. Lightheadedness is very common in pediatric ME/CFS, and prolonged upright posture can aggravate other symptoms, including fatigue, headache, nausea, and cognitive dysfunction. Profound exhaustion and post-exertional worsening of symptoms are hallmarks of ME/CFS. Myalgic encephalomyelitis/chronic fatigue syndrome is characterized by numerous symptoms in multiple body systems, but its diagnosis requires only the presence of a group of specific, core symptoms. • The cardinal feature of ME/CFS is malaise and the exacerbation of symptoms after a	are orthostatic intolerance, cognitive impairment, and pain. The 2015 IOM diagnostic criteria for ME/CFS in adults and children state that three symptoms and at least one of two additional manifestations are required for diagnosis. The three required symptoms are: 1- A substantial reduction or impairment in the ability to engage in pre-illness levels of activity (occupational, educational, social, or personal life) that: • lasts for more than 6 months • is accompanied by fatigue that is: o often profound o of new onset (not life-long) o not the result of ongoing or unusual excessive exertion o not substantially alleviated by rest 2- Post-exertional malaise (PEM)*—worsening of symptoms after physical, mental, or emotional exertion that would not have caused a problem before the	concentration, influenza-like feelings [eg, sore throat], and mood) seen in ME/CFS are distinctive. --- People with ME/CFS may present with a range of symptoms that include a decreased level of functioning, debilitating fatigue, cognitive impairment, orthostatic intolerance, flu-like symptoms, a worsening of their symptoms following exertion, pain, and other symptoms. […] core symptoms: • Substantial reduction or impairment in the ability to engage in pre-illness activity that persists for 6 months or more and is accompanied by fatigue. The fatigue is profound, not lifelong, not the result of ongoing exertion, and not alleviated by rest. • Post-exertional malaise (PEM) in which physical or mental activities result in a typically delayed and prolonged exacerbation of symptoms and reduction in functioning	an exacerbation of symptoms and a further relapse in functioning, following even small physical, cognitive, orthostatic, emotional, or sensory challenges that were previously tolerated. The clinical presentation of severe or very severe ME/CFS includes the features seen in those with milder disease, but some features are more prevalent, and all are much more extreme. This includes: • Profound weakness. May be unable to move or turn over in bed, eat, get to the toilet, etc. • Reduced or lack of ability to speak or swallow. • Severe and often almost constant, widespread pain, severe headaches, and hyperesthesia. • Extreme intolerance to small amounts of physical, mental, emotional, or orthostatic stressors such as sitting, bathing, toileting, eating,

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Be aware that the following symptoms may also be associated with, but are not exclusive to, ME/CFS: • orthostatic intolerance and autonomic dysfunction, including dizziness, palpitations, fainting, nausea on standing or sitting upright from a reclining position • temperature hypersensitivity resulting in profuse sweating, chills, hot flushes, or feeling very cold • neuromuscular symptoms, including twitching and myoclonic jerks • flu-like symptoms, including sore throat, tender glands, nausea, chills or muscle aches • intolerance to alcohol, or to certain foods and chemicals • heightened sensory sensitivities, including to light, sound, touch, taste and smell • pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain or joint pain without acute	symptoms **-** Impaired concentration, short term memory or word retrieval; hypersensitivity to light, noise or emotional overload; confusion; disorientation; slowness of thought; muscle weakness; ataxia • autonomic symptoms **-** orthostatic intolerance – neutrally-mediated hypotension (NMH);postural orthostatic tachycardia (POTS); light headedness; extreme pallor; palpitations; exertional dyspnea; urinary frequency; irritable bowel syndrome (IBS); nausea • neuroendocrine symptoms **- l**ow body temperature; cold extremities; sweating; intolerance to heat or cold; reduced tolerance for stress; other symptoms worsen with stress; weight change; abnormal appetite • immune symptoms **- r**ecurrent flu-like symptoms; sore throats; tender lymph nodes; fevers; new sensitivities to food, medicines,	difficulties, sense of disorientation, or “brain fog”. • Pain: muscle and joint pains, which may affect multiple sites and be migratory, but without local signs of inflammation; headaches (tension or migraine type); existing musculoskeletal symptoms may worsen. **Additional symptoms** • Orthostatic intolerance, defined by symptoms occurring only or worsened in the upright position (particularly when not associated with movement—i.e., in the still position), and improved by lying down, e.g., palpitations, tremors, light-headedness, dizziness, weakness, nausea. • Over-sensitivity to stresses and sensory stimuli such as light, noise, temperature changes, or touch. • Intolerance to dietary and environmental factors, such as to alcohol, selected or	variety of forms of effort (most commonly physical or cognitive activity or orthostatic stress). • Other core symptoms are impaired physical and/or cognitive function, fatigue, sleep disturbance, cognitive symptoms, and pain. Additional symptoms can be present in multiple organ systems. Those that are commoner in young patients include • (a) orthostatic intolerance (OI), • (b) hypersensitivities to light, noise, touch, odors. and/or medications, • (c) thermo-regulatory imbalance including low body temperature, intolerance to heat and cold, and cold hands and feet, • (d) gastrointestinal symptoms such as abdominal pain, nausea, and anorexia, • (e) worsening of fatigue in the days before and during the onset of menses can occur in young women	illness. PEM often puts the patient in relapse that may last days, weeks, or even longer. For some patients, sensory overload (light and sound) can induce PEM. The symptoms typically get worse 12 to 48 hours after the activity or exposure and can last for days or even weeks. 3- Unrefreshing sleep*—patients with ME/CFS may not feel better or less tired even after a full night of sleep despite the absence of specific objective sleep alterations. Additional manifestations: • Cognitive impairment***—** patients have problems with thinking, memory, executive function, and information processing, as well as attention deficit and impaired psychomotor functions. All can be exacerbated by exertion, effort, prolonged upright posture, stress, or time pressure, and may have serious consequences on a patient’s ability to maintain a job or attend	(discussed further below). • Unrefreshing sleep and a variety of sleep disturbances • Either cognitive impairment (often referred to as “brain fog” by patients) and/or orthostatic intolerance (the development of symptoms when upright that are alleviated when lying down) PEM is the clinical hallmark of ME/CFS and its most distinctive symptom. Other ME/CFS symptoms include widespread pain; headaches; additional forms of sleep disturbance; visual disturbances; sensitivities to light, noise, chemicals, foods, and drugs; flu-like symptoms including sore throat and tender lymph nodes; susceptibility to infections; gastrointestinal problems; genitourinary issues; respiratory issues such as air hunger; and thermoregulatory issues.	speaking. These can trigger postexertional malaise and increased weakness. • Hypersensitivity, sometimes extreme, to light, sound, touch, chemicals, or odors. Exposure can increase pain and other symptoms. • Severe cognitive impairment that may impede the patient’s ability to communicate and understand written materials. • Severe gastrointestinal disturbances (e.g., nausea, abdominal pain), early satiety, and food intolerances which can impair adequate nutrition. • Orthostatic intolerance severe enough to prevent upright posture. • Sleep dysfunction such as unrefreshing sleep, shifted sleep cycles, and fractured sleep. Compared to the non-homebound ME/CFS population, homebound

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redness, swelling or effusion. Be aware that people with severe or very severe ME/CFS may experience the following symptoms that significantly affect their lives, including their mobility, emotional wellbeing and ability to interact with others and care for themselves: • severe and constant pain, which can have muscular, arthralgic or neuropathic features • hypersensitivity to light, sound, touch, movement, temperature extremes and smells • extreme weakness, with severely reduced movement • reduced ability or inability to speak or swallow • cognitive difficulties that limit the person's ability to communicate and take in written or verbal communication • sleep disturbance such as unrefreshing sleep, hypersomnia and altered sleep pattern • gastrointestinal	odors or chemicals. Although ME/CFS is a physical illness, psychological symptoms may also be present. Children tend to have more severe symptoms than adults with pain and autonomic dysfunction being prominent.	multiple food intolerances and medications, new allergies. • Infection-like immune symptoms, e.g., frequent and prolonged symptoms of upper respiratory tract infections, such as flu-like symptoms, tender cervical lymph nodes, sore throat, congested nose, shortness of breath. • Symptoms of irritable bowel syndrome. • Weight loss or gain. • Sicca-symptoms (dry eyes, mouth, or the opposite: hypersalivation). • Emotional instability, anxiety, and depression.	*Clinical Features of the very severely affected can include:* • A very high degree of symptom severity. • Bedridden with profound weakness. • Severe body pain and hyperesthesia. • Marked sensitivity to sound, light, touch, odors, some foods, and/or medications. • Hyper-somnolence in the early stages. • Severe nausea, difficulty swallowing, occasionally requiring tube feeding. • Difficulty getting to a toilet, requiring the use of a bottle, bedpan, diapers, and/or indwelling catheter. • Difficulty communicating their needs to a caregiver, due to speech difficulties or exhaustion. • Severe limitations of mental activity, including short-term memory impairment. • Severe OI, might be unable to tolerate sitting up in bed. • Difficulty tolerating being washed in bed due to hyperesthesia. • Emotional changes secondary to the illness: patients can be very	school full time. • Orthostatic intolerance—patients develop a worsening of symptoms upon assuming and maintaining upright posture as measured by objective heart rate and blood pressure abnormalities during standing, bedside orthostatic vital signs, or head-up tilt testing. Orthostatic symptoms including lightheadedness, fainting, increased fatigue, cognitive worsening, headaches, or nausea are worsened with quiet upright posture (either standing or sitting) during day-to-day life and are improved (though not necessarily fully resolved) with lying down. Orthostatic intolerance is often the most bothersome manifestation of ME/CFS among adolescents. Other common symptoms of ME/CFS • Muscle pain • Pain in the joints		patients report more severe and frequent symptoms and greater functional impairment.

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difficulties such as nausea, incontinence, constipation and bloating • neurological symptoms such as double vision and other visual disorders, dizziness • orthostatic intolerance and autonomic dysfunction, such as postural orthostatic tachycardia syndrome (POTS) and postural hypotension.			frightened and struggle with feelings of frustration, despair, and anger. • Vitamin D deficiency in housebound patients and prolonged bed rest can lead to osteopenia. Secondary psychological symptoms can be present in some patients as occurs in many other chronic illnesses, but psychological factors have not been shown to be the cause.	without swelling or redness • Headaches of a new type, pattern, or severity • Swollen or tender lymph nodes in the neck or armpit • A sore throat that is frequent or recurring • Chills and night sweats • Visual disturbances • Sensitivity to light and sound • Nausea • Allergies or sensitivities to foods, odors, chemicals, or medications. […] secondary psychological symptoms such as depression and anxiety may also be present in some patients with ME/CFS. **Symptoms and Diagnosis of ME/CFS in Children** • Children, especially adolescents, with ME/CFS have orthostatic intolerance (dizziness and lightheadedness and other symptoms that are triggered when standing up and sometimes also sitting		

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				upright) more often than adults. It is often the most unbearable symptom and may make other symptoms of ME/CFS worse.
				• Sleep problems in young children may show up as a lack of their usual energy. In adolescents with ME/CFS, sleep problems may be hard to detect, as sleep cycles change during puberty. Many adolescents begin to stay up late and often have trouble waking up early. The demands of classes, homework, after-school jobs, and social activities also affect sleep. Common sleep complaints in children and adolescents with ME/CFS include:
				  ○ Difficulty falling or staying asleep
				  ○ Daytime sleepiness
				  ○ Intense and vivid dreaming
				• Unlike adults with ME/CFS, children and adolescents with ME/CFS do not usually have muscle and joint pain. Yet headaches and stomach pain may		

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				be more common in this age group. Younger children may not be able to describe the pain well. • In children, particularly in adolescents, ME/CFS is more likely to start after an acute illness, like the flu or mononucleosis. Sometimes, ME/CFS in children might begin gradually.		
Malaise post-effort						
The worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. Symptoms can typically worsen 12 to 48 hours after activity and last for days or even weeks, sometimes leading to a relapse. Post-exertional malaise after activity in which the worsening of symptoms: • is often delayed in onset by hours or days • is disproportionate to the activity • has a prolonged recovery time that may last hours, days, weeks or longer.	Mild exertion or even normal activity is followed by malaise: the loss of physical and mental stamina and/or worsening of other symptoms. Recovery is delayed, taking more than 24 hours.	PEM typically has delayed onset, often noticed hours later or the following day, and lasts for variable and often extended periods of time— e.g., from a day in milder cases to many days or weeks in moderately and severely affected individuals. Post-exertional malaise, or post-exertional exacerbation of symptoms: any or all symptoms can get worse following physical or mental efforts and stress—this can happen immediately or more typically delayed after a period following the exertion, e.g., which may be longer than 24 h; recovery to previous levels	The cardinal feature of ME/CFS is malaise and the exacerbation of symptoms after a variety of forms of effort (most commonly physical or cognitive activity or orthostatic stress). Post-exertional symptoms can persist for hours, days, or weeks and are not relieved by rest. This symptom is uncommon in other illnesses. *Post-exertional symptoms*: normal activity or mild/moderate exertion is followed by worsening of malaise, fatigue, and other symptoms. Recovery takes more than 24 h.	A hallmark of ME/CFS is that symptoms can worsen after physical, mental, or emotional effort, a manifestation known as post-exertional malaise (PEM). Post-exertional malaise (PEM)*—worsening of symptoms after physical, mental, or emotional exertion that would not have caused a problem before the illness. PEM often puts the patient in relapse that may last days, weeks, or even longer. For some patients, sensory overload (light and sound) can induce PEM. The symptoms typically get worse 12 to 48 hours after the activity or exposure and can last for	The hallmark symptom of PEM is an exacerbation of some or all of a patient's symptoms and a further reduction in functioning after physical, cognitive, orthostatic, emotional, or sensory challenges that were previously tolerated. PEM is characterized by the following: • Immediate or delayed onset. Onset may be immediate or delayed by hours to days after the challenge. • Prolonged duration. Days, weeks, or months may pass before patients return to their previous baseline. • Disproportionate intensity.	The hallmark symptom is post-exertional malaise (PEM), an exacerbation of symptoms and a further relapse in functioning, following even small physical, cognitive, orthostatic, emotional, or sensory challenges that were previously tolerated.

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
		of functioning and symptom severity may last long (typically from a day to weeks). **Fatigue and intolerance to efforts are key symptoms which are not always easy to interpret** • Intolerance to efforts is a key symptom, which relates to disease severity and previous levels of functioning. The most severely affected may be limited in simple movements in bed, speaking or engaging in conversation, eating, and activities of daily living such as going to bathroom, bathing, showering, or dressing), milder cases who were previously very active (e.g., athletes) may remain active, though much less than previously.		days or even weeks. People with ME/CFS often describe this experience as a "crash," "relapse," or "collapse." During PEM, any ME/CFS symptoms may get worse or first appear, including difficulty thinking, problems sleeping, sore throat, headaches, feeling dizzy, or severe tiredness. It may take days, weeks, or longer to recover from a crash. Sometimes patients may be house-bound or even completely bed-bound during crashes.	The intensity and duration of PEM are unexpectedly disproportionate to the magnitude of the PEM trigger. For the mildly ill, working a few hours or a day can trigger PEM, whereas for the most severely ill, even basic activities of daily living will be sufficient. The nature and severity of PEM symptoms, the degree of reduction in function, and PEM's time course can vary from episode to episode and with the type of activity.	
Fatigue incapacitante/asthénie						
Debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion,	A significant degree of new onset, unexplained, persistent or recurrent physical and/or mental fatigue that substantially	Physical fatigue is often expressed as "lack of energy or stamina", profound tiredness, or general weakness.	Impaired function: there is loss of mental and/or physical stamina and a substantial reduction in ability to take part in	A substantial reduction or impairment in the ability to engage in pre-illness levels of activity (occupational, educational, social, or	aucune information présentée	aucune information présentée

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
and is not significantly relieved by rest. Fatigue in ME/CFS typically has the following components: - feeling flu-like, especially in the early days of the illness - restlessness or feeling 'wired but tired' - low energy or a lack of physical energy to start or finish activities of daily living and the sensation of being 'physically drained' - cognitive fatigue that worsens existing difficulties - rapid loss of muscle strength or stamina after starting an activity, causing for example, sudden weakness, clumsiness, lack of coordination, and being unable to repeat physical effort consistently.	reduces activity levels and which is not the result of ongoing exertion and is not relieved by rest.	- Persistent, debilitating symptoms that include extreme fatigue or lack of energy, assessed by the impairment in the ability to work, study, or undertake domestic tasks, leisure activities, and social interactions. - Persistent exhaustion or unusually high levels of fatigue, aggravated by low levels of exertion, still, upright position, and stress (physical or emotional, such as infections or raised anxiety levels). **Fatigue and intolerance to efforts are key symptoms which are not always easy to interpret** - Fatigue is a main symptom, but its description and interpretation are variable. It usually represents a feeling of intense lack of physical energy or stamina and mental tiredness (reduced mental clarity with slowness in thinking and difficulty in understanding and processing information, focusing attention and	personal, educational, and/or social activities. *Fatigue*: the fatigue is not the result of ongoing exertion, is not relieved by rest, and is medically unexplained. Fatigue can worsen with prolonged upright posture. Patients with ME/CFS experience persisting, overwhelming, physical and cognitive exhaustion that is not relieved by rest or sleep. There is a loss of physical and mental stamina. Sometimes there is a feeling of being tired and wired (overstimulated). Fatigue in ME/CFS is pathological. It is qualitatively and quantitatively different from the normal fatigue experienced by healthy people following exertion which is relieved by a good night's sleep.	personal life) that […] is accompanied by fatigue that is: - often profound - of new onset (not life-long) - not the result of ongoing or unusual excessive exertion - not substantially alleviated by rest		

Guides de pratique clinique retenus		Sources d'information clinique retenues				
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		forgetfulness), which restricts the ability to undertake physical and mental activities.				
Altérations du sommeil						
Unrefreshing sleep or sleep disturbance (or both), which may include: • feeling exhausted, feeling flu-like and stiff on waking • broken or shallow sleep, altered sleep pattern or hypersomnia Unrefreshing sleep means sleep that is non-restorative. Even after a full night's sleep, people do not feel refreshed. People with ME/CFS often report waking up exhausted and feeling as if they have not slept at all, no matter how long they were asleep.	Sleep is un-refreshing: disturbed quantity – daytime hypersomnia or nighttime insomnia and/or disturbed rhythm – day/night reversal Rarely there is no sleep problem. Abnormalities include: initial insomnia, frequent waking, non-restorative sleep (i.e., waking up feeling unrefreshed or as tired as before going to sleep) stiffness or soreness and mental fogginess lasting a few hours after waking. Hypersomnia tends to occur early in the illness and insomnia develops as the illness progresses.	Sleep is characteristically "non-restorative" or "unrefreshing", and difficulty in initiating or maintaining sleep is common. Sleep dysfunction with unrefreshing sleep, i.e., waking up not feeling rested as one would expect following a good night's sleep.	*Sleep problems*: sleep is unrefreshing with disturbed quantity or rhythm that can include daytime hypersomnia, nighttime insomnia, and day/night reversal. Patients with ME/CFS experience unrefreshing sleep. Disturbed sleep patterns include difficulty falling or staying asleep, frequent awakenings, vivid dreams, day/night reversal, and hypersomnia. Hypersomnia (sleeping for up to 20 h a day) can occur in the early stages of the illness and can persist for weeks and occasionally months.	**Unrefreshing sleep*—** patients with ME/CFS may not feel better or less tired even after a full night of sleep despite the absence of specific objective sleep alterations. Patients with ME/CFS have non-restorative sleep and wake up less refreshed than they did before becoming ill. Common sleep complaints in patients with ME/CFS include frequent awakening, intense and vivid dreaming, restless legs, and nocturnal myoclonus (night-time muscular spasm), and awakening unrefreshed. Some also experience difficulty falling asleep and hypersomnia (extreme sleepiness). Unrefreshing sleep can be present even though medications may help patients achieve required hours of sleep. Sleep problems in young children may show up as a lack of their usual energy. In	Patients experience various sleep disturbances, such as problems in falling or staying asleep. However, even when these problems are treated, most patients remain tired or sick on awakening. Unrefreshing sleep can be manifested as feeling unrested and unwell on awakening, regardless of how long the patient slept uninterrupted. Some patients need an hour or more on awakening to start feeling better, with late evenings being their best time of day. Patients may also experience trouble in falling asleep, staying asleep, waking up early, or staying awake during the day. They may experience a shifted sleep cycle.	aucune information présentée

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
				adolescents with ME/CFS, sleep problems may be hard to detect, as sleep cycles change during puberty. Many adolescents begin to stay up late and often have trouble waking up early. The demands of classes, homework, after-school jobs, and social activities also affect sleep. Common sleep complaints in children and adolescents with ME/CFS include: • Difficulty falling or staying asleep • Daytime sleepiness • Intense and vivid dreaming		
Intolérance orthostatique						
A clinical condition in which symptoms such as light-headedness, near-fainting or fainting, impaired concentration, headaches, dimming or blurring of vision, forceful beating of the heart, palpitations, tremulousness and chest pain occur or worsen on standing up and are improved (although not necessarily resolved) by sitting or lying down. Orthostatic intolerance may include postural orthostatic tachycardia syndrome (POTS), which is a significant rise in pulse rate	Orthostatic intolerance – neurally-mediated hypotension (NMH);postural orthostatic tachycardia (POTS); Orthostatic intolerance (OI) is common in ME/CFS patients complaining of dizziness, light-headedness, feeling faint and/or having heart palpitations. In individuals with ME/CFS low BP is associated with decreased blood flow to the brain and fatigue symptoms. This is particularly common in younger patients.	Orthostatic intolerance may be manifested with light-headedness and worsening of symptoms (such as fatigue, malaise, dizziness, nausea, palpitations) when assuming or persisting in the upright position for some time, usually a few minutes, but it may happen very soon after raising from the recumbent position or within up to 10 min or more, depending on severity of the dysautonomia. The most severely affected may be unable to stand for more than a few seconds.	Orthostatic intolerance (OI): prolonged upright posture can induce symptoms such as lightheadedness, increased fatigue, cognitive worsening, headaches, and/or nausea. Postural tachycardia syndrome (POTS) or neurally mediated hypotension (NMH) are often present. The term OI refers to a group of conditions in which symptoms worsen with quiet upright posture and are improved but not always abolished by lying down. Typical symptoms are those	Orthostatic intolerance—patients develop a worsening of symptoms upon assuming and maintaining upright posture as measured by objective heart rate and blood pressure abnormalities during standing, bedside orthostatic vital signs, or head-up tilt testing. Orthostatic symptoms including lightheadedness, fainting, increased fatigue, cognitive worsening, headaches, or nausea are worsened with quiet upright posture (either standing or sitting) during day-to-day life	Orthostatic intolerance commonly is manifested as lightheadedness, palpitations, or syncope. However, patients with ME/CFS often experience subtler symptoms, such as feeling sick, nauseous, tired, or confused during periods of sitting or standing still. Inquiring about symptoms during aggravating (eg, long lines, hot weather) and alleviating situations (eg, lying, sitting down) is helpful.	aucune information présentée

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
when moving from lying to standing, and postural hypotension, which is a significant fall in blood pressure when moving from lying to standing. People with severe orthostatic intolerance may find they are unable to sit up for any length of time.		• Orthostatic intolerance, defined by symptoms occurring only or worsened in the upright position (particularly when not associated with movement—i.e., in the still position), and improved by lying down, e.g., palpitations, tremors, light-headedness, dizziness, weakness, nausea.	of cerebral hypo-perfusion or sympathetic activation. […] higher rates of OI in pediatric patients with ME/CFS than in healthy children and higher rates than in adult patients with ME/CFS. Orthostatic symptoms include any of the following: increased fatigue, lightheadedness, white-outs or black-outs of the visual field, visual dimming, mental fog, headaches, nasuea, pain, or shortness of breath. Upright posture consistently aggravates ME/CFS symptoms […] Postural tachycardia syndrome (POTS) is the most common, neurally mediated hypotension (NMH) is less common, and orthostatic hypotension (OH) is uncommon in pediatric patients.	and are improved (though not necessarily fully resolved) with lying down. Orthostatic intolerance is often the most bothersome manifestation of ME/CFS among adolescents. Patients with orthostatic intolerance develop a worsening of symptoms with quiet upright posture and improvement (though not necessarily full resolution) of symptoms with recumbency. Two common forms of orthostatic intolerance experienced by patients with ME/CFS are: • Neurally-mediated hypotension (NMH): an abnormality in the regulation of blood pressure during upright posture. NMH is sometimes also referred to as neurocardiogenic syncope, vasodepressor syncope, vaso-vagal syncope, "the fainting reflex", and delayed orthostatic hypotension. • Postural orthostatic tachycardia syndrome (POTS): an abnormality in the regulation of heart rate in which a change from lying to		

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				standing causes an abnormal increase in heart rate; the heart is usually structurally normal. These two conditions can occur together. Notably, not all patients with NMH or POTS have ME/CFS, and not all patients with ME/CFS have NMH or POTS. Many patients with ME/CFS may also experience triggering or worsening of symptoms when moving to and/or maintaining an upright posture. This is known as orthostatic intolerance. Symptoms of orthostatic intolerance can include frequent dizziness and light-headedness, palpitations, and feeling faint. Adolescents are particularly affected by this manifestation. Children, especially adolescents, with ME/CFS have orthostatic intolerance (dizziness and lightheadedness and other symptoms that are triggered when standing up and sometimes also sitting upright) more often than adults. It is often the most unbearable symptom and may make other symptoms		

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NICE 2021 **Angleterre**	**TOP 2016** **Canada**	**EUROMENE 2021 - Nacul et al. 2021** **International**	**Rowe et al. 2017** **International**	**CDC[1] 2018 à 2022 selon les sections** **États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web** **États-Unis**	**Montoya et al. 2021** **États-Unis**
				of ME/CFS worse.		
Difficultés cognitives						
Cognitive difficulties (sometimes described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.	Impaired concentration, short term memory or word retrieval; hypersensitivity to light, noise or emotional overload; confusion; disorientation; slowness of thought; muscle weakness; ataxia Neurocognitive issues are very common in ME/CFS and are a significant source of impairment especially with regard to work. Most commonly affected are: working memory, processing speed and attention. Patients complain of slow and effortful thinking. They have poor short term memory, problems tuning out extraneous stimuli and difficulty finding the right word to use.	Mental fatigue is expressed as cognitive problems, such as slowness of response, attention, and concentration problems; they are often referred by patients as “brain-fog” and result in reduced ability to perform “mental tasks”. Complaints of cognitive impairment, such as poor memory, attention, and concentration, slow thinking, reasoning difficulties, sense of disorientation, or “brain fog”.	Cognitive problems: any of the following: difficulty in concentration or focusing, difficulty understanding information and/or expressing thoughts, difficulty finding words or numbers, impaired short-term memory, absent mindedness, slowness of thought. Slow mental processing speed, impaired working memory, poor learning of new information, difficulty with word retrieval, increased distractibility, decreased concentration and attention span, and inability to multitask may be found. Cognitive problems can be provoked by, or worsen with prolonged upright posture and/or physical or mental activity. Cognitive impairments are similar in both adult and young patients with ME/CFS.	Cognitive impairment*—patients have problems with thinking, memory, executive function, and information processing, as well as attention deficit and impaired psychomotor functions. All can be exacerbated by exertion, effort, prolonged upright posture, stress, or time pressure, and may have serious consequences on a patient’s ability to maintain a job or attend school full time.	Decreased information processing speed is the most commonly found cognitive deficit in ME/CFS. Other abnormalities include decreased reaction time, working memory, and attention. These deficits are not due to poor effort, insomnia, or mood disorders. Defects become particularly prominent when patients face deadlines, unrelenting demands, and multiple simultaneous tasks. Motor speed, verbal abilities, and global reasoning remain intact.	aucune information présentée
Douleur						
Pain, including pain on touch, myalgia, headaches, eye pain, abdominal pain or	Pain is widespread, migratory or localized: myalgia; arthralgia (without	Pain can be generalised and referred to joints, muscles, and adjacent soft	*Pain*: can be widespread or localized, commonly seen are: chronic daily	- Muscle pain - Pain in the joints without swelling or	aucune information présentée	aucune information présentée

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
joint pain without acute redness, swelling or effusion. **Pain** Pain is identified as one of the symptoms commonly associated with, but not exclusive to, ME/CFS. […] is particularly intense in people with severe or very severe ME/CFS.	signs of inflammation); and/or headache – a new type, pattern or severity. Rarely there is no pain. Ongoing pain is a common symptom in ME/CFS. Pain can be localized or widespread and ranges from mild to severe. Headaches are common, particularly migraine-type headaches.	tissues, with frequent headaches commonly reported. Pain may be migratory and variable in nature and is not associated with signs of inflammatory arthritis or myositis, with typical absence of joint swelling or redness. Pain: muscle and joint pains, which may affect multiple sites and be migratory, but without local signs of inflammation; headaches (tension or migraine type); existing musculoskeletal symptoms may worsen.	headaches, myalgias, abdominal pain, joint pains, sore throats, and painful lymph nodes. Pain can be worsened by prolonged upright posture. Rarely is pain absent. Pain in ME/CFS can be widespread or localized. Sometimes pain is so severe that the patient is unable to tolerate even a gentle touch. Common types of pain include: headache, abdominal pain, myalgia, joint pain, sore throat, lymph nodes, eye pain and occasionally pelvic pain or dysuria. Myalgia and pain from co-morbid fibromyalgia can be found in from 10 to 30% of pediatric patients with ME/CFS […]. Abdominal pain and Nausea are common. Abdominal hyperalgesia may also occur. Gastrointestinal motility disorders can be present, especially in patients with OI.	redness • Headaches of a new type, pattern, or severity • A sore throat that is frequent or recurring People with ME/CFS often experience deep pain in their muscles and joints. Patients may also complain of headaches (typically pressure-like or migraine-like) and sensitivity of their skin when touched. Unlike adults with ME/CFS, children and adolescents with ME/CFS do not usually have muscle and joint pain. Yet headaches and stomach pain may be more common in this age group. Younger children may not be able to describe the pain well.		

Sources : [CDC, 2022; Bateman *et al.*, 2021; Montoya *et al.*, 2021; Nacul *et al.*, 2021; NICE, 2021; US ME/CFS CC, 2021a; US ME/CFS CC, 2021b; US ME/CFS CC, 2020; Rowe *et al.*, 2017; TOP ME/CFS Working Group, 2016]

[1] Site Web consulté le 23 août 2022.

Tableau E-3 Recommandations et information clinique concernant les modalités de bonne pratique clinique pour l'appréciation de la condition de santé (Question 3a)

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
Généralités						
No evidence was identified for any tests or specific signs and symptoms as predictors of a later diagnosis of ME/CFS. […] ME/CFS is recognised on clinical grounds alone. Recognise that people with ME/CFS need: • timely and accurate diagnosis so they get appropriate care for their symptoms Be aware that people with ME/CFS are unlikely to be seen at their worst because: • debilitating symptoms or the risk that their symptoms will worsen may prevent people from leaving their home • cognitive difficulties may often mean people wait until they feel they can speak and explain clearly before contacting services.	**Recommendations** ***Practice point*** Although there is currently no definitive test or validated tool to diagnose ME/CFS or single proven treatment, symptoms consistent with ME/CFS can be identified and managed successfully within the primary care setting. In the absence of a gold standard test, healthcare providers should diagnose ME/CFS using validated diagnostic criteria and clinical experience. Several visits with the patient are often necessary given the complex history, number of symptoms and cognitive difficulties experienced by some patients. **Children** ME/CFS […] can be difficult to diagnose especially under the age of ten. Children and adolescents may not think to report symptoms because they don't have a period of	Diagnosis is clinical, owing to the absence of biomarkers, and based on detailed clinical history and physical examination by a competent clinician. It is important to note that many symptoms commonly reported in ME/CFS have a low disease specificity and may occur in a number of disease. Although diagnostic confirmation may require a 3- to 6-month period, it is important to contemplate the diagnosis at earlier stages, so that disease management may start, and diagnosis and treatment of alternative diseases are not delayed. Diagnosis of ME/CFS in children is especially challenging for two main reasons: • First, younger children may not report symptoms accurately and might assume fatigue as normal, when not remembering the	No valid, reliable, laboratory test that confirms the diagnosis is currently available. The diagnosis of ME/CFS is purely clinical and is based on the history and the exclusion of other fatiguing illnesses by physical examination and medical testing. […] there are no specific diagnostic clinical signs and frequently the patient does not look ill. The diagnosis depends on the patient's symptoms meeting the criteria of one of several overlapping case definitions. Early diagnosis of ME/CFS can lessen the impact of the illness through timely support and intervention. It is critical to allocate enough time for a careful, comprehensive history to be taken from the patient and the parents. […] taking the history in a thorough and empathetic manner engenders the trust of the	No confirmatory test to diagnose ME/CFS is currently available. A healthcare provider can make the diagnosis of ME/CFS based on a thorough medical history and physical examination, laboratory test results (see Evaluation), and evaluating for other fatiguing illnesses with a targeted work-up. The severity and frequency of the symptoms can vary among patients and can vary for an individual patient. Symptoms can fluctuate during the day, from day to day, and throughout the illness. Some patients may not be obviously ill-appearing during clinical evaluations. However, if patients are severely affected or are having an exacerbation of their symptoms, even visiting a clinic for care might not be feasible at times. Thus, healthcare providers may not see patients when their	Accurately and expeditiously diagnosing ME/CFS is important. The purpose of initial evaluations is to determine whether alternative conditions may account for all of the patient's symptoms, to confirm ME/CFS through recognition of characteristic symptoms and signs, and to identify comorbid conditions. Because there are no definitive diagnostic tests, diagnosis relies on medical history and physical examination and may require multiple visits. Tests and referrals to specialists are used primarily to identify alternative diagnoses and comorbidities. The recent expansion of telemedicine may facilitate the provision of care for all ME/CFS patients. The most severely ill patients are bedbound and unlikely to be seen in the clinician's office but may be seen in emergency	Because they are unable to leave their homes, those who are homebound or bedbound are rarely included in research studies or seen by primary care and other healthcare providers unless there is a crisis, such as a very severe relapse or life-threatening malnutrition. […] and reinforce the importance of compassion, humility, and respect in all clinical interactions.

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NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
Offer home visits to people with severe or very severe ME/CFS to carry out their holistic assessment […]. Suspect ME/CFS if: • the person has had all of the persistent symptoms [debilitating fatigue that is worsened by activity, post-exertional malaise, unrefreshing sleep or sleep disturbance or both and cognitive difficulties] for a minimum of 6 weeks in adults and 4 weeks in children and young people and • the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre-illness levels and • symptoms are not explained by another condition. Recognise that symptoms of severe or very severe ME/CFS may mean that people: • cannot communicate	normalcy with which to compare.	experience of full health. • Second, there are differences in how children perceive and report symptoms of ill health, and proxy reporting by parents may not always accurately reflect children's experience. Primary care professionals may suspect a diagnosis in children and adolescents presenting with persistent or recurrent moderate to severely impaired function, fatigue, and post-exertional symptoms, especially if associated with autonomic symptoms, sleep disturbance, neurocognitive problems, and pain (e.g., headaches and abdominal pain), following history, clinical examination, and routine tests that exclude other diagnoses that may explain the symptoms.	patient and family, shows that the clinician takes the patient's illness seriously, and is an important prelude to management. Teenagers usually need an opportunity for discussion without a parent present. The initial evaluation might require more than one office visit because the history is sometimes lengthy and the patient might lack sufficient stamina. Some patients might need to lie down during office visits. For other seriously ill patients, an office visit might be impossible, and they require home visits. Myalgic encephalomyelitis/chronic fatigue syndrome should not be diagnosed if the patient has an identifiable medical or primary psychiatric condition that could plausibly account for the presenting symptoms. If ME/CFS symptoms persist after adequate treatment of other confounding illnesses, a diagnosis of ME/CFS can be considered. Many [young severely ill] are too debilitated to be brought	symptoms are most severe. When a patient presents with impaired function along with fatigue, PEM, unrefreshing sleep, and either one or both cognitive impairment or orthostatic intolerance, a thorough history, physical (including neurological) and mental health exam, and laboratory testing should be performed to evaluate for other conditions that may explain symptoms. During the evaluation period, healthcare providers can begin considering ME/CFS and schedule periodic follow-up appointments. […] Extensive testing and frequent healthcare provider visits may exacerbate the symptoms of patients with ME/CFS, so when follow-up visits are needed, they need to be scheduled thoughtfully. […] patients benefit when diagnosis and management are timely and appropriate. Diagnose ME/CFS when symptoms last >6 months.	departments and hospitals during a crisis. --- While there are no specific diagnostic tests for ME/CFS, the clinician can rely on medical history, physical exam, laboratory testing results (used primarily to identify alternative diagnoses and comorbidities), and recognition of the hallmark symptoms to diagnose ME/CFS.	

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
without support and may need to choose someone to be their advocate and communicate for them • have problems accessing information, for example because of difficulty with screens, sound and light sensitivity, headaches affecting their ability to read, or brain fog affecting their concentration.			to a doctor's office.	Diagnosis relies on a detailed medical and social history, physical exams, laboratory tests, and evaluation of other conditions that may resemble ME/CFS or be present as comorbidities. A number of factors can make diagnosing ME/CFS more difficult. For example: • There is no laboratory test to confirm ME/CFS. • Fatigue and other symptoms of ME/CFS are common to many illnesses. • The illness is unpredictable and symptoms may come and go. • The type, number, and severity of ME/CFS symptoms vary from person to person. When diagnosing ME/CFS in children and adolescents, it is useful to remember that: • Children and adolescents cannot always accurately describe their symptoms or how they feel. • Parents may describe their child's symptoms differently from how the		

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				child describes his/her symptoms.		
Histoire de santé et évaluation des symptômes						
If ME/CFS is suspected, carry out: • a medical assessment (including symptoms and history, comorbidities, overall physical and mental health) Carry out and record a holistic assessment to confirm the person's diagnosis of ME/CFS and inform their care and support plan. This should include: • a medical assessment (including relevant symptoms and history, comorbidities, overall physical and mental health, anything that is known to exacerbate or alleviate symptoms, and sleep quality) • physical functioning • the impact of symptoms on psychological, emotional and social wellbeing • current and past experiences of medicines (including tolerance and sensitivities), vitamins and mineral supplements	Clinicians must take a thorough medical and social history to accurately identify the core symptoms of ME/CFS. The information collected should include pre-illness functioning including job/school performance, social and family relationships, and their current living situation including daily routine activities, stressors, major life changes, and support. A review of their past medical records, diagnostic reports, and lab tests may also provide useful information to assist in the assessment. --- Hypersomnia tends to occur early in the illness and insomnia develops as the illness progresses. Children tend to have more severe symptoms than adults with pain and autonomic dysfunction being prominent.	Careful medical history, including social and occupational history and circumstances associated with the start of symptoms and subsequent progress will give significant clues on diagnosis. Information should be obtained on current and previous treatments, including prescribed and over the counter medicines and supplements as well as self-management strategies and alternative therapies. It is important to check for medications potentially leading to fatigue as well as autonomic-related and other symptoms. --- Acute infectious onset and PEM should always prompt to consider ME/CFS. […] The presence of PEM, however, raises the level of suspicion, as this is quite typical, though not specific of ME/CFS. History reveals the main symptoms […] that are worsened by physical or	The clinician might find it helpful to first ask the patient to list current symptoms in order of severity, to get a sense of the areas that will need to be explored. […] the history requires attention to the full range of defining symptoms of ME/CFS, recording both frequency and severity. --- Symptoms often fluctuate significantly during the day and from day-to-day. […]. Reduced ability to function after activity (physical, cognitive, emotional, orthostatic stress, or academic pressure)—often referred to as "a crash" by patients—with prolonged recovery is a feature. The presence of post-exertional malaise and exacerbation of symptoms after increased cognitive or physical effort increases the likelihood that ME/CFS is the correct diagnosis.	Assess patient for symptoms (duration, frequency, and intensity): • Impaired function (with fatigue not relieved by rest, new onset, not the result of unusual excessive exertion) • Post-exertional malaise (PEM) • Unrefreshing sleep • Cognitive impairment and/or orthostatic intolerance Getting a detailed medical history as well as social and occupational histories is critical to assessing the effects of the illness on patient's daily functioning. Healthcare providers can use questions similar to those below to elicit an accurate description of symptoms, including PEM and fatigue: • What are you able to do now? How does it compare to what you were able to do before you became sick? • How long have you felt this way? • How do you feel after	[…] it is important for clinicians to ask explicitly about the symptoms composing the criteria for ME/CFS. […] Family members may need to respond for the most severely ill. It may help patients and clinicians to identify PEM if patients keep a daily diary of their symptoms and activities for two weeks. --- Patients often describe a waxing and waning pattern or sometimes remission to normal health followed by relapse. The onset of ME/CFS is often sudden. Frequently, patients report that an infectious-like syndrome or infectious disease (such as infectious mononucleosis or flu-like illness) preceded the onset of their disease. They […] may experience other symptoms but not link them to their illness or have difficulty describing them.	Investigate medical issues that may be impacting the patient's symptom burden or level of functioning. […] Each symptom should be assessed individually to determine whether it is the result of another specific diagnosis that needs to also be treated. Assess non-medical issues that contribute to the patient's level of morbidity. Evaluate the patient's basic and instrumental activities of daily living (ADLs and IADLs). Documenting ADLs has the added benefit of supporting applications for disability. Assess the patient's individual energy limits (their "energy envelope") and the energy they expend on ADLs and IADLs. Assess the patient's psychological status using methods appropriate for chronic disease. Pay attention to affective symptoms (e.g., sadness, worry) and be careful about

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• dietary assessment (including weight history before and after their diagnosis of ME/CFS, use of restrictive and alternative diets, and access to shopping and cooking).		mental effort. There is significant intolerance to efforts, both physical and mental, with post-exertional aggravation of symptoms or PEM. Importantly, the symptoms of ME/CFS lead to substantial reductions in previous levels of activity and function. Patients with ME/CFS tend to be multi-symptomatic and often have long clinical histories, which may include various failed attempts to obtain a diagnosis and treatment. Multiple previous investigations are not uncommon; however, often, symptoms presented are discarded by clinicians as "exaggerated" or "imagined", related to excessive work or studies or as mood-related. *Steps to Recognising ME/CFS in Children* Symptoms usually start acutely, often following symptoms of infection, e.g., flu-like symptoms, or gastroenteritis, but may have an insidious or episodic onset. In children, about half of the cases of	[…] worsening of fatigue in the days before and during the onset of menses can occur in young women. Myalgic encephalomyelitis/chronic fatigue syndrome is characterized by numerous symptoms in multiple body systems […]. Information about diet, sleep patterns, depressed mood, anxiety, school performance, relationships with family and friends, drug use, and family and developmental history needs to be obtained. The family history might reveal other family members with ME/CFS symptoms and there is also a higher prevalence of disorders such as fibromyalgia, joint hypermobility, temporomandibular joint dysfunction, anxiety, syncope, and irritable bowel disease.	sleeping or resting? • What makes you feel worse? What helps you feel better? • What symptoms keep you from doing what you need or want to do? • How much activity, either physical or mental, does it take for you to feel ill? • What types of activities do you now avoid because of what will happen if you do them? Consider asking patients to document their activities and symptoms for a couple of weeks in a diary. --- PEM may be delayed after onset of other symptoms, and some patients may not recognize PEM at the start of their illnesses. The severity and frequency of the symptoms can vary among patients and can vary for an individual patient. Symptoms can fluctuate during the day, from day to day, and throughout the illness. The illness has a pattern of remission and relapse,	These core features of illness must be moderate to severe and present at least 50% of the time; this is key to separating ME/CFS from other common causes of chronic fatigue. PEM can help differentiate ME/CFS from other conditions […]. Chronologic patterns can vary. In some patients, all of the ME/CFS symptoms develop within hours or days of the instigating event, whereas others report symptoms appearing more gradually over weeks and months.	attributing somatic symptoms (e.g., fatigue, insomnia, gastrointestinal disturbances) to psychological/psychiatric conditions. Assess non-medical issues that contribute to the patient's level of morbidity. Examples include lack of social services, caretaking, transportation, finances, food, and/or supportive devices --- The severity of specific symptoms and the level of functional impairment seen in ME/CFS can vary widely from person to person and over time.

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		ME/postinfectious fatigue syndrome manifest after typical Epstein–Barr-virus (EBV)-associated infectious mononucleosis. Symptoms are usually fluctuating in type and severity (especially in the early stages of the disease), with patients typically reporting "good" and "bad" days. **Symptoms' characteristics** • Symptoms may start following infectious or other insults or insidiously. These are persistent, but they may fluctuate from day to day or during the day. Some people experience temporary partial remission of symptoms, which is followed by recurrence and may occur after physical or mental exertion beyond their tolerance level. • Although specific symptoms vary in presentation and severity, the symptoms tend to follow a typical pattern of inter-relatedness. This means that patients may have difficulties in distinguishing whether their symptoms arise from lack of energy, pain, or		which can be unpredictable. Onset of illness can be either acute or gradual. Acute onset may follow an infectious-like syndrome (e.g., fever, malaise, aching muscles, respiratory or gastrointestinal symptoms) or a specific acute infection (e.g., acute infectious mononucleosis from a new infection with Epstein-Barr virus). The illness also may follow other trauma such as car accidents or surgery. Gradual onset can occur over months or years. To diagnose ME/CFS, the child's doctor may undertake the following: • Ask about child's and family's medical history, including a review of any medications and recent illnesses		

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		sleep deprivation, for example.				
Évaluation des malaises post-effort						
aucune information présentée	aucune information présentée	aucune information présentée	aucune information présentée	Example questions • What happens when you try to push to do activities (physical or mental) that are now hard for you? • How long does it take for you to start feeling worse after such exertion? • How long does it take for you to recover after such exertion? • What happens when you (try to) exercise?	• What happens to you as you engage in normal physical or mental exertion? or after? • How much activity does it take you to feel ill? • What symptoms develop from standing or exertion? • How long does it take to recover from physical or mental effort? • If you go beyond your limits, what are the consequences? • What types of activities do you avoid because of what will happen if you do them? The key symptom of PEM is often not mentioned spontaneously as patients may not be familiar with the concept. […]. If the patient is unable to clearly answer the PEM questions suggested […], ask the patient to keep a journal for 1 or 2 weeks detailing activities and symptoms (type, intensity,	aucune information présentée

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					frequency, duration). The patient may be in a constant state of PEM, making it difficult to recognize the impact of overexertion. During the next visit, clinicians should review this journal with the patient to identify the distinctive features of PEM: odd symptoms that would not normally follow exertion (eg, sore throat, problems in thinking), intensity or duration of symptoms out of proportion to preceding activities (eg, having to lie down for an hour after a few hours of sedentary work), a further reduction of function after activity, and typically delayed onset of symptoms (eg, a few hours or a day later).	
Évaluation de la fatigue incapacitante/asthénie						
aucune information présentée	aucune information présentée	aucune information présentée	To assess function, ask about what happens when the young person tries to do activities that she/he previously tolerated, and about activities the individual must now limit or avoid. This can indicate very significant life changes and losses experienced by the	**Profound fatigue** • Example questions ○ How long have you been experiencing fatigue? When did it start? How often does it occur? How severe is it? ○ How much activity, either physical or	• How fatigued are you? What do you mean by fatigued?" and "On a scale of 0 (no energy) to 10 (full energy), how fatigued are you?". • What helps your fatigue the most (resting, lying	aucune information présentée

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			patient.	mental, does it take for you to feel ill? o How would you characterize it? Is the fatigue physical, mental, or both? **Impaired function** • Example questions o What types of activities do you now avoid because of what will happen if you do them? o What symptoms keep you from doing what you need or want to do?	down, quiet situations, not exercising or avoiding exercise)? What makes the fatigue worse? • What are you able to do now? • How does it compare with what you were able to do before? • Think back to what you were able to do before you became sick. How much has this illness affected: (a) your ability to work? (b) your ability to take care of yourself/your family and to do chores? • What happens when you try to push through the fatigue?	
Évaluation de l’intolérance orthostatique						
aucune information présentée	aucune information présentée	aucune information présentée	Upright posture consistently aggravates ME/CFS symptoms and patients report worsening fatigue and other symptoms while standing in line, in hot environments like a shower, or in the summer heat. Many patients adopt postural counter-maneuvers—such as sitting with knees to chest, doing homework in a reclined position, crossing the legs when standing, fidgeting in	• Do you ever feel dizzy or lightheaded? Have you been falling more often than before? Do you feel worse waiting in line, standing for more than 5 minutes, or when in warm environments? As patients may not recognize that they have orthostatic intolerance, it can be helpful to ask additional questions to elicit this information:	• How do you feel when you have been standing still for more than a few minutes? • What happens to you after you get up rapidly after lying down or sitting for a long time? • How long can you stand before feeling ill? For example, can you do the dishes? Can you stand in line for a bus or movie?	aucune information présentée

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			line—but are not aware of why they have done so. Some adolescents might not report lightheadedness, so asking about symptoms that emerge during prolonged upright posture can be revealing.	• How do you feel when you have been standing still for more than 1-2 minutes? • What happens after you get up rapidly from sitting for a long time? • How long can you stand before feeling ill? For example, o Can you do the dishes? o Can you stand in a line for a bus or movie? o Are you able to grocery shop or be at the mall for more than a few minutes? o Can you take a hot shower or hot bath without feeling tired and lightheaded? • Example questions o Do you have symptoms when you stand or sit upright? What are they? o How long can you stand before you feel ill? o Are the symptoms relieved by lying down?	Are you able to grocery shop or go to a mall? • How does hot weather affect you? • Do you study or work lying down, in bed or a recliner? Why?	
Évaluation des difficultés cognitives						
aucune information présentée	Neurocognitive impairment can be validated (quantitatively) by	aucune information présentée	aucune information présentée	Example questions • Are you able to think as clearly as you did before	• Do you have problems doing the following activities: driving,	aucune information présentée

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	neurocognitive […] through psychologists.			you became ill? • Do you find that since the onset of your illness that you process information slower than you used to?	watching a movie, reading a book/magazine, completing complex tasks under time constraints, following/participating in conversation, doing more than 1 thing at a time? • Compared with before your illness, how is your performance at work or school now?	
Évaluation des altérations du sommeil						
aucune information présentée	Excessive sleepiness can be measured by a score of greater than 10 on the Epworth sleepiness scale and may require a workup for primary sleep disorders and referral to sleep specialist.	aucune information présentée	aucune information présentée	**Unrefreshing sleep** • Example questions ○ When you awaken from sleep, do you typically feel refreshed? ○ Do you have any problems getting to sleep or staying asleep?	**Perturbations du sommeil** • Do you have any problems getting to sleep or staying asleep? • Do you feel rested in the morning or after you have slept? • Tell me about the quality of your sleep. • Do you need too much sleep? • Do you need to take more naps than other people? (There may be other sleep disruptors as well.)	aucune information présentée
Autres conditions à considérer (diagnostics différentiels et comorbidités)						
Be aware that other conditions may coexist with ME/CFS and should be investigated and managed according to best practice. […] multimorbidity, thyroid disease and irritable bowel syndrome in adults […]	Many other illnesses have symptoms which overlap with ME/CFS. Other active disease processes that could explain the major symptoms of fatigue, sleep disturbance, pain, and neurocognitive dysfunction must be ruled out by history,	There is considerable symptom overlap between ME/CFS and fibromyalgia, and a concomitant diagnosis of fibromyalgia is often made. The latter requires pain to be generalised (present in at least 4 of 5 body regions)	Co-morbid illnesses are common and require appropriate treatment. […] there is also a higher prevalence of disorders such as fibromyalgia, joint hypermobility, temporomandibular joint	Identify and treat other conditions / consider ME/CFS Comorbid conditions are often present and may include: sleep disorders, irritable bowel syndrome, fibromyalgia, depression or	Medical conditions that present similarly to myalgic encephalomyelitis/chronic fatigue syndrome • ***Endocrine/metabolic disorders:*** Primary adrenal insufficiency, hypercortisolism, hyperthyroidism or	Concerns for neglect or abuse must be evaluated with full comprehension of the nature of ME/CFS and the level and types of debility that can result. For instance, weight loss or decreased consumption of food and fluids may not be

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[…] identifying and treating associated or comorbid anxiety, depression or mood disorders […] When ME/CFS is suspected: • continue with any assessments needed to exclude or identify other conditions Recognise that people with ME/CFS, particularly those with severe or very severe ME/CFS, are at risk of their symptoms being confused with signs of abuse or neglect. If a person with confirmed or suspected ME/CFS needs a safeguarding assessment, directly involve health and social care professionals who have training and experience in ME/CFS as soon as possible. If a person with confirmed or suspected ME/CFS needs to be assessed under the Mental Health Act 1983 or the Mental Capacity Act 2005, directly involve health and social care professionals who have training and experience in	physical examination and medical testing. **Exclusionary Illnesses** This list has not been validated: • anemias • autoimmune diseases such as rheumatoid arthritis, lupus • Cardiac disease • Endocrine disorders such as diabetes, Addison's disease, thyroid disease, menopause • Infectious diseases such as tuberculosis, HIV/AIDS, chronic hepatitis, Lyme disease • Intestinal diseases such as celiac or Crohn's disease • Malignancies • Neurological disorders such as multiple sclerosis, Parkinson's disease, myasthenia gravis • Primary psychiatric disorders and substance abuse (but not clinical depression) • Significant pulmonary disease • Primary sleep disorders such as sleep apnea	and is widespread and accompanied by other symptoms, such as fatigue, poor sleep, and cognitive difficulties. Since fatigue is a common complaint in daily life and in association with a range of medical problems, it is important to note that most people with ongoing fatigue do not have ME/CFS but rather have symptoms that are caused by other conditions, emotional well-being, or life-style-factors. The presence of PEM, however, raises the level of suspicion, as this is quite typical, though not specific of ME/CFS. The list of co-morbid conditions and differential diagnoses is not exhaustive. In general, when one of these conditions is present and is not well-controlled, the patient should be offered optimum treatment and stabilization, before a diagnosis of ME/CFS is considered. Severe conditions should be explored early and excluded or treated promptly. Action is prompted by clinical suspicion and red flags,	dysfunction, anxiety, syncope, and irritable bowel disease. Muscle tenderness is a feature of co-morbid juvenile fibromyalgia. Fibromyalgia is less common in children with ME/CFS than in adults. If present, co-existing conditions should be evaluated independently […]. Co-morbid conditions are seen frequently in young patients with ME/CFS and are major contributors to illness severity. Fatigue is an early symptom in many medical conditions and can be present before the appearance of the diagnostic features of the underlying illness. Careful follow-up over time is needed in order to identify illnesses that might mimic ME/CFS in their early stages. **Headaches** Chronic, daily headaches, which can fluctuate in severity from week-to-week, are common. If they are episodic, a diagnosis of migraine should be	anxiety. The presence of these conditions does not exclude the diagnosis of ME/CFS. Several conditions can cause symptoms that may resemble ME/CFS. If suggested by the history and physical examination, these conditions should be appropriately tested for, and treated if confirmed. Based on clinical presentation and history, these conditions could include: • Any active medical condition that may explain the presence of fatigue such as untreated hypothyroidism (including Hashimoto's disease), hyperthyroidism, diabetes mellitus, iron deficiency anemia, other treatable anemia, iron overload syndrome, adrenal insufficiency, Cushing's syndrome, anorexia nervosa, or iatrogenic conditions such as side effects or interactions of medication(s) or supplements • Rheumatological disorders (rheumatoid arthritis, lupus,	hypothyroidism, diabetes, hypercalcemia • ***Rheumatologic disorders:*** Systemic lupus erythematosus, rheumatoid arthritis, polymyositis, polymyalgia rheumatica • ***Neurologic disorders:*** Multiple sclerosis, Parkinson disease, myasthenia gravis, vitamin B12 deficiency, cerebrospinal fluid leak, Chiari malformation, traumatic brain injury, spinal stenosis, craniocervical instability, seizures • ***Infectious diseases:*** Human immunodeficiency virus infection, Lyme and other tick-borne diseases, hepatitis B/C, tuberculosis, giardiasis, West Nile virus, Q fever, coccidioidomycosis, syphilis, Epstein-Barr virus infection*, parvovirus B19 • ***Sleep disorders****:* Sleep apnea*, narcolepsy, periodic limb movement disorder*	due to intentional self-harm or anorexia nervosa but rather due to undiagnosed gastrointestinal issues that impede nutrition As with other chronic diseases, ME/CFS patients can experience secondary depression and anxiety. […] However, ME/CFS is not a mental illness. A careful differential diagnosis is required to ensure an accurate diagnosis. Increased prevalence of comorbidities common to ME/CFS (e.g., mast cell activation syndrome, postural orthostatic tachycardia syndrome) and/or complications of being homebound or bedbound (e.g., osteoporosis, constipation, pressure ulcers, aspiration pneumonia, depression, and deconditioning). These can increase disease burden and complicate management.

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ME/CFS as soon as possible. Recognise that the following are not necessarily signs of abuse or neglect in children and young people with confirmed or suspected ME/CFS: • physical symptoms that do not fit a commonly recognised illness pattern • more than 1 child or family member having ME/CFS • disagreeing with, declining or withdrawing from any part of their care and support plan, either by them or by their parents or carers on their behalf • parents or carers acting as advocates and communicating on their behalf • reduced or non-attendance at school. In many cases, symptoms are thought to have been triggered by an infection but it is not simple post-illness fatigue. It lasts longer and even minimal mental or physical activity can make symptoms worse. Be aware that recognising	**Non-Exclusionary Conditions** **[…]** commonly co-occur with and are not thought to exclude a diagnosis of ME/CFS. There are several studies to show these conditions co-occur but […] there is no rigorous validation of this list: • Some co-morbid entities commonly occur in association with ME/CFS. They include: allergies, fibromyalgia (FM), irritable bowel syndrome (IBS) and multiple chemical sensitivities (MCS). • Any medical condition that has been adequately treated and is stable • Any isolated physical abnormality or laboratory test that is insufficient to diagnose an exclusionary condition • ME/CFS and FM are often closely associated and are considered to be overlapping syndromes. • If the patient has unexplained, prolonged fatigue but has an insufficient number of symptoms to meet the criteria for ME/CFS, the illness should be classified	such as unintentional weight loss, prolonged fever ≥ 38 C, persistently elevated inflammatory markers, significant abnormalities in physical examination, or suicidal ideation. Further referral may be required when alternative diagnoses are suspected. This may include referral to a neurology or multiple sclerosis (MS) clinic and/or to specialists in ophthalmology, ENT, immunology (autoimmunity, immune dysfunction), allergology, orthopaedics, physical therapy, infectious diseases (travel-related disease), psychiatry, or gastroenterology. Co-morbid conditions which do not exclude ME/CFS diagnosis • Fibromyalgia • Restless legs syndrome, periodic limb disorder • Postural orthostatic tachycardia syndrome (POTS) • Neuro-mediated hypotension • Irritable bowel syndrome • Food intolerances and atopic conditions • Mild anxiety	considered. **Common conditions in the differential diagnosis of ME/CFS:** • Adrenal insufficiency • Athletic overtraining syndrome • Bowel disorders: celiac disease, inflammatory bowel disease, and eosinophilic gastroenteritis • Chiari malformation or cervical spine stenosis • Lyme disease and other tick-borne infections • Major depression • Narcolepsy • Obstructive or central apnea • Post-concussion syndrome • Severe anemias • Systemic lupus erythematosis and similar autoimmune conditions • Untreated hypo- or hyper-thyroidism **Non-exclusionary overlapping conditions:** • Autoimmune ○ Sicca syndrome • Cardiovascular ○ Autonomic dysfunction ○ Mitral valve prolapse ○ Orthostatic intolerance ○ Neurally mediated	polymyositis, polymyalgia rheumatica, Sjogren's Syndrome, Ehlers Danlos Syndromes [Hypermobility type]) • Other heritable disorders of connective tissue (Marfan syndrome, Stickler syndrome, and others). • Multiple sclerosis • Celiac disease (Note: Patients with celiac disease can present without gastrointestinal symptoms) • Immune disorders such as HIV/AIDS • Sleep disorders, including obstructive sleep apnea • Prior illnesses may relapse or may not have completely resolved during treatment. Examples are certain malignancies and leukemia, as well as infectious diseases such as tuberculosis and chronic hepatitis • Active primary psychiatric disorders (e.g., eating disorders, alcohol or substance use disorder) Many patients with ME/CFS	• ***Primary psychiatric disorders:*** Anxiety*, depression*, bipolar affective disorder • ***Gastrointestinal disorders:*** Celiac disease, food allergy/intolerance*, inflammatory bowel diseases, small intestinal bacterial overgrowth* • ***Cardiovascular disorders:*** Cardiomyopathy, coronary artery disease, pulmonary hypertension, valvular heart disease, arrhythmias • ***Hematologic disorders:*** Anemia (iron deficiency, other treatable forms), iron overload • ***Illnesses related to toxic substance exposures:*** Substance abuse disorder, heavy metals (eg, lead, mercury), mold/mycotoxins, adverse medication effects, Gulf War illness • ***Oncologic disorders:*** Primary and secondary cancers • ***Miscellaneous:*** Severe obesity (body mass	

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and responding to possible child abuse and neglect (maltreatment) is complex and should be considered in the same way for children and young people with confirmed or suspected ME/CFS as with any child with a chronic illness or disability.	as idiopathic chronic fatigue. **Fibromyalgia (FM)** If chronic widespread pain is a complaint, a fibromyalgia evaluation is indicated […]. FMS and ME/CFS share some key symptoms such as fatigue, cognitive impairment and unrefreshing sleep. In ME/CFS post exertional malaise is the key symptom while in FM it is chronic widespread pain. FMS can be suspected by the typical grouping of FM symptoms and by exclusion of other inflammatory and metabolic diseases that could account for the symptoms. As with ME/CFS, diagnosis is completely dependent on subjective symptom reporting and functional impairment. There is currently no definitive diagnostic test or tool to diagnose this condition. Excessive sleepiness can be measured by a score of greater than 10 on the Epworth sleepiness scale and may require a workup for primary sleep disorders and referral to sleep specialist. **Depression/Anxiety/Distress**	• Mild depression • Hypermobility Ehlers–Danlos syndrome • Myofascial pain syndrome • Small fibre neuropathy • Sicca symptoms • Chronic pelvic pain, endometriosis • Interstitial cystitis • Hashimoto thyroiditis; hypothyroidism controlled clinically) • Migraine • Mast cell activation disorder, eosinophilic esophagitis List of diseases where fatigue may be a prominent feature, which may preclude a diagnosis of ME/CFS if the disease largely explains the symptoms. They may, however, be co-morbidities with ME/CFS if they do not fully explain symptoms characteristic of ME/CFS (including fatigue, cognitive complains, sleep dysfunction, PEM). • Hypothyroidism • Hyperthyroidism • Malignancy • Rheumatoid arthritis, systemic lupus erythematosus, polymyositis, Sjogren syndrome, psoriasis arthritis • Crohn's disease,	hypotension ○ Postural tachycardia syndrome (POTS) ○ Delayed orthostatic hypotension or tachycardia • Endocrine/metabolic ○ Insulin resistance ○ Hypoglycemia ○ Metabolic syndrome ○ Polycystic ovary syndrome ○ Severe obesity • Gastrointestinal ○ Eosinophilic esophagitis ○ Gastroesophageal reflux ○ GI motility disturbances ○ IgE-mediated food allergy, non-IgE mediated milk protein or other food protein hypersensitivity ○ Irritable bowel syndrome ○ Lactose/fructose intolerance • Gynecological ○ Dysmenorrhea ○ Endometriosis ○ Pelvic congestion syndrome/pelvic venous incompetence ○ Premenstrual syndrome/dysphoric disorder ○ Vulvodynia • Hematological ○ Iron deficiency	are affected by comorbid conditions with symptoms that may overlap or worsen those caused by ME/CFS. These conditions should be treated according to best clinical practices and available recommendations and in a way that does not worsen ME/CFS symptoms. Common comorbidities include: • Fibromyalgia • Irritable bowel syndrome • Depression • Anxiety • Allergies and chemical sensitivities If a patient has had impairment in function with severe fatigue for 6 months or longer but does not have all the required symptoms, the healthcare provider may make a diagnosis of idiopathic fatigue (fatigue with an unknown cause). In practice, patients with idiopathic fatigue are managed like patients with ME/CFS. Children with ME/CFS may miss school, which may be mistaken for school phobia. But unlike those with school phobia, children with ME/CFS are still ill and	index >40 kg/m^2), overwork, athletic overtraining syndrome, asthma, chronic obstructive pulmonary disease *These conditions can also commonly coexist with myalgic encephalomyelitis/chronic fatigue syndrome. Common comorbidities include fibromyalgia, mast cell activation syndrome, postural orthostatic tachycardia syndrome, Ehlers-Danlos syndrome, sleep apnea, irritable bowel syndrome, and secondary depression/anxiety. Conditions which commonly co-exist with ME/CFS • ***Autonomic dysfunction:*** Postural orthostatic tachycardia syndrome, neurally mediated hypotension, orthostatic hypotension • ***Rheumatological disorders:*** Fibromyalgia[1], Ehlers-Danlos syndrome, temporomandibular joint dysfunction, sicca syndrome • ***Neurological disorders :*** Sensory	

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	It is important to distinguish the secondary psychological reactions to ME/CFS from a MDD or anxiety disorder To distinguish between ME/CFS and MDD [major depressive disorder] identify the presence of symptoms such as post exertional malaise that is unique to ME/CFS and does not occur in primary MDD. Other symptoms, e.g., recurrent flu-like symptoms, sore throats, tender lymph nodes, orthostatic intolerance and hypersensitivity to light, noise and medications also distinguish ME/CFS from a primary MDD.	ulcerative colitis, coeliac disease • Post-concussion syndrome, post-ICU syndrome, post-traumatic stress disorder • Heart disease, such as heart failure • Severe chronic obstructive pulmonary disease, other severe respiratory diseases • Severe anaemia, vitamin B12 deficiency, haemochromatosis • Renal failure • Diabetes mellitus • Addison's or Cushing's disease, hyperparathyroidism, and other endocrine disorders • Bipolar disorder, schizophrenia, major depression, anorexia, bulimia, autism • Multiple sclerosis, myasthenia gravis, other neuroimmunological diseases, paraneoplastic syndromes • Parkinson's disease, Alzheimer's disease, stroke, other serious neurodegenerative diseases • Sleep apnoea • Narcolepsy • Hepatitis, tuberculosis, HIV/AIDS,	○ Mast cell activation disorder • Neurological ○ Chiari 1 malformation ○ Migraines ○ Thoracic outlet syndrome ○ Hypersensitivity to light, touch, sound, odors, and medicines • Respiratory ○ Allergic rhinitis ○ Asthma ○ Chronic sinusitis • Rheumatological ○ Joint hypermobility syndrome ○ Juvenile fibromyalgia ○ Myofascial pain syndrome ○ Ehlers-Danlos syndrome ○ Temporomandibular joint disease • Sleep disorders ○ Periodic limb movement disorder ○ Restless leg syndrome • Urinary ○ Interstitial cystitis Urinary In the early, acute, febrile stage of ME/CFS, the diagnosis can be uncertain and other causes of fever need to be considered. **Psychological reactions**	inactive on weekends and holidays. It is important that healthcare providers talk with family members and children about the child's lifestyle and behaviors to find out how the illness impacts the child's daily life. For example, the child's lack of energy may be because of ME/CFS or caused by normal changes in sleep cycles that often happen in puberty.	hypersensitivities[2], poor balance, migraine headaches, peripheral neuropathy, small fiber neuropathy • ***Immunological disorders :*** New or worsened allergies, mast cell activation syndrome, multiple chemical sensitivities, chronic infections & immunodeficiencies • ***Gastrointestinal disorders :*** Food allergies/intolerances[3], gut motility issues, celiac disease, irritable bowel syndrome, small intestinal bacterial overgrowth • ***Endocrine/metabolic disorders:*** Hypothyroidism, hypothalamus-pituitary-adrenal axis dysregulation[4], metabolic syndrome • ***Sleep disorders:*** Sleep apnea, restless leg syndrome, periodic limb movement disorder • ***Psychiatric disorders:*** Secondary anxiety, secondary depression • ***Gynecological disorders:*** Endometriosis, premenstrual	

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		neuroborreliosis, other chronic infections • Excessive consumption/abuse of alcohol or other substances	**secondary to ME/CFS: distinction from depression and anxiety disorders** Studies focusing on psychological problems in pediatric ME/CFS patients are limited. It is important to distinguish: (a) normal emotional reactions to ME/CFS from (b) clinically significant psychiatric symptoms such as depression or anxiety secondary to ME/CFS and from (c) a primary psychiatric illness such as Major Depressive Disorder (MDD) or an anxiety disorder without co-existing ME/CFS. **Differentiating ME/CFS from Primary Depressive and Anxiety Disorders without Co-Existing ME/CFS** This can be challenging. Symptoms common to both ME/CFS and psychiatric illness include fatigue, change in activity levels, reluctance to engage in social activities, difficulty sleeping, poor memory and concentration, appetite/weight changes and absence from school.		syndrome, vulvodynia • ***Miscellaneous:*** Interstitial cystitis, overactive bladder, nutritional deficiencies (e.g. vitamin B12, D), obesity [1] People with fibromyalgia without ME/CFS do not experience post-exertional malaise and the worsening after exercise seen in ME/CFS. As a result, they can be helped by exercise. Fibromyalgia is associated with widespread muscle pain, which may not be seen in ME/CFS patients who do not have fibromyalgia. […] An 18-point tender point exam can be used to evaluate the widespread pain seen in fibromyalgia. [2] To light, sound, touch, smell, etc. [3] Intolerance to certain foods, including gluten, sugar, and milk protein is not rare. [4] Low-normal or flattened cortisol curve upon awakening. In general, PEM is a distinctive feature that can help differentiate ME/CFS from other diseases. Therapeutic trials may also help; if treatment for the alternative diagnosis	

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			In patients with ME/CFS, long-lasting post-exertional exacerbation of fatigue and other symptoms can follow mild exertion or even normal activity, whereas patients with major depression or anxiety often feel better after increased activity, exercise, or mental effort. OI, hypersensitivities to light, noise and medications and/or low body temperature, and intolerance to heat and cold are typical of ME/CFS, but not typical of psychiatric illnesses. **Psychiatric Illnesses That May be Misdiagnosed in Young Patients with ME/CFS** Lack of familiarity with the clinical diagnostic features of ME/CFS and skepticism about its existence has often resulted in a misdiagnosis with one of the following conditions: • Factitious disorder by proxy (Munchausen syndrome by proxy, fabricated or induced illness) (FDP/MSBP). • School refusal (school phobia). • Pervasive refusal syndrome (PRS).		completely eliminates a patient's symptoms, ME/CFS is not the correct diagnosis. As with alternative conditions, history, physical examination, tests, and therapeutic trials can help diagnose these comorbidities. Treating these conditions will not cure ME/CFS but can reduce symptom burden and improve quality of life.	

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			• Somatoform disorder. **Other Psychiatric Conditions** Some additional psychiatric conditions might need to be differentiated from ME/CFS. ME/CFS symptoms such as poor concentration and loss of short-term memory, noticed in the patient's classroom, can sometimes lead to an erroneous diagnosis of attention deficit disorder without hyperactivity. If the young patient is unable to eat properly due to nausea and gastrointestinal symptoms, ME/CFS must be distinguished from an eating disorder. ME/CFS may also need to be distinguished from substance abuse. **Joint hypermobility, connective tissue laxity, Ehler's-Danlos syndrome [comorbidity]** Clinicians can have an increased index of suspicion for joint hypermobility if their patients have been swimmers, dancers, and gymnasts. In taking the history, the clinician should ask whether the patient has had subluxations or dislocations (including "nursemaid's elbow" in early			

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			childhood), and whether the patient can perform "tricks" with their joints. Joint hypermobility can be overlooked unless the clinician performs specific measurements such as the Beighton score, a nine point measure in which scores of 4 or higher indicate joint hypermobility. To obtain a Beighton score, the examiner needs a goniometer to measure joint angle, assigning one point for the ability to dorsiflex each fifth finger past 90°, one point on each side for bringing the thumb to the forearm, one for more than 190° of hyperextension at each elbow, one point for more than 10° of hyperextension of each knee, and the ninth point is for the ability to place the palms on the floor bending over at the waist, with the legs straight. Some with joint hypermobility can have associated postural dysfunctions such as thoracic kyphosis, scoliosis, a head-forward posture, lumbar lordosis, and pes planus. Diagnosing joint hypermobility is important, as the condition can be			

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			associated with pain, add to the burden of illness in ME/CFS and it requires different approaches in physical therapy. The evaluation and management of these patients often is helped by consultation with a physical therapist. **Gynecological issues [comorbidity]** Common problems for adolescent females with ME/CFS are the exacerbation of ME/CFS symptoms (especially OI) in the week before and during the menses, and the onset of, or an increase in severity of, gynecological symptoms, including dysmenorrhea, menorrhagia, pelvic pain and premenstrual syndrome. An occasional problem is cessation of the menses following the onset of ME/CFS. In older adolescents, sexual activity can cause post-exertional symptom exacerbation. • Dysmenorrhea: Clinical experience has shown that in some adolescents, the onset of dysmenorrhea may be concurrent with the onset of ME/CFS and menstrual symptoms can improve as			

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			ME/CFS symptoms improve. • Endometriosis: In adolescents with ME/CFS who have co-morbid endometriosis, pelvic pain and associated gastrointestinal or urinary symptoms are typically worse during the menstrual cycle. […]. Associated symptoms can include constipation, pain with defecation, and urinary symptoms such as dysuria, urgency, frequency, and hematuria. Dyspareunia can also be present. • Pelvic congestions syndrome: […] can cause chronic pelvic pain, associated with low BP and chronic fatigue, […]. It is associated with varicose ovarian and internal iliac veins. Symptoms include chronic, non-cyclical, pelvic pain and perineal heaviness, occasionally associated with lower back pain. Pain is usually present throughout the month, but often worsens with the menses. Unlike endometriosis, this form of pelvic pain worsens at the end of the day or with prolonged standing due to progressive distention of			

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			varicosities in the pelvis. Also in contrast to endometriosis, PCS symptoms get better with prolonged supine posture or after a night in bed. Vulvar and thigh varices are less common in adolescents with PCS than in adults. **Gastrointestingal issues** Gastrointestinal conditions which can be present include: gastroesophageal reflux, gastrointestinal motility disorders, celiac disease and non-celiac gluten sensitivity, lactose intolerance, food allergies (e.g., nut, milk, eggs, and wheat), post-infectious or irritable bowel syndrome and constipation. These conditions should be considered in the differential diagnosis of gastrointestinal complaints and if present should be treated appropriately. Another recently recognized gastrointestinal problem […] is intolerance of specific food proteins. Milk protein is the most common offending food, but soy, wheat, and egg proteins can also cause symptoms. Many young patients are unaware that			

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			milk or other specific proteins are a problem, because immediate reactions are absent, and symptoms can be delayed for several hours after ingestion. Symptoms that indicate the possibility of a non-IgE-mediated allergy or an intolerance of a food protein are: (a) epigastric or abdominal pain, (b) gastroesophageal reflux symptoms (heartburn, retro-sternal discomfort, acid taste in the mouth, sometimes a mucousy form of vomiting), and (c) appetite disturbance (early satiety, picky appetite). Other associated symptoms can include recurrent aphthous ulcers, intermittent fevers, headaches (including migraines), worsening lightheadedness, myalgias, sinusitis, and either constipation or diarrhea. Skin testing in people with delayed gastrointestinal hypersensitivities is usually negative. **Allergies [comoribidity]** […] IgE-mediated allergies are recognized by the presence of immediate allergic symptoms, including wheezing, pruritus, urticaria, lip and tongue swelling, and			

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			more severe features of anaphylaxis. Skin prick tests and RAST blood tests are abnormal in those with IgE-mediated allergies. A mast cell activation syndrome (MCAS) might be present. Symptoms [of MCAS] can include fatigue, lightheadedness, facial flushing, rashes, itching, hives, bone and muscle pain, nausea, vomiting, abdominal pain, diarrhea, brain fog, migraines, and intolerance to multiple medications. Joint hypermobility is also associated with a MCAS and a subset of POTS patients have MCAS. […] Clinicians should have a higher index of suspicion for MCAS in those diagnosed with ME/CFS who report the symptoms listed above. **Neuroanatomic abnormalities [comorbidity]** […] these disorders represent a very small proportion of those with ME/CFS, but their prevalence can be higher among more severely affected patients or those unresponsive to the usual interventions. Symptoms of			

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			these various abnormalities can include: sub-occipital headaches, made worse by neck flexion or extension, coughing, or straining, back and leg pain, problems swallowing, weakness, coordination difficulties, numbness in the face and limbs, and/or frequent urination. A neurological examination might reveal nystagmus, diplopia, absence of the gag reflex, hyper-reflexia and decreased sensation in the pelvis and lower limb. In those with prominent symptoms including headache, evaluation needs to exclude intracranial hypertension and intracranial hypotension. Referral to a neurologist can be helpful. Chronic, daily headaches, which can fluctuate in severity from week-to-week, are common. If they are episodic, a diagnosis of migraine should be considered. **Oral and dental issues [comorbidity]** Dental and orofacial problems are found in many young people with ME/CFS, but are often neglected			

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			because the young patient is too ill to make dental office visits. Correction of dental problems can improve overall health. Commonly reported problems are xerostomia (dry mouth), dental caries, periodontal disease, bruxism, temporomandibular joint disorder (TMD) and impacted third molar teeth. Temporomandibular joint disorders (TMD) and bruxism (tooth grinding) are more prevalent in ME/CFS patients than in the population at large and joint hypermobility co-morbid with ME/CFS is a risk factor. Bruxism often results in loss of tooth structure and can exacerbate TMD. These conditions can cause significant TM joint pain and/or headache. They should be considered in the differential diagnosis of headache in patients with ME/CFS.			
Examen à réaliser						
If ME/CFS is suspected, carry out: • a physical examination.	Neurocognitive impairment can be validated (quantitatively) by neurocognitive testing […].	Physical examination and routine bloods tests are required to increase diagnostic accuracy and detect alternative conditions explaining the symptoms.	A thorough physical examination, including a neurological exam is important to exclude other causes of fatigue. Physical signs in ME/CFS are subtle and none are diagnostic.	Physical, neurologic, mental status exams. Tests can be useful to assess if and how patients' cognitive skills, such as concentration, memory, and	Potentially Abnormal Physical Examination Findings in ME/CSF (Most patients will have an unremarkable physical examination; an abnormal finding is not required for	Aucune information présentée

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		--- General physical examination may be entirely normal. However, some patients present with general aspect of tiredness or of being unwell. Nutritional status is usually satisfactory, though overweight or obesity may result from long-term inactivity or as a neuro-endocrine manifestation of the disease. On the other hand, signs of weight loss or low body mass index (BMI) may be present, more commonly in severely affected patients, although they may also raise suspicion of other severe morbidity; signs of neglect or poor care with basic needs, if noticed, should raise concerns about the wellbeing of the patient. Paleness and cold extremities may be noted. Skin: Paleness and cold extremities may be noted, often aggravated by upright position, which may be associated with low peripheral perfusion or autonomic dysfunction. Redness of lower extremities when sitting or standing may also be noted	The physical exam should include an assessment for common co-morbid conditions such as OI [heart rate (HR) and blood pressure (BP) sitting and standing], joint hypermobility, and postural dysfunctions. --- Many patients do not look ill, but noticeable facial pallor is sometimes apparent and often precedes the onset of extreme tiredness in the patient. The pallor can be associated with sub-orbital dark shadows. The pharynx can show non-exudative pharyngitis and cervical and axillary lymph nodes might be palpable and tender. Muscle tenderness is a feature of co-morbid juvenile fibromyalgia. The hands and feet can be unusually cold and dependent rubor of the legs is often present when standing or sitting. At illness onset, pyrexia can be present and this can persist for some weeks. If fever is present several months into the illness,	organization, are or become impacted by illness. --- Direct measures of OI can be obtained with a relatively simple standing test, such as the NASA lean test. A formal tilt table test may be considered. These tests are not required for diagnosis, but will identify patients with an abnormal response to standing; increased heart rate (also known as POTS or postural orthostatic tachycardia syndrome), and/or low or high blood pressure (known as orthostatic hypo- or hypertension). Patients with symptoms of orthostatic intolerance can benefit from evaluation by a cardiologist and/or neurologist. **Clinical observations – cognitive difficulties** Difficulties with thinking during clinic visit, trouble remembering medications/history or expressing oneself **Clinical observations – profound fatigue** Progressive fatigue during a prolonged clinical exam	diagnosis.) The physical examination may help identify alternative diagnoses and comorbidities. The neurologic examination, in particular, may eliminate neurologic disorders. Abnormal physical findings beyond those associated with ME/CFS should be followed up as potential indications of other conditions may be used to identify alternative conditions and comorbidities Some tests can be used to characterize aspects of ME/CFS. The passive standing or tilt table tests can objectively confirm orthostatic intolerance. --- **Overall appearance :** ● Fatigability over the course of a visit ● Inability to maintain cognitive focus ● Worsening of symptoms ● Need to lay down during visit ● Use of eyeglasses/ear plugs to minimize light/sound sensitivity ● Pallor **Vital signs:**	

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		as a consequence of venous congestion. Head and neck: Enlarged lymph nodes may be noted especially on the neck and might be tender; non-exudative pharyngitis might be observed, and crimson crescents in the oral pharyngeal region have often been described. Chest and cardio-vascular: Examination of the lungs and heart is usually unremarkable, except for possible changes in heart rate and blood pressure. Mild regular tachycardia may be present at rest. Postural tachycardia (standing heart rate of >30/min above normal in patients older than 20 years and > 40/min above normal in younger patients, compared to lying down or >120 standing heart rate at any age) may happen immediately or within 10 min or more after standing up from the recumbent or sitting position; it may result from dysautonomia or relative hypovolemia and result in the diagnosis of postural tachycardia syndrome (POTS). Some patients develop	other causes of fever should be sought. In established cases, slightly subnormal temperature, 96.8–98.0°F (36.0–36.7°C), is common. Some children with ME/CFS have higher resting HRs than expected and occasional patients have resting hypotension. More commonly, HR and BP abnormalities emerge in response to upright posture. **Orthostatic intolerance** The detection of POTS, NMH, and OH require a prolonged period of orthostatic stress and they can be missed with brief duration 1–2 min orthostatic vital sign measurements. We recommend a 10 min standing test in all young people with ME/CFS to ascertain whether orthostatic symptoms occur and determine whether POTS and/or OH are present. Patients with NMH are generally symptomatic soon after standing, but longer duration tilt table testing is required to elicit the hypotension. Tilt table testing requires referral to a specialist center and is costly.	To diagnose ME/CFS, the child’s doctor may undertake the following: • Do a thorough physical and mental status examination	● Low-grade fever ● Elevated heart rate and/or blood pressure drop with orthostatic testing or 10-minute passive standing test ● Increased respiratory rate **Head, eyes, ear, nose, throat:** ● Pupillary oscillation when eyes exposed to light ● Enlarged and/or tender cervical lymph nodes ● Crimson crescents or striae in pharynx which may worsen after a passive standing test **Abdominal:** ● Abdominal tenderness **Musculoskeletal:** ● Multiple tender joints without redness, warmth, or swelling ● Tender muscles **Extremities:** ● Cold hands and feet ● Axillary lymphadenopathy **Neurologic:** • Allodynia/hyperalgesia • Reduced pinprick/ thermal/ vibratory sensation • Confusion • Difficulty asking/answering	

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		hypotension upon standing, sometimes after a brief period of raised blood pressure. These signs are more common in the young and in some over-medicated patients and may be associated with postural hyperaemia or cold extremities. Abdomen: General standard examination is conducted to rule out other explaining diseases; mild diffuse abdominal tenderness is not uncommon. Musculoskeletal: Joints appearance is usually normal (no oedema or redness); tenderness of joints and soft tissues may also be present. Some patients have hypermobile joints or fulfil the clinical criteria of hypermobile Ehlers–Danlos syndrome (hEDS), which should be recognized as a comorbidity. Orientation and cognition; patients are oriented, but they may show signs of slow thinking, poor attention and short memory and be lost for words; long consultations may elicit increasing cognitive and	*POTS*: In adolescents, this diagnosis requires the reproduction of orthostatic symptoms together with a 40 bpm change in HR, from supine to 10 min upright, or a HR of ≥120. Some individuals who have POTS early in upright posture go on to develop NMH if the orthostatic challenge is prolonged beyond 10 min. *Neurally mediated hypotension* requires the production of orthostatic symptoms with a 25 mm Hg drop in systolic BP, usually without an increase in HR, and can be associated with junctional rhythm (recognized by a loss of P waves on the EKG) at the time of pre-syncope or syncope. The terms vasovagal syncope, neurocardiogenic syncope and NMH are synonymous. Syncope need not be present to make the diagnosis of NMH, as many affected individuals with lightheadedness and other symptoms sit or lie down before fainting. *Orthostatic hypotension* is defined by a BP reduction of at least 20 mm Hg systolic or 10 mm Hg diastolic within		questions, concentrating and performing multiple, simultaneous tasks • Abnormal Romberg	

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		physical difficulties as the patient tires; on the other hand, some patients may show signs of anxiety and "wired-tiredness", where they are restless in spite of being very tired physically and mentally. Emotional responses may be triggered as patients go through their histories and common difficulties experienced with their symptoms and lack of validation of their diagnosis and degree of disability, which are often not obvious to the untrained observer. In general, patients are highly motivated and willing to do whatever may be needed to improve their symptoms. However, secondary anxiety and depressed mood may be observed, and lack of motivation or despondency should raise the possibility of associated low mood. Brief neurological examination: This is usually normal, muscle fatiguability is shown by lower handgrip strength compared to healthy individuals or by a rapid fall in grip strength measures during repetitive muscle contractions, particularly in severely affected cases. Sensory examination may be normal,	the first 3 min of upright posture. This problem is rarely seen in pediatric patients except at times of hypovolemia, such as febrile illness, acute dehydration, hemorrhage, adrenal insufficiency, or excessive histamine release. **In-office standing test :** Five minutes supine, then at least 10 min of quiet standing, leaning against a wall, with instructions to the young person to remain still, not fidget or shift her/his weight. Changes in HR and BP should be recorded each minute, supine and upright, along with intensity of orthostatic symptoms and fatigue on a 0–10 scale. The patient must be carefully observed due to the risk of syncope. The development of pallor, warmth, and/or nausea can be prodromal signs of hypotension or syncope. This test will identify POTS and orthostatic hypotension (OH), but is usually not sufficiently prolonged for neurally mediated hypotension (NMH) **Head-up tilt table tests :** HR and BP are measured supine and during 70° head-			

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		though hyperalgesia or allodynia may be present. Cognitive difficulties and the occasional fasciculation may be noticeable. Brisk symmetrical reflexes in arms and legs may be observed. Cranial nerve examination is usually normal; however, pupil reaction might be slow. Subtle gait abnormalities may be associated with a feeling of instability, although a full-blown Romberg sign at examination is atypical. A brief psychiatric assessment may show signs of associated anxiety or mood disorders or the presence of an alternative diagnosis. Signs suggestive of specific neurological or psychiatric abnormalities should be investigated further. In the more severely affected, signs of frailty may be evident; patients may be virtually bed-bound, sit in a wheelchair, have a pale and puffy face, have cold extremities, and not be able to remain or feel very uncomfortable in the upright position for longer than a few seconds or minutes. There is a general sense of weakness and lack of	up tilt. POTS or OH can be identified by 10 min tests. Prolonged testing of 40–45 min might be required to identify NMH --- Characteristic physical appearances include facial pallor and a reddish-purple discoloration of the dependent limbs (acrocyanosis) when sitting or standing for more than a few minutes. Symptoms of OI can occur without prominent changes in heart rate and blood pressure, but are often associated with objective circulatory disorders.			

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		stamina, and short periods of break during clinical assessment may be required as the patient becomes visibly tired and shows signs of increasing cognitive difficulty. Symmetrical reduction in limb muscle strength may be observed on formal neurological examination, and the hand grip manometer will usually show reduced power, with decreasing values on repeated measurements. Further patient characterization may involve the use of standard questionnaires— which may be self-completed or applied by an interviewer, and physical measures, which are used to assess function and disease severity. They are useful for patient's baseline evaluation, and, when repeated subsequently, they provide indicators of disease course and evaluation of response to treatment. Core assessments shown in Box 8 include examples of tests that may be used routinely for that aim. CORE ASSESSMENTS:				

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		- severity assessment: UKMEB-PQsymp; DPQ, RAND-36, Pain and fatigue analogue scales - Disabilité screening: RAND-36 summary scales (physical and mental component summaries - Muscle power and general health: Hand grip measurements, dynamometer				
Analyses et investigations						
No evidence was identified for any tests or specific signs and symptoms as predictors of a later diagnosis of ME/CFS. If ME/CFS is suspected, carry out: - investigations to exclude other diagnoses, for example (but not limited to): ○ urinalysis for protein, blood and glucose ○ full blood count ○ urea and electrolytes ○ liver function ○ thyroid function ○ erythrocyte sedimentation rate or plasma viscosity ○ C-reactive protein ○ calcium and phosphate	Although there is currently no definitive test or validated tool to diagnose ME/CFS […]. The two-day cardio pulmonary exercise test (CPET) protocol may be a way to measure post exertional malaise though the side effects of the test are considerable and less rigorous tests are being sought.	Physical examination and routine bloods tests are required to increase diagnostic accuracy and detect alternative conditions explaining the symptoms. Further laboratory tests and imaging studies may be needed to identify potential co-morbidities, and/or to exclude other diagnoses. These should be guided by clinical assessment and the need to exclude conditions that may explain the symptoms. Examples of useful screening tests for initial investigations in primary care include full blood count, ferritin, liver enzymes, renal function,	No valid, reliable, laboratory test that confirms the diagnosis is currently available. Basic laboratory studies should be performed to identify other causes of fatigue and any organ system dysfunction. Measures of iron stores, vitamin B12 level, and screening for celiac disease are recommended because of their subtle or absent manifestations on physical examination. Additional testing is based on history, examination and laboratory findings. Serology for some infectious illnesses	Evaluation of ME/CFS requires multiple stages based on patient symptoms and complete history, physical exam findings, review of any recent laboratory test results, and clinical judgment. As for any condition, healthcare providers typically determine the sequence and prioritization of laboratory testing based on individual patients' presentations. While not all of the tests listed below may be needed initially or at the same time, the tests below are performed routinely for patient evaluations by healthcare providers with clinical expertise in ME/CFS, largely with the goal of identifying other	There is no validated diagnostic test. […] there are many diagnostic tests to help identify other fatiguing illnesses or comorbid conditions that are often found in people with ME/CFS. […] Beyond helping to establish a diagnosis, tests can also be important in developing treatment plans to address comorbid conditions. Testing can also guide treatment decisions and objectively document disability. For instance, ME/CFS experts may use microbial panels and natural killer cell activity, a measure of immune functioning, to	Aucune information présentée

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○ HbA1c ○ serum ferritin ○ coeliac screening ○ creatine kinase. Use clinical judgement to decide on additional investigations to exclude other diagnoses (for example, vitamin D, vitamin B12 and folate levels; serological tests if there is a history of infection; and 9am cortisol for adrenal insufficiency).		thyroid function, high-sensitivity C reactive protein (CRP) or erythrocyte sedimentation rate, electrolytes including sodium, potassium, calcium, inorganic phosphate, creatine phosphokinase (CK), and fasting glucose or glycated haemoglobin. Serology screening for EBV, hepatitis B and C, HIV, Lyme, and other tick-borne diseases may be useful according to clinical and epidemiological features . Other tests may be required according to availability of resources or as clinically guided. These are usually reserved for specialist centres or are done through referral to other specialties. These are usually aimed at differential diagnosis but could also be used for better characterization of pathology or for the assessment of function and disability. Examples include anti-CCP, transglutaminase antibodies, morning cortisol, vitamin B12, NT-pro BNP, and vitamin D3 or 25(OH)D. In some cases, an extended auto-immune screening, allergy testing, serum tryptase levels, and/or	can be weakly positive. Although standard serology for EBV and CMV can help with categorizing whether the illness might have been initiated by these organisms, these test results usually do not change management. MRIs of the brain and spine are not routinely indicated, but clearly are important if there are abnormal neurological signs. **Routine laboratory testing** • Complete blood count with differential • Erythrocyte sedimentation rate • Electrolytes • Calcium • Phosphate • Fasting glucose • C-reactive protein • Liver function: bilirubin, alkaline phosphatase, gamma glutamyl transaminase, alanine transaminase, aspartate transaminase • Total protein, albumin/globulin ratio • Renal function: urea, creatinine, glomerular filtration rate • Thyroid function: thyroid stimulating hormone, free	illnesses: • Complete blood count with differential • Erythrocyte sedimentation rate (ESR) • Electrolytes • Fasting glucose • Renal function: creatinine, blood urea nitrogen (BUN), glomerular filtration rate • Calcium • Phosphate • Liver function: bilirubin, alanine aminotransferase (ALT), alkaline phosphatase (ALP), aspartate aminotransferase (AST), gamma-glutamyl transferase (GGT), total protein, albumin/globulin ratio • C-reactive protein • Thyroid Function: thyroid-stimulating hormone (TSH), free thyroxine (free T4) • Iron studies to assess for both iron overload and deficiency: serum iron, transferrin saturation, ferritin • Celiac disease screening laboratory tests • Urinalysis If abnormal laboratory findings are present, further	help guide treatment decisions. Neuropsychological testing can demonstrate cognitive impairment and repeated cardiopulmonary exercise testing an inability to repeat or to sustain physical activities. However, these tests involve a challenge that may induce severe or long-lasting PEM. This risk may be warranted for disability evaluations, but they are not recommended as a diagnostic aid in all patients. **Routine Diagnostic Tests Recommended for All Patients** • Complete blood count with differential • Rheumatoid factor • Comprehensive metabolic panel • Antinuclear antibody • C-reactive protein • Erythrocyte sedimentation rate • Ferritin • Four-point salivary cortisol (eg, wakening, at noon, 4:00 PM, and bedtime) • AM cortisol • Thyroid-stimulating hormone, free thyroxine	

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		lymphocyte differentiation may be required. Imaging and other specialised tests may be appropriate in some cases but are usually reserved for specialist centres, e.g., brain or spine MRI, cardiopulmonary exercise testing (CPET), cognitive testing panel, echocardiography, and tilt table or standing test. **Additional assessments:** • Routine tests not done recently and justified clinically : test as appropriate • If clinical history suggests autoimmune or immunodeficiency: ANA, ENA, TPO, AMA, APA, immunoglobulins, and others according to clinical findings • Serious neurocognitive symptoms that increase risks for patients: Neurocognitive tests—e.g., Creteil battery of tests; NIH CDE Toolbox (National Institute of Neurological Disorders and Stroke (NINDS), 2018)] • Neuroimaging as needed for further neurological investigations : MRI scan, CT	thyroxine (free T4) • Anti-nuclear antibodies • Iron studies: serum iron and transferrin or ferritin • Vitamin B 12 and folate • Vitamin D3, 25-hydroxy cholecalciferol • Celiac screening: tissue transglutaminase IgA and IgG, with serum IgA • Urinalysis **Tests to be considered when indicated** • Allergic: skin tests, RAST tests, serum tryptase • Cardiac: chest x-ray, EKG (ECG), echocardiogram in those with heart murmurs, tilt testing for those with prominent orthostatic symptoms but no hemodynamic abnormalities in the office 10-min standing test • Endocrine/metabolic: morning cortisol, FSH, LH, estradiol, testosterone, prolactin, lactate, pyruvate, IGF-1 and IGF-3, thyroid autoantibodies • Gastrointestinal: upper GI endoscopy, colonoscopy, gastric emptying study, HIDA scan, ultrasound of gallbladder • Gynecological: ultrasound, laparoscopy, ovarian venogram (to evaluate for	evaluation is warranted. […] Additional tests such as imaging and physiological assessments may be needed to diagnose underlying illnesses. These tests might include: • Specific cultures or serological tests if an ongoing or recent infection is suspected. • MRI or other neuroimaging procedures to evaluate abnormal findings on the neurological examination and to assess for diseases such as multiple sclerosis. • Physiological testing such as sleep studies, exercise testing (including VO2max), or tilt table testing to address specific questions, often in consultation with a specialist. However, healthcare providers should be cautious of extensive testing in the absence of clinical suspicion because of the risk of false-positive tests. -- Despite being substantially debilitated, most people with ME/CFS have routine	• Vitamin B12 • Vitamin D, 25-dihydroxy • Urinalysis **Tests to Be Considered Depending on Presentation** • Autonomic Disorders: Passive standing test, tilt table test, capnography* • Rheumatological Disorders: Antinuclear antibody, rheumatoid factor, creatine kinase Early Sjogren's panel, SSA, SSB in patients with dry eyes, mouth* • Infectious Disease: Epstein-Barr virus antibody panel, cytomegalovirus antibody panel, human immunodeficiency virus test, hepatitis B antibody panel, hepatitis C antibody panel, purified protein derivative skin test or interferon gamma release assays, rapid plasma reagin or treponemal antibody test, West Nile serum IgM and IgG antibody, parvovirus B19 vector-borne disease*, anti-streptolysin O titer* • Oncologic Disorders:	

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		• Obstructive sleep apnoea suspected : Sleep studies, polysomnography • Signs of small fibre neuropathy, peripheral neuropathy, marked muscle symptoms, objective peripheral findings: Nerve conduction studies, electromyography (EMG), skin (for intradermal nerve fibre density) or muscle (rarely necessary) biopsy • POTS, orthostatic intolerance : Tilt table test or repeated recumbent and standing heart rate and blood pressure (standing test) • Objective assessment of PEM or disability: 2-day CPT (use with caution as can cause or aggravate PEM) • Other more recent tests which may be useful: Metabolomics, e.g., those revealed through organic acid testing and amino acid urine and serum, cytokine panels, and autoantibodies to receptors such as adrenergic receptors. * A selection or the full range of tests may be conducted routinely or in support of disability	ovarian varices) • Immunological: anti-double stranded DNA, anti-neutrophil cytoplasmic antibodies, quantitative immunoglobulins, functional antibodies, response to pneumococcal vaccination • Infectious diseases: infectious mononucleosis, lyme, and other tick-borne diseases (Babesia microti, Anaplasma phagocytophilum, Ehrlichia chaffeensis) in endemic areas • Neurological: MRI studies if Chiari malformation, cervical stenosis, tethered spinal cord, or MS are suspected • Pulmonary: pulmonary function tests • Sleep: polysomnography, multiple sleep latency testing Urological: cystoscopy --- Routine blood tests are usually normal. Most routine laboratory tests are within the normal range, and do not correlate with overall function, even in the presence of substantial debilitation.	laboratory test results that are within normal ranges. Further testing may be indicated to confirm a diagnosis for illness other than ME/CFS if suggested by an individual patient's history and/or physical findings. To diagnose ME/CFS, the child's doctor may undertake the following: • Order blood, urine or other tests	Specific screening and tests based on symptoms, physical signs, and/or risk factors • Cardiovascular/Pulmonary Disorders: Chest x-ray, pulmonary function tests, electrocardiogram, trans-thoracic echocardiography, arrhythmia monitoring, exercise testing for coronary artery disease • Neurological Disorders: Magnetic resonance imaging of brain (T2 weighted), cervical spine, or lumbar spine; lumbar puncture; and other imaging as appropriate if evidence of neurological symptoms/signs* • Allergies: Histamine, tryptase and chromogranin A, allergy skin tests or radioallergosorbent test in patients with allergies* • Immunological Disorders: Total immunoglobulins, IgG subclasses in patients with prolonged or frequent infections* • Endocrine/Metabolic Disorders: Hemoglobin A1c if evidence of elevated	

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		assessment. --- Tests results will often be unremarkable, though subtle abnormalities may be observed. Routine inflammatory markers are usually not elevated in ME/CFS. […] Marked abnormalities should raise the suspicion of an alternative diagnosis.			glucose, suspicion of diabetes* Parathyroid hormone, ionized calcium in older patients*. Follicle stimulating hormone if patient may be peri or post-menopause*. Free and total testosterone if evidence of hypogonadism*. Adrenocorticotropic hormone if abnormal AM cortisol and evidence of adrenal insufficiency or Cushings syndrome* • Gastrointestinal Disorders: Esophagogastroduodenoscopy, colonoscopy, food sensitivity tests as appropriate* • Pain: Small punch biopsy of skin in patients with evidence of neuropathy, widespread hyperalgesia* • Psychiatric Disorders: Clinical psychiatric screens; recommend those with less emphasis on somatic symptoms to avoid misdiagnosis as a mental illness (e.g. Patient Health Questionnaire-4, Generalized Anxiety Disorder Scale-7)	

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					• Sleep: Home sleep studies, polysomnography • Miscellaneous: Vitamin B6 if clinical concern for neuropathy or patient taking vitamin B6 supplements* * Followup tests that are typically used later in the diagnostic process. --- Standard tests typically return normal results […].	
Critères diagnostiques à privilégier						
[…] no one set of [existing] criteria was agreed to be better overall. --- Diagnose ME/CFS in a child, young person or adult who has the [four main] symptoms [debilitating fatigue, post-exertional malaise, unrefreshing sleep or sleep disturbance (or both), and cognitive difficulties] that have persisted for 3 months and are not explained by another condition.	From the review it appears that researchers are unable to determine differences in accuracy between case definitions because there is no universally accepted reference standard for diagnosing ME/CFS. Some tools are more simplistic and user friendly than others but as a result compromise sensitivity and specificity, and some include criteria for ME/CFS not found in other case definitions. --- **Recommendations** ***Practice point*** Although there is currently no definitive test or validated	None of the criteria used in adults have been validated for the diagnosis of paediatric ME/CFS. --- A case of ME/CFS in an adult patient requires the presence of symptoms for at least 6 months and are typically present for at least half of the time [Institute of Medicine criteria]. [Institute of Medicine/National Academy of Medicine criteria] relative simplicity makes them ideal for use in primary care : **Required symptoms**	Most of the case definitions were developed for adults and they can exclude some young people with ME/CFS. Several varied clinical criteria are currently used to diagnose ME/CFS in children and adolescents. None have been clinically validated in formal studies. --- The following diagnostic criteria are offered by our experienced clinicians and are based on their collective experience and insight. The criteria provide useful diagnostic sensitivity within	--- The 2015 IOM diagnostic criteria for ME/CFS in adults and children state that three symptoms and at least one of two additional manifestations are required for diagnosis. The three required symptoms are: 1) A substantial reduction or impairment in the ability to engage in pre-illness levels of activity (occupational, educational, social, or personal life) that: a) lasts for more than 6 months	--- The NAM criteria enable a proactive diagnosis based on these core symptoms [substantial impairment in function accompanied by fatigue, PEM, unrefreshing sleep, and either cognitive impairment or orthostatic intolerance]. In addition, disease experts often use the 2003 Canadian Consensus Criteria or the 2011 ME International Consensus Criteria to confirm a diagnosis of ME/CFS	[…] the diagnostic approaches used for all ME/CFS patients […]

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	tool to diagnose ME/CFS or single proven treatment, symptoms consistent with ME/CFS can be identified and managed successfully within the primary care setting. **Suggested Assessment and Diagnosis** Consider the Fukuda and Canadian consensus criteria which are most commonly reported in the literature and are available. • A validated, sensitive and specific tool (Canadian consensus) is suggested for use. • The Fukuda Criteria" require the presence of four of eight symptoms over six months. With no mandatory criteria the permutations are many (8X7X6X50). Limitations include heterogeneity, not having post exertional malaise (PEM) – the core symptom of ME/CFS as required for diagnosis, and psychiatric patients may be misdiagnosed as having ME/CFS from overlapping criteria, especially with major depressive disorder.	1. Substantial reduction or impairment in the ability to engage in pre-illness levels of activity (occupational, educational, social, or personal life) with profound fatigue of new onset, which is present for at least 6 months, is not explained by ongoing or unusual excessive exertion and is not substantially relieved by rest 2. Post-exertional malaise (PEM) 3. Unrefreshing sleep **At least one of the following:** 1. Cognitive impairment 2. Orthostatic intolerance The Canadian Consensus Criteria (CCC) are particularly suitable for diagnosis confirmation and case sub-grouping in secondary care, as well as in research. The required symptoms, listed below, must be persistently or recurrently present for at least 6 months in adults (3 months in children and adolescents). If other conditions have the same symptoms, those conditions must be	a heterogeneous pediatric ME/CFS patient population. A symptom severity scoring system is included to increase the specificity of the diagnostic criteria. Criteria for the diagnosis of ME/CFS in children and adolescents: • Impaired function, post-exertional symptoms, fatigue, sleep disturbance, neurocognitive problems, and pain. • Some or all symptoms are present every day (symptoms often fluctuate significantly in intensity during the day or from day-to-day). • The symptoms are mostly moderate to severe. • Symptoms have persisted or recurred for at least 6 months (a provisional diagnosis and appropriate management can be instituted before 6 months).	b) is accompanied by fatigue that is: i) often profound ii) of new onset (not life-long) iii) not the result of ongoing or unusual excessive exertion iv) not substantially alleviated by rest 2) Post-exertional malaise (PEM)*—worsening of symptoms after physical, mental, or emotional exertion that would not have caused a problem before the illness. PEM often puts the patient in relapse that may last days, weeks, or even longer. For some patients, sensory overload (light and sound) can induce PEM. The symptoms typically get worse 12 to 48 hours after the activity or exposure and can last for days or even weeks. 3) Unrefreshing sleep*—patients with ME/CFS may not feel better or less tired even after a full night of sleep despite the absence of specific objective sleep alterations. At least one of the following two additional		

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	• In addition, the Institute of Medicine recently suggested a simple three-question diagnostic tool. It is easy to use but lacks specificity for ME/CFS so will generate higher numbers of false positives than the Canadian criteria In order to increase confidence of diagnosis in patients screening positive for ME/CFS using IOM criteria, one could follow with the more detailed and validated Canadian Consensus Criteria. However, there are no studies to date supporting this "triaging" or combination approach. -- The Fukuda Criteria" require the presence of four of eight symptoms over six months. With no mandatory criteria the permutations are many (8X7X6X50). Limitations include heterogeneity, not having post exertional malaise (PEM) – the core symptom of ME/CFS as required for diagnosis, and psychiatric patients may be misdiagnosed as having	assessed and treated optimally first before a diagnosis of ME/CFS can be made. Exclusionary conditions should be ruled out by a combination of clinical history, physical examination, and complementary tests. • Pathological fatigue • Post-exertional malaise and worsening of symptoms • Sleep dysfunction • Pain • Cognitive symptoms (at least two symptoms from a list provided) In addition, at least one symptom from two from the following categories of symptoms are required: • Autonomic • Neuroendocrine • Immune The CDC-1994/Fukuda et al. criteria may also be used as a screening tool for diagnosis in clinical practice, but we recommend that only cases with post-exertional malaise (PEM) (which is optional in that definition), are included for diagnosis **Primary symptoms** • Clinically evaluated,	• Other fatiguing illnesses have been excluded by history, physical examination, and medical testing [Core] symptoms: 1. impaired function 2. post-exertional symptpoms 3. fatigue 4. Sleep problems 5. cognitive problems 6. pain [Core] symptoms severity score: absent (0), mild (1), moderate (2), and severe (3) Other symptoms present in many, but not all, pediatric patients with ME/CFS: • Orthostatic intolerance • Hypersensitivity • Termo-regulatory imbalance • Gastrointestinal symptoms To diagnose ME/CFS: • Symptom criteria 1, 2, and 3 are present together with at least two of criteria 4, 5, and 6. • Symptoms are present for 6 months and some	manifestations must be present: 1) Cognitive impairment*—patients have problems with thinking, memory, executive function, and information processing, as well as attention deficit and impaired psychomotor functions. All can be exacerbated by exertion, effort, prolonged upright posture, stress, or time pressure, and may have serious consequences on a patient's ability to maintain a job or attend school full time. 2) Orthostatic intolerance—patients develop a worsening of symptoms upon assuming and maintaining upright posture as measured by objective heart rate and blood pressure abnormalities during standing, bedside orthostatic vital signs, or head-up tilt testing. Orthostatic symptoms including lightheadedness, fainting, increased fatigue, cognitive worsening, headaches,		

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	ME/CFS from overlapping criteria, especially with major depressive disorder. In addition, the Institute of Medicine recently suggested a simple three-question diagnostic tool. It is easy to use but lacks specificity for ME/CFS so will generate higher numbers of false positives than the Canadian criteria.	unexplained, persistent, or relapsing chronic fatigue that is: ○ Of new or definite onset (has not been lifelong); ○ Is not the result of ongoing exertion; ○ Is not substantially alleviated by rest; ○ Results in substantial reduction in previous levels of occupational, educational, social, or personal activities; ○ Is associated with post-exertional malaise (PEM)*. **Additional symptoms** The concurrent occurrence of three or more of the following symptoms: • Substantial impairment in short-term memory or concentration; • Sore throat; • Tender lymph nodes; • Muscle pain; • Multi-joint pain without swelling or redness; • Headaches of a new type, pattern, or severity; • Unrefreshing sleep. These symptoms must have persisted or reoccurred during 6 or more consecutive months of	or all symptoms are present daily. • No other diagnosis found from the history, physical examination, and medical testing. • Symptom severity score: 0–4 ME/CFS unlikely; 5–12 mild/moderate ME/CFS; 13–18 moderate/severe ME/CFS	or nausea are worsened with quiet upright posture (either standing or sitting) during day-to-day life and are improved (though not necessarily fully resolved) with lying down. Orthostatic intolerance is often the most bothersome manifestation of ME/CFS among adolescents. *The frequency and severity of these symptoms need to be evaluated. The IOM committee specified that "The diagnosis of ME/CFS should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity." A diagnosis of ME/CFS requires at least 6 months of illness. However, children and other patients should be seen by doctors and get support as soon as they become ill.		

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		illness and must not have started before the fatigue. * Modified for use in clinical diagnosis of ME/CFS, to include PEM as compulsory symptom (EUROMENE recommendation). We recommend paediatricians use the full criteria from Rowe et al. (2017) as part of diagnostic approach and the CCC 2003 criteria if symptoms are present for 3 months. **Paediatric diagnosis of ME/CFS.** A diagnosis is based on persistent symptoms as below: *Compulsory symptoms:* • Impaired function • Post-exertional symptoms • Fatigue In addition, 2 of 3 groups of symptoms are required: • Sleep problems • Cognitive problems • Pain A diagnosis is made if all the criteria below apply: • Symptoms are persistent for 6 months (or for 3 months if post-infection) and at least some occur daily and are at least of moderate				

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		severity • Other diagnoses are excluded by history, physical examination, and medical testing, including learning disabilities • Severity of symptoms over a pre-determined cut-off score **The ME/CFS Specialist Consultation** For diagnosis confirmation, we recommend the use of the CCC in both adults and children.				

Sources : [CDC, 2022; Bateman *et al*., 2021; Montoya *et al*., 2021; Nacul *et al*., 2021; NICE, 2021; US ME/CFS CC, 2021a; US ME/CFS CC, 2021b; US ME/CFS CC, 2020; Rowe *et al*., 2017; TOP ME/CFS Working Group, 2016]

[1] Site Web consulté le 23 août 2022.

Tableau E-3 Recommandations et information clinique concernant les modalités de bonne pratique clinique pour la prise en charge des signes et symptômes (Question 3b)

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 Plusieurs pays**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
Généralité						
Be aware that ME/CFS symptoms can be managed but there is currently no cure (non-pharmacological or pharmacological) for ME/CFS. Refer to relevant NICE guidance for managing symptoms that are not covered in [the document], taking into account the recommendations in the sections on principles of care for people with ME/CFS, access to care and support and energy management. Health and social care professionals should: • take time to build supportive, trusting and empathetic relationships • acknowledge to the person the reality of living with ME/CFS and how symptoms could affect them • use a person-centred approach to care and assessment • involve families and carers (as appropriate) in discussions and care	**Recommandations** ***Practice Point*** Although there is currently no definitive test or validated tool to diagnose ME/CFS or single proven treatment, symptoms consistent with ME/CFS can be identified and managed successfully within the primary care setting. ***Practice Point*** Many symptoms associated with ME/CFS are common in other chronic conditions and can be treated and/or managed as per usual care with a few symptoms requiring special considerations. Acknowledge the legitimacy of the condition and respect the patient's lived experience. Often patients are more ill than they look. Manage ME/CFS symptoms: • Develop a mutually agreed upon action plan (between patient and physician). • Prioritize symptoms and manage the most	There is no causal treatment for the disease. With symptom-oriented support, there can be improvement with time, or patients may learn to manage their illness. In the absence of disease-specific treatment, key roles of the health professional include confirming the diagnosis, explaining to the patient the importance of avoiding overexertion and mental stress, "pacing", and symptomatic medication as needed and appropriate for the patient. Treatment of pain and sleep dysfunction are key, as they may have an indirect impact on other symptoms. However, symptoms should be managed as in usual clinical practice. Initial management and referral may be considered when diagnosis is suspected or with 3 months of symptoms, as appropriate.	Currently, there is no treatment protocol or intervention which will cure ME/CFS. The role of the physician is, therefore, first, to do no harm, second, to try to improve daily function, expand activity, and ameliorate specific symptoms, and third to support the patient and the family. Since there is no medication or intervention which will cure ME/CFS, clinical care focuses on managing symptoms and improving function. A management plan might include: • Educating the patient, the parents, the family, and the school about the illness (e.g., using handouts). • Guidance on determining the optimum balance of rest and activity to help prevent post-exertional symptom worsening. • Advice on diet, social interactions, and	[…] patients benefit when diagnosis and management are timely and appropriate. Treatment to address symptoms and improve quality of life The symptoms should be addressed and managed and any identified comorbidities treated to improve quality of life. There are no confirmatory tests, cures, or drugs approved by the U.S. Food and Drug Administration (FDA) specifically for ME/CFS. While some patients and healthcare providers have reported improvement in ME/CFS after the use of off-label or unlicensed medications, the efficacy of these medicines has not been tested in multiple, large, well-controlled clinical trials. Patients benefit from talking with their healthcare providers about potential therapies, including the risks and expense of unproven treatments. Patients also	The NAM criteria require that symptoms exist for 6 months because acute medical conditions or lifestyle issues should resolve within that time. During these 6 months, the provider should observe patients closely to detect other causes for their symptoms while also beginning treatment as discussed later. Whether in the hospital or at home, the very severely ill require individualized care that accounts for their severe energy limitations and sensory sensitivities. Validate the patient's illness experience and educate patients, family members, and others (eg, employers, schools). While there is no cure for ME/CFS, treating a patient's symptoms and comorbidities can help reduce the symptom burden and improve a patient's quality of life.	Recognize and express sympathy for the challenging experiences patients may have faced previously. A patient-centered, collaborative approach to care that is grounded in compassion and respect for the patient in all interactions will be of benefit to everyone. The following approaches can help: • Respect the nature and severity of the patient's disease in all clinical interactions. Ask patients and caregivers beforehand about any factors (e.g., fragrances, fast movements, brightly colored clothes, loud noises, bright lights, and touch) that exacerbate the patient's specific sensory sensitivities. Minimize these factors as much as possible. Interact with patients at a pace, time of day, and length of time the patient can manage. Even home visits may tax the patient so leverage the caretaker where possible

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planning if the person with ME/CFS chooses to include them • be sensitive to the person's socioeconomic, cultural and ethnic background, beliefs and values, and their gender identity and sexual orientation, and think about how these might influence their experience, understanding and choice of management. Care for people whose ME/CFS is managed in primary care should be supported by advice and direct clinical consultation from an ME/CFS specialist team. When working with children and young people with ME/CFS, ensure their voice is heard by: • taking a child-centred approach, with the communication focusing on them • discussing and regularly reviewing with them how they want to be involved in decisions about their care • taking into account that they may find it difficult	severe, disabling and problematic symptom(s) first. • Address symptoms using a stepwise approach over time. • DO NOT try to address all or too many symptoms in one visit. • Encourage patients to learn as much as they can about the condition allowing them to self-manage their symptoms using available resources, many of which are provided in this guideline. • Refer for group therapy if available. - Group sessions can be particularly beneficial for this patient population as they can learn from each other and feel supported. Consider a combination of non-pharmacological and pharmacological interventions. Monitor progress and assess for any other emerging conditions with regular patient follow-up. Use one treatment for multiple symptoms where possible	In general, irrespective of referral to secondary care, whenever possible, the primary care team should continue to take responsibility for the long-term care and monitoring of patients with ME/CFS and their treatment, whenever possible in partnership with the specialist team. The doctor-patient partnership, informed choices and risk minimisation are essential components of care. The primary care provider will still have major responsibilities for searching for alternative diagnoses where relevant and dictated by clinical judgement, for dealing with co-morbidities, the onset of new co-morbidities, and other diseases that may be not directly related to the diagnosis of ME/CFS, and for referring to different specialists as appropriate. Over-investigation and over-treatment are discouraged, but a very passive approach to illness may also be counterproductive, and such discouragement should not	education. • The treatment of symptoms with non-pharmacological interventions and/or medications. • Regular assessment of progress and watchfulness for the emergence of other illnesses. Young patients can do well when treated in a primary care setting, but given the complexity of this illness, appropriate referral to other health practitioners (preferably those familiar with ME/CFS) is often needed. […] paucity of peer-reviewed literature on the management of ME/CFS in this age group, […]. Due to variation in symptoms and co-morbid conditions, no single approach works for all patients. Management requires careful attention by the patient, the family and the practitioner to factors that provoke symptoms and a willingness to try several approaches before improvement is achieved.	benefit from thorough medical evaluations and good clinical care. Care focuses on alleviating symptoms through both pharmaceutical and non-pharmaceutical interventions and guiding patients through self-managementexternal icon. While there are no medications specifically licensed for the treatment of ME/CFS, there are drugs licensed for the treatment of some co-morbid conditions. Helping patients get relief from symptoms and achieve improvement in quality of life are the main goals of treatment. In working toward these goals, it is important to prevent harm that can occur from triggering post-exertional malaise. It is also important to acknowledge the clinical significance of the condition and to validate the experience and concerns of patients and their loved ones. To care for patients with ME/CFS, healthcare providers experienced in managing this illness typically develop an individualized treatment plan	**Teach pacing**. Reducing PEM can help alleviate fatigue, cognitive defects, sleep disturbances, pain, and other symptoms while helping to avoid repeated post-exertional relapses that can have a long-term impact. **Treat the Symptoms of ME/CFS**. Although there are no approved treatments specific to ME/CFS, clinicians can reduce the severity of symptoms with standard pharmacologic and nonpharmacologic treatments. **Treat comorbidities.** Treatment of comorbidities can positively affect a patient's quality of life and severity of symptoms.	to conserve the patient's limited energy. Creative approaches may be required if the patient's ability to speak is limited. • Accept the validity of the patient's report of symptoms. Gain the trust of the patient, caregiver, and family. Listen to what they report with understanding and compassion. • Be honest about the limits of medical knowledge but reassure the patient that you will do what you can to help them. • Partner closely with the caregiver, if one is involved, and if needed, other healthcare professionals to provide the resources, services, education, and practical help needed by the patient and caregiver. A specialty consultation may help diagnose and manage those aspects of ME/CFS with which you are unfamiliar. Engage a targeted set of other professionals as necessary and as tolerated by the patient. These could include physical therapists, occupational therapists,

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to communicate and describe their symptoms and may need their parents or carers (as appropriate) to help them • recognising that they may need to be seen on more than 1 occasion to gain trust (with or without their parents or carers, as appropriate). Personal care and support for people with severe or very severe ME/CFS should be carried out by health and social care practitioners who are: • known to the person and their family or carers wherever possible • aware of the person's needs. Risk assess each interaction with a person with severe or very severe ME/CFS in advance to ensure its benefits will outweigh the risks (for example, worsening their symptoms) to the person. For people with very severe ME/CFS, think about discussing this with the person's family or carers on their behalf (if appropriate), while keeping the focus of the engagement	Manage children and adolescents with ME/CFS similarly to adults. Ensure patient priorities and preferences are reflected in treatment plan. Treat symptoms for ME/CFS 1. Acknowledge this is a physical condition and not psychological/ psychiatric condition 2. Work with patient to prioritize treatment goals. 3. Have patient identify 1-2 (worst) symptoms/ functions to focus on first. Consider pharmacotherapy that address multiple symptoms and titrate to efficacious dose. Use health care team and community resources for non-pharmacotherapy as required and/or available. Managing fatigue and post exertional malaise is at the core of stabilizing patients with ME/CFS. If the patient does not meet all criteria the patient should be treated for existing	result in patients being denied treatment or testing needed to monitor changes in their condition. People who have severe ME/CFS […] It is therefore important that the management and care plan is flexible and reviewed regularly. People may have severe ME/CFS for years, and recovery is uncertain. Health services need to be prepared to attend to the specific needs of the severely affected, including home visits or virtual health consultations. The goal of the management/treatment programme is to treat the most distressing symptoms (sleep disturbance, pain, orthostatic intolerance, or others) and empower the patients to be in control of symptoms and the disease by encouraging them to trust their own experiences and enhance their awareness of the activities and environments in which they can cope without exacerbating symptoms, and “pace” themselves accordingly. The program should aim at optimizing the patient’s ability to maintain	Most young people can achieve functional improvement. But even in the absence of improvement, the practitioner can help affected young people simply by continuing to evaluate them, providing encouragement, and discussing any new treatments that emerge. Management is based on: early diagnosis, educating the patient, the family and school personnel about the illness, determining the dominant causes of post-exertional symptoms, treating symptoms with non-pharmacological and pharmacological interventions, providing guidance on activity, diet, maintaining social contacts and educational opportunities, and monitoring progress. Clinical management can be improved by the following suggestions: • Obtain a written list of the patient’s most troublesome symptoms. • Agree with the patient and family to focus on a limited number of symptoms.	as a team effort between patients and their providers, as well as caregivers and loved ones. This individualized treatment program that best meets the needs of the patient is re-evaluated periodically based on each patient’s progress**.** Each patient’s program typically includes a combination of: • Therapies to address symptoms • Techniques to help patients cope • Strategies to manage daily activities ME/CFS affects patients in different ways, and treatment plans should be tailored to address symptoms that are most disruptive or disabling for each patient. It is best to proceed slowly. Expecting patients to return to usual activities should not be the initial management goal because physical and mental exertion can aggravate symptoms and debilitate patients. An important strategy for patients to learn is how to manage their activities to avoid triggering post-exertional malaise (PEM).		nurses, home health aides, social workers, and mental health experts. Home visits by optometrists/ophthalmologists and dentists may be required. Ensure these other professionals are knowledgeable about ME/CFS. • While providing access to essential healthcare providers, care must be taken not to overwhelm the patient with too many providers or too many visits. Where feasible, leverage the caregiver to save the patient’s energy. For example, capitalize on the caregiver’s intimate knowledge of the patient’s needs, preferences, and status. Teach them to provide certain services to minimize the need for additional healthcare providers. Reserve patient visits for those times where patient input is required or there is a need to examine the patient in-person. Thus, recommendations for treatment and management of severe or very severe ME/CFS must be individually tailored to each patient. These

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on the person with ME/CFS. Offer home visits to people with severe or very severe ME/CFS to carry out their holistic assessment and develop their care and support plan. Develop and agree a personalised care and support plan with the person with ME/CFS and their family or carers (as appropriate) informed by their holistic assessment. Include the following, depending on the person's needs: • information and support needs • support for activities of daily living • mobility and daily living aids and adaptations to increase or maintain independence • education, training or employment support needs • self-management strategies, including energy management • physical functioning and mobility • managing ME/CFS and symptom management, including medicines • guidance on managing	symptoms and monitored.	function in everyday activities, being as active as possible within their boundaries and then gently extending those boundaries. This may be challenging, especially in the more severely affected who may be able to tolerate only very low levels of activity; those with less severe forms of disease are likely to “overdo” and may have frequent exacerbations of symptoms (“crashes”) as a consequence.	• Recommend that a family member write down or record medical advice. In reviewing the patient's most troublesome symptoms, special attention should be paid to those factors which exacerbate symptoms, e.g., upright posture. Then a decision can be made about which symptoms should be addressed first. Severely ill young patients are often difficult to manage and frequently have received little help from medical practitioners. They can be socially isolated and frequently have to confront disbelief in the reality of their illness from family members, school personnel, social workers and physicians. They are in need of a great deal of practical help, emotional support and comfort. A vital part of management is to gain the trust of the young patient and caregivers by reassuring them that the illness is recognized as a physical illness, it is taken very seriously, that the autonomy of the young patient will be	When expertise is available and accessible, these plans can sometimes be enhanced through collaboration with a team of other health care professionals. Healthcare providers and patients need to establish which symptoms are most disruptive or disabling and tailor management plans accordingly. Treatment should be directed toward the most problematic symptoms as prioritized by the patient. It is also important to incorporate strategies to prevent worsening of symptoms into initial and subsequent treatment plans. **Severely ill ME/CFS** The treatment plan for these patients usually includes: • Developing a careful medication and/or supplement plan that is kept to a necessary minimum. It is important to discuss risks and benefits of each medication or supplement. As for all patients, potential for adverse drug interactions should be assessed.		recommendations should be implemented if ME/CFS is suspected, even if the patient has not reached the six-month requirement typical of ME/CFS criteria: • Recommendations for minimising post-exertional malaise and sensory sensitivities • Recommendations for treatment and management approaches • Recommendations for follow-up visits, advance care directives, and hospitalization Caring for such vulnerable patients requires a patient-centered, collaborative approach in all clinical interactions, one that is grounded in compassion, humility, and respect for the nature and severity of the patient's disease. Where possible, leverage the caregiver to minimize the number of providers directly engaging the patient. Even so, compassionate, high-quality clinical care can help improve the quality of life, decrease the overall symptom burden, and

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flare-ups in symptoms and relapses • details of the health and social care professionals involved in the person's care, and who to contact. Provide care for people with ME/CFS using a coordinated multidisciplinary approach. Based on the person's needs, include access to health and social care professionals with expertise in the following as a minimum, with additional expertise depending on symptoms: • medical assessment and diagnosis • developing personalised care and support plans • self-management strategies, including energy management • symptom management, including prescribing and medicines management • managing flare-ups and relapses • activities of daily living, including dental health • psychological, emotional and social wellbeing, including family and sexual relationships			respected, and that all management/treatment options that are offered will be fully discussed with the patient and caregivers and informed consent will be requested prior to implementation of any therapy. The patient can be reassured that improvement is common, even if it takes months or years, and that recovery is possible, but cannot be guaranteed. **Management of the Very Severely Affected** Ideally one physician should accept responsibility for the patient's care for the duration of the severe stage of the illness. […]. If the patient is very severely affected from the outset, confirmation of the diagnosis is first necessary. Where there is a marked deterioration in a moderately severely affected patient, the practitioner might need to exclude other illnesses. Consultation with physicians from other disciplines, who are familiar with ME/CFS, can be helpful. While remaining optimistic, the physician might find that she/he will need to accept the continuing severity of the illness.	A realistic goal with severely ill patients is focusing on reducing stiffness and maintaining joint range of motion by passive range-of-motion exercises and gentle stretching (if touch can be tolerated). Patients, their families, and healthcare providers need to work together to decide which symptom causes the most problems. They should discuss the possible benefits and harms of any treatment plans, including medicines and other therapies. A treatment plan for a child who might have ME/CFS should focus on the most disruptive symptoms first		prevent a worsening of the disease.

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• diet and nutrition • mobility, avoiding falls and problems from loss of dexterity, including access to aids and • rehabilitation services • social care and support • support to engage in work, education, social activities and hobbies.			The best people to take care of the young patient are usually the parents. If the patient has to be admitted to an institution, attempts should be made to have one or two individual nurses be assigned to the patient.			
Traitement pharmacologique						
Do not offer any medicines or supplements to cure ME/CFS. **Medicines for symptom management** • Offer people with ME/CFS a medication review in line with the NICE guidelines on medicines adherence and medicines optimisation. • Take into account when prescribing that people with ME/CFS may be more intolerant of drug treatment. Consider: ○ starting medicines at a lower dose than in usual clinical practice ○ gradually increasing the dose if the medicine is tolerated. • Drug treatment for the symptoms associated with ME/CFS for children and young	Because ME/CFS is a chronic condition, long term medication use may be required. Therefore, the risk/benefit profile over the long term must be carefully assessed. Ongoing review is required with periodic attempts to decrease or change medications as symptoms vary over time. Medications which address co-morbidities are commonly used. Since patients are often sensitive to medication side effects, sedating medications should be started at a low dose. Use both pharmacotherapy and non-pharmacotherapy for ME/CFS symptoms, e.g., sleep, activity. management, pain, autonomic, gastrointestinal symptoms, mood, stress, etc. Consider pharmacotherapy	It is important to consider that patients with ME/CFS may be more sensitive to a range of medications; this also needs to be considered when treating other conditions, having in mind also the possibility of drug interactions. Physicians may consider starting symptomatic treatment at a lower than usual dose, due to frequent medication sensitivities in this population. The dose may be carefully increased. Treatment and repeat prescription may be continued in primary care, depending on the patient’s preference and local circumstances. Evidence of the effects of various drugs or supplements is scarce and often based on their use for	Medication can be most helpful in the relief of some individual symptoms. Since many pediatric patients with ME/CFS respond to much lower than standard doses of medication (1/2 or 1/4 of the usual dose), the dosage should start low and be increased slowly. In general any change in medication should be made one medication at a time, so that any favorable or unfavorable effects can be attributed to one medication. **Very severely ill patients** Medications should be limited to those absolutely necessary and initially prescribed in very low doses and they should be increased slowly, as tolerated. • Provide generous pain relief (including opioids if necessary).	A combination of over-the-counter and prescription medicines, as well as non-prescription supplements, are often used to treat sleep difficulties, cognitive problems, pain, and other symptoms of ME/CFS. Many patients with ME/CFS are sensitive to medications. This is particularly true of any medication that acts on the central nervous system, such as sedating medications: therapeutic benefits can often be achieved at lower-than-standard doses. Patients with ME/CFS might tolerate or need only a fraction of the usual recommended doses for medications. After initial management with lower dosing, one or more gradual increases may be considered as necessary and as tolerated by the patient.	Medications should be initiated at lower dosages and slowly titrated up to avoid triggering drug sensitivities common in ME/CFS. To reduce polypharmacy, medications that treat more than 1 symptom should be favored. Clinicians should also be aware of sensitivities to anesthesia and medication ingredients considered to be inactive (eg, fillers, vehicles, preservatives). In deciding on the specific treatment approach, the treating physician should consider the presentation and needs of the individual patient along with up-to-date drug product information for approved uses, dosages, and risks of specific treatments for specific indications. Some people with ME/CFS may have a	• Drugs should be used conservatively and parsimoniously. When drugs are used, start with very low doses and titrate up slowly as tolerated. […] Decrease the risk of side effects and drug–drug interactions by favoring medications which may treat more than one symptom or condition, e.g., both pain and sleep.

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people should only be started under guidance or supervision from a medical professional trained and experienced in paediatric prescribing.	that address multiple symptoms and titrate to efficacious dose.	related conditions or on reported use in ME/CFS and clinicians experience. […] many patients have already been taking a range of medications and supplements before reaching the ME/CFS specialist; again, in these cases, it is important to discuss continuation or otherwise with the patient; evidence of benefit on the individual patient, costs, potential side effects, or interactions with other medicines are important considerations. Treatment for children and young people should usually be started by a paediatrician or a ME/CFS secondary care specialist centre that includes a paediatrician.	- Treat problems such as migraine, dysmenorrhea and orthostatic symptoms. - Consider vitamin D supplementation in view of lack of exposure to sunlight. - In rare cases that remain bedbound for prolonged periods, consider bisphosphonates for prevention of osteoporosis. - Immunoglobulin therapy has shown some benefit […]. It can be given - IV or IM. The IM injection can be painful. - Regular use of IV saline can be helpful.	All medications can cause side effects, which may lead to new symptoms or worsen existing symptoms, so it is important to monitor routinely all prescription drugs, over-the-counter medicines, and supplements. It is also important to be mindful of possible interactions. Some drugs act on multiple body systems and symptoms. For instance, tricyclic drugs may not only improve mood, but can help with sleep and pain. In some, however, they can worsen orthostatic intolerance. Prescribing such drugs can allow the use of fewer medications to address multiple symptoms, sometimes with minimal or tolerable side effects.	heightened sensitivity to medications. For these patients, drugs should be started at low doses and increased slowly to avoid triggering drug sensitivities common in ME/CFS. Clinicians should also be aware of any potential impact of ingredients considered to be inactive in medications (e.g. fillers, vehicles, preservatives). For patients sensitive to drug fillers, the physician might speak with a compounding pharmacy to determine if a liquid preparation is an alternative.	
Traitement non pharmacologique						
Do not offer any medicines or supplements to cure ME/CFS. Be aware that people with ME/CFS may be at risk of vitamin D deficiency, especially those who are housebound or bedbound. For advice on vitamin D supplementation, see the	***Practice Point*** The evidence on effectiveness of complementary alternative medicine (CAM) in ME/CFS is weak. However some patients may benefit. The physician's role is to support the patient in his/her choice of CAM and assist in minimizing any harm.	Evidence of the effects of various drugs or supplements is scarce and often based on their use for related conditions or on reported use in ME/CFS and clinicians experience. Recent studies suggest that there may be a role for cognitive behaviour therapy	The benefit of CBT as a psychotherapeutic intervention for ME/CFS is currently ambiguous. Furthermore, CBT that includes rigidly enforced graded exercise frequently leads to severe relapse in patients with ME/CFS. The patient should also be advised that CBT does not	People with ME/CFS frequently use vitamins and other nutritional and herbal supplements. Since these products are unregulated and information on potency and side effects is often unknown, healthcare providers and patients need to talk about nutritional and herbal supplements to	Because of these concerns [controversies on therapeutic efficiency], the US Centers for Disease Control and Prevention and health agencies in some countries have since removed recommendations for CBT and GET. Other nations are in the process of updating their guidance […]	Aucune information présentée

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NICE guideline on vitamin D. Explain to people with ME/CFS that there is not enough evidence to support routinely taking vitamin and mineral supplements as a cure for ME/CFS or for managing symptoms. If they choose to take a vitamin or supplement, explain the potential side effects of taking doses of vitamins and minerals above the recommended daily amount. **Graded exercise therapy and cognitive behavioural therapy** Both treatments [GET and CBT] are controversial for this condition, and there as disagreements and uncertainty about their effectiveness among both people with EM/CFS and health providers. […] CBT has sometimes been assumed to be a cure for ME/CFS. However, it should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness.	**Cognitive Behavioral Therapy (CBT)** Therefore, CBT can be helpful in ME/CFS but is rarely if ever curative or sufficient. Other treatment options should be considered based on specific symptoms as well as ongoing monitoring of symptoms and reassessment of treatments. CBT can also assist in optimizing self-management. However, it should be noted that for patients with ME/CFS, CBT may not be sufficient as a stand-alone treatment and other interventions may be required **Diet, Nutritional Supplementation and Alcohol** An appropriate daily multivitamin and/or additional specific vitamin or mineral supplements (e.g., vitamin D and calcium if restricting dairy products) may be required to ensure that recommended nutrient intake is obtained. Getting nutrition from food sources is preferred to taking supplements. Referral to a dietitian, preferably	(CBT) in the management of ME/CFS. It may have long-term benefits in chronic fatigue, but there is little evidence of this, and it needs to be used with considerable care to avoid distress. It should be appreciated that it is a supportive therapy and not curative.	cure the illness, but it can help in learning to live within its limitations. If the diet is good, supplements should not be needed, although sometimes they can be beneficial. Occasionally, an excess of supplements can cause problems […]. While cognitive behavioral therapy (CBT) and graded exercise therapy (GET) have been promoted as of value in mild and moderate ME/CFS, there is no evidence that they are of therapeutic value in very severely affected patients. Inflexible, pre-ordained GET is often harmful and leads to exacerbation of symptoms in severe cases. **Supplements** Iron tablets for iron deficiency with/without anemia (the cause of anemia should be determined), take with citrus juice to aid absorption. **Alternative and complementary medicine** Many alternative and complementary therapies have been promoted for ME/CFS. It is difficult to	consider safety, effectiveness, and possible interactions between prescribed medications and over-the-counter supplements. Nutritional supplements cannot take the place of good diet and nutrition. A well-balanced diet is important for everyone, including people with ME/CFS, and should be encouraged. It is important to educate patients about all potential therapies because many treatments that are promoted as cures for ME/CFS are unproven, often costly, and could be dangerous.		

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Lightning process Do not offer the Lightning Process, or therapies based on it, to people with ME/CFS. **Energy management** Discuss with people with ME/CFS the principles of energy management, the potential benefits and risks and what they should expect.	knowledgeable in ME/CFS, may be necessary if dietary guidance is needed. **Treatment option** Use health care team and community resources for non-pharmacotherapy as required and/or available. **Non-pharmacotherapy Options Based on Symptoms and Patient Preference/Willingness to Try** • Activity management: pacing or graded exercise as appropriate • Symptom self-management (sleep hygiene, active pain management) • Nutrition (e.g., treat intolerances, ensure adequately nourished) • Cognitive behavioural therapy (CBT) (web-based/in person/telephone options) if mood/anxiety and/or coping issues identified • Complementary alternative medicine (CAM) if helpful and patient preference (no evidence for effectiveness in ME/CFS)		determine whether these therapies actually work, because the symptoms of ME/CFS vary so much from day-to-day. A review of alternative medicine studies in adults with ME/CFS revealed generally poor methodologies and limited evidence of any benefit. The clinician should identify the use of herbal/natural remedies or supplements. The contents of complementary medicines are not regulated for dose or composition. Caution must be exercised regarding side effects because if used with prescribed medications, there can be interactions.			

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Prise en charge des malaises post-efforts et de la fatigue incapacitante/asthénie						
Energy management Discuss with people with ME/CFS the principles of energy management, the potential benefits and risks and what they should expect. Explain that it: • is not curative • is a self-management strategy led by the person themselves with support from a healthcare professional in an ME/CFS specialist team • includes all types of activity (cognitive, physical, emotional and social) and takes into account overall level of activity • helps people learn to use the amount of energy they have while reducing their risk of post-exertional malaise or worsening their symptoms by exceeding their limits • recognises that each person has a different and fluctuating energy limit and they are experts in judging their own limits • can include help from a healthcare professional to recognise when they are approaching their limit (children and young people in particular may	**Suggested Management:** There are two evidence-based interventions for fatigue. There is active debate among experts as to the better approach. • Pacing: identifying one's energy at a given time and adapting activity level to energy level. There is less chance of symptom setback associated with pacing. • Graded exercise: gradually increasing activity level over time. If using this approach, careful monitoring is required as the patient can have a debilitating symptom setback if they inadvertently exceed their energy envelope too often or too severely. Using both interventions is possible by incorporating pacing within a graded exercise regimen.	"Pacing" refers to breaking up physical or mental activities with periods of rest, before a significant level of tiredness or exacerbation of symptoms is achieved or is expected following exertion, e.g., PEM, which may manifest many hours after the effort. A general rule of thumb is the recommendation to keep the activity at 2/3 of the duration and of the intensity that is expected (based on previous experience) to cause post-exertional symptoms though flexibility should be exercised in order to reflect the particular needs and circumstances of individual patients **Supplements** which may be tried for symptoms such as fatigue or cognitive dysfunction • Iron (if ferritin < 50 ug/l, transferrin saturation <20%) • Vitamin D • L-carnitine or acetyl-carnitine • CoQ-10 or MitoQ • NADH • Vitamin B12	Young people with ME/CFS often do better when they (and their parents) learn to adapt their lifestyles to live within their capabilities, and pace or spread out their activities so that they can avoid a boom and bust cycle of over-activity on a given day followed by a "crash" the following day. Remaining as active as possible while avoiding post-exertional flare-ups delineates an optimal zone of activity termed the "energy envelope." --- **Activity and exercise** • Adding an exercise program to the schedule of a young person who can barely manage to cope with limited educational activities can be counterproductive. […] No studies have shown that exercise can produce a cure for ME/CFS. • Prolonged periods of complete bed rest should be avoided except in the most severely affected patients. • Striking the right balance between rest and activity	PEM can be mitigated by activity management (pacing). The goal is to avoid PEM flare-ups and illness relapses by balancing rest and activity. Any activity or exercise plan for people with ME/CFS needs to be carefully designed based on individual presentation with input from each patient. If possible, evaluation by a rehabilitation specialist may be beneficial. […]. While vigorous aerobic exercise can be beneficial for many chronic illnesses, patients with ME/CFS do not tolerate such exercise routines**.** Standard exercise recommendations for healthy people can be harmful to patients with ME/CFS. However, it is important that patients with ME/CFS maintain activities that they can tolerate since deconditioning is also harmful to patients. For some patients, it might be first necessary to treat orthostatic intolerance and improve patients' capacities to tolerate being upright	**Postexertional malaise** *Nonpharmacologic approaches to conserve energy and to minimize postexertional malaise* • Pacing of physical and cognitive activity *Pharmacologic approaches* • No specific recommendations Pacing is an individualized approach to energy conservation and management used to minimize the frequency, duration, and severity of PEM. Typically, patients must decrease the total amount of their activities and restrict their exposures to PEM-inducing stimuli as much as possible. Once patients are effectively pacing without triggering PEM, some patients may be able to engage in very short periods of activity to increase their stamina. This must be individualized for the patient's level of severity and specific triggers of PEM and must be done in such a way that it does not provoke PEM. Even for those patients who can tolerate such activity, the expected	*Recommendations for Minimizing Post-Exertional Malaise and Sensory Sensitivities* • Ensure the patient and caregiver understand post-exertional malaise. Educate them about energy conservation strategies, such as pacing, to minimize the physical, mental, orthostatic, and emotional stressors that could trigger post-exertional malaise with its consequent worsening of symptoms and functioning.

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find it harder to judge their limits and can overreach them) • uses a flexible, tailored approach so that activity is never automatically increased but is maintained or adjusted (upwards after a period of stability or downwards when symptoms are worse) • is a long-term approach - it can take weeks, months or sometimes even years to reach stabilisation or to increase tolerance or activity. --- **Incorporating physical activity and exercise** Do not advise people with ME/CFS to undertake exercise that is not part of a programme overseen by an ME/CFS specialist team, such as telling them to go to the gym or exercise more, because this may worsen their symptoms. Only consider a personalised physical activity or exercise programme for people with ME/CFS who: • feel ready to progress		• α-lipoic acid • Magnesium • Omega-3 or omega-3/omega-6 combination • D-Ribose • Vitamin B1, B2, and/or B6 • Vitamin C	while avoiding post-exertional symptoms requires trial and error. • However, for some patients with less severe ME/CFS, or during a remission, a suitable exercise program can improve function and provide some enjoyment. Any exercise program should not take priority over activities of daily living, education and socialization. Special care also needs to be taken to ensure that exercise is not advanced too rapidly or too soon, as by definition, excessive exercise can exacerbate ME/CFS symptoms. It is most important for a patient with ME/CFS that any attempt to increase her/his activity level or to exercise be flexible, rather than rigid, permitting the patient to avoid exceeding her/his energy limit. Guidelines for exercise in healthy, but sedentary young people are inappropriate for patients with ME/CFS, because strict adherence to these guidelines can cause post-exertional relapse. For some	before any activity can be considered for careful implementation. Patients who are tolerating their current level of activity and have learned to "listen to their bodies" might benefit from carefully increasing exercise to improve their physical fitness and avoid deconditioning. Some healthcare providers with expertise in ME/CFS refer their patients to an exercise physiologist who understands ME/CFS and uses an individualized and flexible approach to advancing activity levels. If exercise plans are not designed and executed carefully, patients may experience setbacks and serious deterioration in function and health. Expectations need to be managed, as exercise cannot be expected to be a cure. However, improved function is a long-term goal of managing ME/CFS; tolerance of aerobic exercise and normal levels of activity is also a long-term goal that can be related to improved function but should be pursued cautiously as described above.	level of improvement may be small and is not seen in all patients.	

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their physical activity beyond their current activities of daily living or • would like to incorporate physical activity or exercise into managing their ME/CFS. Tell people about the risks and benefits of physical activity and exercise programmes. Explain that some people with ME/CFS have found that they can make their symptoms worse, for some people it makes no difference and others find them helpful. If a physical activity or exercise programme is offered, it should be overseen by a physiotherapist in an ME/CFS specialist team. If a person with ME/CFS takes up the offer of a personalised physical activity or exercise programme, agree a programme with them that involves the following and review it regularly: • establishing their physical activity baseline at a level that does not worsen their symptoms • initially reducing physical activity to be below their			young patients, it might be necessary to first treat their OI and improve their ability to remain upright before any exercise can be adequately tolerated. Consultation with a physical therapist or rehabilitation specialist knowledgeable about ME/CFS is often helpful. **Recommendations for improving activity levels** • **Moderately impaired -** Exercise while lying down should be advised when exercise while sitting or standing is poorly tolerated. Manual forms of physical therapy to improve mobility can be a bridge to tolerating exercise without prolonged exacerbations, especially for those with impaired range of motion on examination. Exercise should begin with as little as 1–2 min of gentle stretching followed by rest. When recovery has occurred another 1–2 min can be attempted. When stretching exercises do not trigger post-exertional symptoms, intervals of recumbent exercise can be added such as leg lifts while supine, or the use of a recumbent stationary	For some pediatric patients with ME/CFS, activities of daily living, education, and social engagement can result in PEM, while for other pediatric patients with ME/CFS, such activities with careful planning might sometimes be well-tolerated. Starting an exercise program for a patient who cannot tolerate or barely tolerates routine activities can be counterproductive and even harmful. However, for some patients with less debilitating symptoms, a carefully managed exercise routine can help improve functionality and yield enjoyment. It is important to ensure that exercise is not increased prematurely, as excessive exertion might result in PEM. As for adults with ME/CFS, achieving the optimal balance between activity and rest while preventing PEM symptoms requires "trial and error." Best practice: prevent harm! In the past, patients have been advised to be more active without any precautions about PEM. However, studies have demonstrated a lowered anaerobic threshold in		

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baseline level • maintaining this successfully for a period of time before attempting to increase it • making flexible adjustments to their physical activity (up or down as needed) to help them gradually improve their physical abilities while staying within their energy limits • recognising a flare-up or relapse early and outlining how to manage it. Do not offer people with ME/CFS: • any therapy based on physical activity or exercise as a cure for ME/CFS • generalised physical activity or exercise programmes – this includes programmes developed for healthy people or people with other illnesses • any programme that does not follow the approach in recommendation [above] or that uses fixed incremental increases in physical activity or exercise, for example, graded			bicycle. The individual can be encouraged to increase the duration of activity very gradually, provided that the prior period of activity has not aggravated symptoms, until a reasonable exercise volume has been achieved. Rest between activities is needed, and young people are advised to avoid the "push-crash" cycle of excessive activity on a good day followed by prolonged post-exertional collapse. Exercise in a swimming pool is sometimes better tolerated, provided the water is not too warm, as there is an external counter-pressure from the water that can improve circulatory function. • **Mildly impaired patients** - Leisurely walking with an initial duration of 5–15 min followed by a rest is suggested. The duration or pace of the walking can be increased gradually provided post-exertional symptoms do not occur. • **Higher functioning patients -** An exercise program might involve joining some organized	patients with ME/CFS, suggesting impaired aerobic energy metabolism. Increased activity can thus be harmful if it leads to PEM. For some patients, even activities of daily living can trigger PEM. Any recommendation for increased activity or movement should take into account the patient's energy limits (i.e., the "energy envelope") and must be specific regarding the intensity, duration, frequency, and type of activity, especially for patients who are severely ill or experience orthostatic intolerance when upright.		

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exercise therapy [defined as first establishing an individual's baseline of achievable exercise or physical activity, then making fixed incremental increases in the time spent being physically active]. • physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS Refer people with ME/CFS to a physiotherapist or occupational therapist working in an ME/CFS specialist team if they: • have difficulties caused by reduced physical activity or mobility or • feel ready to progress their physical activity beyond their current activities of daily living or • would like to incorporate a physical activity or exercise programme into managing their ME/CFS. Refer people with severe or			sporting activities at school, but with modified participation. The effect of exercise on ME/CFS should be discussed with the student, her/his parents and the school personnel. Everyone should be reminded that when the patient feels that she/he has done enough, she/he *must* stop and rest and never force her/himself to achieve more. Fluctuations in illness severity are also common and patients might find that they need to reduce their activities for a period of time. • **Activity management for the homebound patient -**However, movement is important to help reduce stiffness, maintain range of motion and prevent contractures. In very severely affected patients who are confined to bed, movement is limited to tolerated activities of daily living. For those who can tolerate touch, a knowledgeable physical therapist can provide gentle, passive range-of-motion activity and gentle, passive stretching for brief periods of time (1			

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very severe ME/CFS to a physiotherapist or occupational therapist working in an ME/CFS specialist team for support on developing energy management plans.			min at a time followed by a rest). Any increase of activity, including moving around in bed, needs to be determined by the young patient her/himself. When possible, the gradual resumption of some activities of daily living can be encouraged, but the patient should not be pressured into this. Orthostatic symptoms might need to be treated before the patient is able to sit up for very long. Even when the patient can sit up, activity/physical therapy is usually easier when lying flat. Further progress is shown when the patient can tolerate sitting out of bed in a chair. When there is progress to the point that standing up is possible, minimal leisurely walking, for a few minutes daily can be tried. Any activity program should allow severely ill patients to pace themselves and stay within their energy envelope, however small that might be.			
Prise en charge de l’intolérance orthostatique						
Medicine for orthostatic intolerance in people with	**Suggested Management:** • Manage as per usual	Recommendations for a non-pharmacological	The lack of treatment studies in young people with	Strategies to address orthostatic problems	**Orthostatic intolerance** *Nonpharmacologic*	Aucune information présentée

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ME/CFS should only be prescribed or overseen by a healthcare professional with expertise in orthostatic intolerance. Refer people with orthostatic intolerance to secondary care if their symptoms are severe or worsening, or there are concerns that another condition may be the cause. […] managing orthostatic intolerance […] can involve advice on diet, daily activities and activity support and needs to be tailored to each person, taking into account their other ME/CFS symptoms.	care. For patients diagnosed with orthostatic intolerance, the usual treatment approach should be offered (e.g., salt, fluids, florinef, midodrine).	approach to the relief of ME/CFS symptoms. **Autonomic dysfunction, e.g., POTS** • Stockings • Increase in water intake (>2 litres/day) or rehydration solutions, drinking frequently • Increase in salt intake • Sleep with feet in higher position (a few centimetres higher, increasing very slowly each night, up to what is tolerated) Examples of pharmacological approaches for relieving/managing ME/CFS symptoms **Autonomic dysfunction, e.g., POTS** − Fludrocortisone − SSRI − Midodrine − Ivabradine − Pyridostigmine	OI and the lack of specialists with experience in OI contribute to difficulties in managing this condition. Some young patients have characteristic symptoms of OI, but at the time of testing have a standing HR rise or BP fall which is insufficient to diagnose POTS, NMH, or OH. They might still benefit from treatment. *The first step* in management is non-pharmacological and emphasizes four main points: **a)** avoid conditions that increase pooling of blood, • […] avoiding prolonged standing or sitting, such as by moving around during longer classroom lectures, standing and stretching periodically to break up study sessions, and shopping at off hours. • […] avoid saunas, hot-tubs and sunbathing, and take short, cool baths, and showers. • Small, frequent meals are often better tolerated. **b)** improve venous return	include: • Avoiding factors that aggravate symptoms (hot environments, prolonged standing, inadequate salt and fluid intake) • Increasing salt and fluid intake for those patients with ME/CFS who do not have hypertension, renal failure, congestive heart failure, or other contraindications • Postural counter-maneuvers • Compression and cooling garments If symptoms do not improve with these non-pharmacological measures, prescription medications for the management of postural orthostatic tachycardia syndrome (POTS) and neurally mediated hypotension (NMH) as well as prescription-strength support stockings can be helpful. For children with ME/CFS who do not have heart or blood vessel disease, their doctor might suggest patients increase daily fluid and salt intake and use support stockings. If symptoms do not improve,	*approaches* • Salt and fluid loading, electrolyte drinks • Compression stockings • Positional changes; avoid prolonged sitting or standing • Consistent, tailored exercise as long as the patient can perform them without triggering postexertional malaise; may need to exercise lying down, seated, or in water • Treat comorbidities that may contribute to orthostatic intolerance *Pharmacologic approaches* • Fludrocortisone, low-dose beta blockers, alpha-adrenergic agonists, pyridostigmine, desmopressin, ivabradine • Intravenous saline	

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			to the heart, • Adolescents can utilize the muscle pump of the lower limbs by e.g., crossing their legs and shifting from one leg to the other while standing, sitting with their knees higher than their hips, or with their knees to their chests, or by performing leg muscle contraction exercises before standing. • Sitting on a high stool with the legs dangling freely should be avoided, as there is no resistance to blood pooling in the legs. • Compression garments such as support hose with 20–30 mm Hg compression can be helpful (waist-high garments are more effective than thigh-high, which are more effective than kneehigh). • A time-honored recommendation to improve blood volume is to elevate the head of the bed slightly by 10–15°. **c)** avoid depletion of salt and water and other causes of low blood volume, and	prescription medication can be considered.		

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			• Patients need to drink 2–3 liters of fluid daily and take in adequate sodium. We recommend drinking fluids every 2 h during the day. There is no specific amount of sodium that works for each individual. • Food should be salted according to taste and supplemental buffered salt tablets should be considered if needed. Oral rehydration fluids can also be beneficial. • Healthy higher sodium food options include dill pickles, olives, tomato juice, soups, salsa, salted nuts, and soy sauce. **d)** avoid increasing catecholamines beyond their baseline levels (which can be elevated). • Stress avoidance can help with symptom management. • Examine whether medications are helping or making symptoms worse. • Caffeine intake (including soft drinks or coffee) can help symptoms by acting as a vasoconstrictor, but			

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			some patients experience adverse effects. Alcohol consumption usually aggravates OI symptoms. *The second step* in management is to treat other ME/CFS symptoms and co-morbid conditions. • Treating symptoms, especially pain and sleep problems, can improve OI symptoms. *The third step* in management is pharmacological intervention, aiming for monotherapy, but often rational poly-therapy produces better symptom control. • All medications should be started at low doses and increased very slowly. • […] initial medication can be selected depending on the specifics of the patient's condition and existing co-morbidities. • Adolescent girls with dysmenorrhea, acne or peri-menstrual exacerbation of OI symptoms can benefit from hormonal contraceptive therapy. […]			

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			A long-acting injectable progesterone can be considered. • The use of several medications with different pharmacologic effects, e.g., a vasoconstrictor, a mineralocorticoid, and a beta blocker concurrently might be necessary for the improvement of severe OI. • Among those refractory to treatment, it is important to question whether the OI is exacerbated by another co-morbid condition. **Medications for treating orthostatic intolerance (OI) in adolescents.** • Vasoconstrictors – Midodrine; Start at 2.5 mg q 4 h while awake. Increase every 3–7 days by mg to optimal dose or max. of 10 mg q 4 h while awake; First-line therapy for those with low blood pressure (BP) (SBP < 100 or low normal BP). Monitor BP as supine hypertension can occur. Avoid prior to bedtime. – Methylphenidate; Immediate-release			

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			form: 5–10 mg bid, increasing gradually to 15–40 mg/day; First-line therapy for those with prominent cognitive dysfunction, personal or family history of ADHD, joint hypermobility. The optimum dosage of dextroamphetamine is usually half the optimum dose of methylphenidate – Dextroamphetamine; Sustained-release form: 5–10 mg q AM. Increase by 5–10 mg q AM weekly until optimal dose or 15–40 mg daily • Volume expanders – Sodium chloride; Oral: 1 g tablets with meals, IV: 1–2 L over 1–2 h; IV saline is seldom practical over the longer term, but can help restore baseline function after illnesses or as emergency "rescue" therapy – Fludrocortisone; 0.05 mg daily for 1 week, then 0.1 mg daily. Increase gradually to maximum of 0.2 mg daily; First-line therapy in those with			

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			baseline hypotension or increased salt appetite. Add KCl 10 m Eq for every 0.1 mg fludrocortisone to prevent hypokalemia – Hormonal Contraceptives, Medroxyprogesterone; Most are fine. Conventional dosage or continuous pills for 84 days (one period every 3 months); First-line therapy for females with dysmenorrhea or when symptoms worsen with menses. Drospirenone containing pills can have diuretic effect – Desmopressin acetate; 0.1 mg at bedtime, increasing to 0.2 mg daily; Useful for those with nocturia. Monitor for hyponatremia • Sympathetic tone modifiers – Beta blockers Atenolol; 12.5–25 mg daily, increase by 12.5 mg increments until optimal effect. Usual dose; First-line therapy for those with resting heart rate >100, anxiety or			

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			prominent headache. Higher doses can aggravate fatigue and lightheadedness. – Propranolol; 0.5–1 mg/kg body weight 10–20 mg 3–4 times daily – Pyridostigmine bromide; Rapid release: 30 mg daily, increase by 30 mg every 3–7 days to 60 mg BID or TID. Sustained-release: 180 mg daily; Effective in both POTS and neurally mediated hypotension. Can also help with GI motility problems – Clonidine; 0.05 mg at bedtime. Increase after 1 week to 0.1 mg nightly.Occasionally higher doses tolerated; Consider in those with anxiety, problems with attention or insomnia. – Reported to improve blood volume • Selective serotonin reuptake inhibitor/SNRI – Escitalopram; 5 mg daily for 2–4 weeks, increase to 10 mg daily up to max. of 40			

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			mg daily; Consider for dysthymia, depression, or anxiety – Duloxetine; 20–30 mg daily for 2 weeks, increase to max of 60–90 mg daily; Consider if myalgias are prominent – Sertraline 25–100 mg daily			
Prise en charge des troubles du sommeil						
Give people with ME/CFS personalised sleep management advice that includes: • explaining the role and effect of sleep disturbance in ME/CFS • identifying the common changes in sleep patterns seen in ME/CFS (such as broken or shallow sleep, altered sleep pattern or hypersomnia) • developing good sleep habits • taking into account the need for rest in the day, and balancing this against how them person is sleeping at night • introducing changes to sleep patterns gradually. If sleep management strategies do not improve the person's sleep and rest,	**Suggested Management:** • Use typical sleep hygiene principles. • Consider and if necessary prescribe sleep medication. • Refer to sleep specialist if a primary sleep disorder is suspected (one or more sleep disorders are present in 20% of cases). Non-pharmacologic treatment should be prescribed at the outset and patients should commit to trying improved sleep hygiene before or with sleep medication General sleep hygiene suggestions recommended for patients in general and often helpful for patients with ME/CFS include:	Recommendations for a non-pharmacological approach to the relief of ME/CFS symptoms. **Sleep** − Sleep hygiene − Relaxation strategies Examples of pharmacological approaches for relieving/managing ME/CFS symptoms **Sleep** • Tricyclics, e.g., amitriptyline • Trazodone • Melatonin • Doxepin low dose • Diphenhydramine • Promethazine • Benzodiazepines and Z-drugs (for short periods only) • Gabapentin/pregabalin	For many young patients, naps are important to get through the day, but marked daytime sleepiness can result from conditions such as sleep apnea. Sleepiness can be measured using the Epworth sleepiness scale. Young people who sleep for more than 12 h at a time can develop dehydration. During wakeful periods, the young patient's parents/caregivers need to ensure adequate hydration and nourishment. When oral hydration and nourishment are inadequate, tube feeding is necessary. If hypersomnia persists for months, the young person should be evaluated by a sleep specialist, preferably one who is familiar with	When patients follow good sleep hygiene techniques but are still waking unrefreshed, sleep medication might be indicated. Initial medications to consider are over-the-counter sleep products. If this does not improve sleep quality, healthcare providers may prescribe medication for sleep starting at the smallest dose and using for the shortest possible time. Unrefreshing sleep can be present even though medications may help patients achieve required hours of sleep. If possible, a sleep specialist may evaluate patients whose sleep remains non-restorative following standard interventions. It is very important for	*Nonpharmacologic approaches* • Sleep hygiene practices are a part of treatment but may be marginally effective in most patients; need to be tailored for severely ill and those with orthostatic intolerance • Meditation and relaxation exercises • Ear plugs and eye masks • Light therapy • Blue light filters *Pharmacologic therapies* • Trazadone, low-dose tricyclic antidepressants (eg, amitriptyline, doxepin), mirtazapine, antiepileptics (eg, gabapentin, pregabalin), clonazepam,	Aucune information présentée

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 **Angleterre**	**TOP 2016** **Canada**	**EUROMENE 2021 - Nacul et al. 2021** **Plusieurs pays**	**Rowe et al. 2017** **International**	**CDC[1] 2018 à 2022 selon les sections** **États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web** **États-Unis**	**Montoya et al. 2021** **États-Unis**
think about the possibility of an underlying sleep disorder or dysfunction and whether to refer to an appropriate specialist. Review the use of rest periods and sleep management strategies regularly as part of the person's care and support plan.	• Perform relaxing wind-down activities for one hour prior to bed time. • Ensure regular sleep and wake times. • Pace activities so symptom exacerbation including adrenaline spikes doesn't interfere with sleep. • Avoid taking naps after 3 p.m. but rest and relax as needed. • Spend time in the morning under full spectrum light (sunshine) either outdoors, by a window, or use artificial light. • Reduce or eliminate caffeine-containing beverages and food. • Use earplugs or soundproofing for noise, sleep in a different room if you have and hear (a snoring) bedroom partner. • Ensure the bedroom is dark by using a sleep mask or black-out window coverings. • Get up and move to another room if you can't sleep and do a quiet activity such as reading, listening to soft music, or relaxation tapes until sleepy but do not use a computer, iPad, or TV. • Do not try to force sleep.		ME/CFS. Conventional sleep hygiene measures for insomnia in otherwise healthy people can be ineffective in young people with ME/CFS, but the following measures can be helpful: • Balance daytime activity with rest (pacing of activity), to avoid post-exertional symptom exacerbation, which can interfere with sleep. • Eliminate caffeine-containing beverages in the late afternoon and evening. • Avoid television, computers, and electronic devices before and after bedtime, (light from electronic devices can aggravate insomnia and fatigue). • A carbohydrate snack at bedtime might be helpful. If insomnia or sleep reversal is profound, sleep medications, can be started at a low-dose. The risk of adverse effects needs to be balanced with the gains from a better night's sleep	healthcare providers to get a careful sleep history and recommend a sleep study if indicated. People with a primary sleep disorder such as sleep apnea or narcolepsy may benefit from treatment but, if the person also has ME/CFS, not all ME/CFS symptoms will go away with treatment of the sleep disorder. A subset of patients with ME/CFS are affected so severely that many standard recommendations regarding sleep such as those for sleep hygiene are not sufficiently helpful or might have limited applicability. Good sleep habits (sometimes referred to as "sleep hygiene") can help you get a good night's sleep. Some habits that can improve your sleep health: • Be consistent. Go to bed at the same time each night and get up at the same time each morning, including on the weekends • Make sure your bedroom is quiet, dark, relaxing,	cyclobenzaprine, zolpidem, eszopiclone, tizanidine, suvorexant, topiramate, hydroxyzine, alpha blockers (eg, clonidine, guanfacine, prazosin), diphenhydramine	

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	- Try a carbohydrate snack at bedtime Cognitive behavioural therapy insomnia (CBT-I) has not been formally tested in ME/CFS. […] the majority of patients will require additional treatment to optimize daytime function. Since patients are often sensitive to medication side effects, sedating medications should be started at a low dose. The medication should be taken early enough so that sedation occurs close to the patient’s usual bed time. Given this sensitivity follow-up is important, i.e., no longer than one month after starting medication and until the patient is on a stable dose. If tolerance to one medication develops, it may be more effective to change/rotate medications than to continue one type of drug ongoing. Medication typically used for patients with sleep problems: - melatonin; 1-3 mg 2-3 hours before bedtime; Use to stabilize circadian ryth. Benefir variable but risks are low. Could refer		and sleeping the same hours as other family members. The medications chosen should be safe for long-term use and should be taken early enough to be effective at bed time. For more severe problems, Zolpidem and trazodone can be used with caution. Controlling pain will often help sleep. **Medications for sleep** - Melatonin; 3 mg (range 1–12 mg); Use dose that is effective given half to 1 h before bedtime - Diphenhydramine; 25 mg at bedtime; Can cause excessive sedation or dry mouth - Tricyclics (TCAs); Amitriptyline 10–25 mg at bedtime; Dothiepin 25 mg at bedtime; Can be helpful for pain and headaches. Can cause weight gain, dry mouth, lightheadedness, and excessive sedation - Clonazepam; 0.5–1 mg at bedtime; Helpful if anxiety is affecting sleep. Can help restless leg syndrome. Using low doses, taken only at night, physiological	and at a comfortable temperature - Remove electronic devices, such as TVs, computers, and smart phones, from the bedroom - Avoid large meals, caffeine, and alcohol before bedtime - Get some exercise. Being physically active during the day can help you fall asleep more easily at night. When children try these tips but are still unable to sleep, their doctor might recommend taking medicine to help with sleep.		

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	to the CFPA website as a reference. • zopiclone; 3,75 – 7,5 mg; zolpidem; 2,5 – 10 mg; Use for sleep initiation. Should allow at least eight hours in bed. Behaviours like sleep eating and memory problems can occur. Risk of physical tolerance and dependence. • cyclobenzaprine; 2.5 mg – 10 mg; Use in low dose for co-morbid fibromyalgia and/or when muscle tension and pain interferes with sleep. • tricyclic antidepressants: amitriptyline, doxepin, nortriptyline; 3 – 50 mg; Use for sleep initiation and maintenance and co-morbid pain. □ Take 1-3 hours before bedtime. May worsen dry mouth, constipation, orthostatic intolerance, or cause daytime sedation. • trazodone; 12,5 – 200 mg; Use for sleep initiation and maintenance • quetiapine; 12,5 – 100 mg; Use in low dose with co-morbid anxiety. May cause weight gain or		dependence is unlikely			

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	extrapyramidal symptoms. Lengthens QTc interval. • gabapentine; 100 – 1500 mg; Use in low dose with co-morbid pain. May help restless legs syndrome. • pregabalin; 24 – 450 mg; Use in low dose with co-morbid pain. Helpful for nocturnal pain, but very sedating for some and weight gain is problematic. • antihistamines: diphenhydramine;50 mg; Anticholinergic side effects and tolerance are common. Not suitable for long term, regular use. • clonazepam; 0,25 – 1 mg; Use for comorbid restless legs, muscle spasms or anxiety. • ropinirole ou pramipexole; 0,125 – 0,25 mg; Use for comorbid restless legs syndrome. • mirtazapine; 7,5 – 15 mg; Use with comorbid anxiety and depression. May cause daytime sedation; tolerance develops quickly. * There are no studies specifically studying any sleep medications in					

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	ME/CFS. * Use compounding pharmacies if patients require lower than available doses.					
Prise en charge des problèmes cognitifs et de la fatigue mentale						
Aucune information présentée	**Suggested Management:** • Pace cognitive tasks similar to pacing physical activity. • Plan important tasks for the "best time of day." • Suggest strategies to keep information, appointments and personal items organized […]. ✗ Avoid high intensity or multisensory situations or events Individuals with ME/CFS often work more slowly and need more breaks than healthy individuals due to post exertional malaise. To sustain functional capacity patients must learn how to pace their cognitive activities and manage stress. Cognitive functioning is often slower to improve than other symptoms. Managing cognitive difficulties: • Use a "memory book or device " to document	**Supplements** which may be tried for symptoms such as fatigue or cognitive dysfunction • Iron (if ferritin < 50 ug/l, transferrin saturation <20%) • Vitamin D • L-carnitine or acetyl-carnitine • CoQ-10 or MitoQ • NADH • Vitamin B12 • α-lipoic acid • Magnesium • Omega-3 or omega-3/omega-6 combination • D-Ribose • Vitamin B1, B2, and/or B6 • Vitamin C	Trials of medications for fatigue have not been conducted in children and adolescents with ME/CFS. There have however been no randomized placebo controlled trials of vitamin B12 for ME/CFS in young people. Medications for fatigue might need to be reserved for potentially exhausting occasions such as school exams. If effective, the young person should try to avoid exceeding their individual energy envelope. The young patient needs to recognize issues that aggravate cognitive difficulties and when possible, avoid them. Aggravating factors include mental and physical activity; distraction by noise or bright lights; and prolonged standing. Cognitive problems can be improved by:	Tests can be useful to assess if and how patients' cognitive skills, such as concentration, memory, and organization, are or become impacted by illness. This additional testing can also be useful in identifying particular areas in which specific tools or strategies might help. Assessments and strategic interventions may be particularly helpful to children and adolescents with ME/CFS. Academic attendance and performance are important for these patients, and their specific educational needs should be addressed. For some patients with ME/CFS, memory problems might be managed to some extent by using memory aids such as organizers or portable notebooks to record information, like to-do lists, appointments, and people's names. Electronic devices such as smartphones and tablets can offer an additional	Cognitive dysfunction and fatigue *Nonpharmacologic approaches* • Cognitive pacing (eg, focus on only 1 task at a time, limit reading time) • Simple memory aids (eg, calendar reminder systems, notes) • Positional changes: perform cognitive functions lying down and stay hydrated if orthostatic intolerance is a problem *Pharmacologic approaches* • Methylphenidate, modafinil, armodafinil, amantadine • Caffeine if well tolerated	Aucune information présentée

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	important activities, tasks, events, appointments etc. (and keep the book in an open location where it can't be misplaced). • Develop habits such as leaving keys or glasses or always parking in the same spot. • Try to avoid situations where multisensory bombardment and fast-paced activity is likely to occur. • Limit time and intensity of cognitive effort (similar to pacing physical activity). • Limit or discontinue (i.e., take a break from) cognitive effort with exacerbation of cognitive symptoms. Stimulants can be helpful when patients complain of excessive daytime "sleepiness" versus "fatigue." Although stimulants can be helpful, they can be poorly tolerated or lead to "crashes" due to over-activity. This can cause long term setbacks. Stimulants including caffeine should be used with caution.		• Pacing of activities: the young person should be mentally active for short periods of time, followed by adequate periods of rest; she/he should learn to recognize when she/he is tired. • Performing mental work lying down can sometimes be better than sitting up. • The effective treatment of insomnia, pain, depression, and/or anxiety. • Snacks and frequent drinks. • Self-medicating with caffeine-containing drinks. • The use of prescribed stimulants such as low-dose methylphenidate can benefit some patients; the patient should be warned that there is a risk that a sense of well-being can lead to over-activity. • Learning to cope with the stress of having a chronic illness. **Supplements** • Vitamin B12 injections can help with low energy/brain fog, or	bonus of setting reminders for medications and appointments. As with physical activity and exercise, patients should employ careful planning and monitoring of cognitive activities throughout the day to avoid mental overexertion (see also post-exertional malaise). Planning periods of rest after any anticipated mental activity is critical in avoiding exacerbation of symptoms. Some patients may need to avoid highly stimulating activities based on their individual capacities. Caution is warranted in prescribing stimulants for cognitive problems. Mild stimulants may be helpful for some patients, but stronger stimulants can lead to a relapse as patients may attempt to do too much when they feel better (the so-called "push-crash cycle:" do too much, crash, rest, start to feel a little better, do too much once again, and so on). Patients need to be followed carefully to monitor for insomnia, weight loss, and other adverse effects. Many stimulants can be habit-forming, and tolerance may		

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	Medication typically used for neurocognitive disorders • methylphenidate; 5-20 mg tid; May be habituating. • dexamphetamine; 5-10 mg tid; May affect BP and HR; may be habituating. • amphetamine salts; 5-20 mg tid; May affect BP and HR; may be habituating. • modafinil; 100-200 mg qd; Start with a small dose and increase slowly to the most effective dose. • caffeine; patients often self-medicate with caffeine containing products, may disturb sleep if taken late in the day. Note: There are no studies specifically studying the use of stimulants in ME/CFS. Stimulants need to be used with caution and can be counterproductive.		vitamin B12 can be taken as sub-lingual tablets.	develop if used daily. For children with ME/CFS who have concentration problems, some doctors have prescribed stimulant medications, like those typically used to treat Attention-Deficit / Hyperactivity Disorder (ADHD). While stimulants might help improve concentration for some patients with ME/CFS, they might lead to the "push-and-crash" cycle and worsen symptoms. "Push-and-crash" cycles are when someone with ME/CFS is having a good day and tries to push to do more than they would normally attempt (do too much, crash, rest, start to feel a little better, do too much once again).		
Prise en charge de la douleur						
Investigate and manage the person's pain according to best practice, referring to specialist pain services if appropriate.	**Suggested Management:** • Identify the types of pain. • Suggest using pacing activity log. • Assess the patient's	Recommendations for a non-pharmacological approach to the relief of ME/CFS symptoms. **Pain** − Relaxation	It is important to treat localized pain such as headache, because pain can amplify other symptoms.	Over-the-counter pain relievers, like acetaminophen, aspirin, or ibuprofen, can be considered first. If these do not provide enough pain	*Nonpharmacologic approaches* • Pacing to avoid flare-up of pain • Hot or cold packs as needed to relieve the	If other pain medications have not been effective or cause significant side effects, it may be necessary to consider opioid medications. Consider

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Refer to the following for advice on treating neuropathic pain or headaches: – NICE's guideline on neuropathic pain in adults – NICE's guideline on headaches in over 12s.	need for and use typical pain medications. • For fibromyalgia pain consider treatment options suggested in 2012 Canadian Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome • For migraine/headache see TOP's Guideline for Primary Care Management of Headache in Adults. Localized pain such as migraine and arthritis should be treated as pain begets more pain due to neuroplastic changes in the brain. Non-pharmacologic pain management is very individual. […] One may try: • pacing activities, • exercise, (aerobic is best for those with fibromyalgia pain according to the Ottawa Consensus) • physical therapy, • massage, • stretching, • acupuncture, • hydrotherapy, • chiropractic, • yoga,	– Meditation/mindfulness – Manual methods (e.g., physiotherapy, acupuncture, and acupressure)	Chronic, daily headaches […] Possible triggers include inadequate sleep, stress, skipped meals, specific foods and supplements (including, but not limited to chocolates, nuts, and aspartame). Initial intervention focuses on avoiding the common triggers. Migraine-prevention drugs are worth a trial for both episodic and non-episodic chronic, daily headaches. Beta blockers can help headaches that are associated with OI. Helpful, non-pharmacological remediation for pain includes: pacing of activity to avoid flare-ups […], hot or cold packs for treatment of tender points, warm baths, muscle liniments, physical therapy, transcutaneous electrical nerve stimulation, acupuncture, massage, yoga or Tai Chi, biofeedback, and mindfulnessbased stress reduction techniques. These interventions might not be effective in some patients and might be poorly tolerated in others. For persistent pain, medications might be	relief, evaluation by a pain specialist may be indicated. As for any patient with chronic pain regardless of etiology, counseling for pain management techniques is also advisable and can be helpful. Other non-pharmacological pain management methods can also be beneficial to some patients with ME/CFS, including stretching and movement therapies, manual physical therapy, gentle massage, heat, toning exercises, and hydrotherapy. While methods that involve physical activity such as stretching might be helpful, initiating or resuming stretching and movement therapies require careful consideration to avoid post-exertional malaise. Acupuncture, when done by a licensed practitioner, might help with pain for some patients. Children with ME/CFS often have headaches and stomach pains. Doctors may want to check for food allergies and vision problems. Gentle massage and heat may relieve pain for some patients. Parents/guardians should always talk to their	specific source of pain • Physical therapy, massage, myofascial release, acupuncture, dry needling of trigger points • Chiropractic treatments • Meditation and relaxation • Neurofeedback techniques may be helpful *Pharmacologic approaches* • Low-dose naltrexone, serotonin-norepinephrine reuptake inhibitor (eg, duloxetine, milnacipran), antiepileptics (gabapentin, pregabalin), muscle relaxants (eg, cyclobenzaprine, tizanidine, baclofen), medical marijuana, nonsteroidal anti-inflammatory drugs (eg, celecoxib, meloxicam), acetaminophen, amitriptyline, tramadol	starting a medication to counter constipation at the time opioids are prescribed.

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	• Tai Chi and • meditation (relaxation response). **Pharmacologic Treatment** One treats pain symptoms in ME/CFS similarly to pain in other chronic medical conditions: • Use the lowest effective dose, titrate carefully and monitor closely. • Select an agent based on the type of pain, e.g., arthritis, abdominal, fibromyalgia, other neuropathic, headache. • Opiates are discouraged and should be used as a last resort and cautiously. If opiates are considered, it is preferable to refer the patient to a pain specialist. Medications typically used for pain: • acetaminophen, paracetamol; 500-1000 mg prn (q8 hours); Often ineffective. • aspirin; 300–600 mg prn q 6-8 hours; Often ineffective. • NSAIDS: diclofenac, 75-100 mg daily; naproxen, 500-1000 mg daily; Often ineffective. May		needed. Over-the counter medications such as aspirin, acetaminophen, paracetamol and NSAIDS are rarely effective for ME/CFS pain, but NSAIDS can ameliorate dysmenorrhea. Topical treatment for pain includes lidocaine patches. We recommend beginning at a low-dose and increasing very cautiously. If pain is generalized, the higher dosages might be needed. Multiple trials of medication might be necessary to achieve adequate relief. Young people with severe pain sometimes need strong analgesics. Opiates are occasionally necessary. Their use requires full documentation. For young people with complex pain syndromes, referral to a pain clinic (preferably one that is familiar with ME/CFS) might be helpful. **Medication for headaches** • Supplements – Riboflavin; 200 mg bid or 400 mg daily; Available as a single supplement or in combination with others (e.g., MigreLief)	child's healthcare provider before trying any medication. Doctors may recommend trying over-the-counter pain-relievers, like acetaminophen or ibuprofen		

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	exacerbate gastritis or reduce renal function. • tricyclics: amitriptyline, doxepin, nortriptyline; 5-100 mg; Also helpful for most chronic pain – same dosage as for sleep: Take 1-3 hours before bedtime. May worsen dry mouth, constipation, orthostatic intolerance, or cause daytime sedation. • SNRIs: duloxetine, 20-90 mg daily; May increase sweating, bruxism, blood pressure or heart rate. • opiates: codeine phosphate • opiates such as oxycodone, hydrocodone; morphine; doses vary, consult guidelines; Constipation/habituation. Opiates should be avoided if possible. • tramadol; 50-100 mg, qd q 6-8 hours; Seizure risk and interaction with drugs that raise serotonin. Additional suggestions: • pregabalin ME/CFS and fibromyalgia; 25-400 mg; Effective for neuropathic pain but		– Co-enzyme Q10: 300 mg daily in 2–3 divided doses – Magnesium; 250 mg daily • Antihistamines – Pizotifen; 1–1.5 mg nightly; Helpful for co-morbid insomnia and for poor appetite. Can cause weight gain. Pizotifen is not available in all countries – Cyproheptadine; 2–8 mg nightly • Tricyclics – Amitriptyline; 10–25 mg nightly (Up to 50 mg may be tolerated); Useful for co-morbid fibromyalgia and abdominal hyperalgesia. Can cause lightheadedness and fatigue even at low doses. Can take 4 weeks to become effective. **Medications for generalized pain.** • Tricyclics – Amitriptyline; 10–25 mg nightly (Up to 50 mg may be tolerated); Useful for co-morbid fibromyalgia and abdominal			

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	side effects of weight gain, sedation and cognitive symptoms problematic. • equivale topiramate; 250-500 mg bid, 50-400 mg/day; Helpful if migraine is part of symptom profile. * There are no studies specifically studying pain medications in ME/CFS.		hyperalgesia. Can cause lightheadedness and fatigue even at low doses. Can take 4 weeks to become effective. • Selective serotonin reuptake inhibitors or SNRIs – Sertraline HCl 25–100 mg daily; – Escitalopram 5–20 mg daily – Venlafaxine HCl 37.5–225 mg daily – Duloxetine HCl 20–60 mg daily – Bupropion HCl 150–300 mg daily – Consider in patients with co-morbid anxiety or depression. These medications should not be stopped suddenly. Patients should be weaned very gradually off them, especially duloxetine. Duloxetine can be helpful for fibromyalgia • Anticonvulsants – Topiramate (Topamax); 25–100 mg bid; Helpful for widespread pain, continuous headaches, and fibromyalgia. Can cause weight loss Adverse effects of topiramate include suicidal feelings and			

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			cognitive problems with doses >50 mg daily – Gabapentin; 300–1,200 mg tid; Gabapentin can cause somnolence and weight gain – Pregabalin (Lyrica); 25–50 mg at night increasing to 25–100 mg tid; – Valproic acid; 250–500 mg bid **Supplements** • Vitamin D if patient lacks sunlight, due to light sensitivity or if seldom outside. Low vitamin D levels can be associated with headaches and pain and these symptoms improve with raising vitamin D blood levels. • Magnesium at bedtime can help with pain and cramps (take with apple juice or apple to aid absorption) […].			
Prise en charge des comorbidités						
Be aware that other conditions may coexist with ME/CFS and should be investigated and managed according to best practice. When managing coexisting conditions in people with ME/CFS, take into account	Medications which address co-morbidities are commonly used. Fibromyalgia is present in about half of all individuals with ME/CFS. • Manage symptoms for	The primary care provider will still have major responsibilities for searching for alternative diagnoses where relevant and dictated by clinical judgement, for dealing with co-morbidities, the onset of new co-morbidities, and	Co-morbid conditions are seen frequently in young patients with ME/CFS and are major contributors to illness severity. Their successful management can result in substantial lessening of the burden of illness.	Be aware that a patient can have ME/CFS and a co-existing condition that causes fatigue or other ME/CFS symptoms (e.g., blood pressure abnormalities), and these co-existing conditions should be treated	Treatment of comorbidities can positively affect a patient's quality of life and severity of symptoms. Ensure that treatments for comorbidities are also appropriate for ME/CFS. For example, whereas exercise	Caution on stretching is advised for patients with comorbid hypermobile Ehlers-Danlos syndrome. Monitor for emerging comorbidities and complications and whether changes in management

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the recommendations in the sections on principles of care for people with ME/CFS, access to care and support and energy management. For recommendations on multimorbidity, thyroid disease and irritable bowel syndrome in adults, refer to the: • NICE guideline on multimorbidity • NICE guideline on thyroid disease • NICE guideline on irritable bowel syndrome in adults. For recommendations on identifying and treating associated or comorbid anxiety, depression or mood disorders, see the: • NICE guideline on depression in adults • NICE guideline on depression in adults with a chronic physical health problem • NICE guideline on depression in children and young people • NICE guideline on generalised anxiety disorder and panic disorder in adults • NICE guideline on	individuals with FM similar to management of ME/CFS. For fibromyalgia pain consider treatment options suggested in 2012 Canadian Guidelines for the Diagnosis and Management of Fibromyalgia Syndrome. **Depression, Mood and Anxiety Disorders Suggested Management:** • Treat and manage co-morbid psychiatric conditions as per usual care. (**Note** that patients with ME/CFS tend to be more sensitive to medication side effects than primary psychiatric patients.) • Suggest evidence-based psychotherapy, e.g., cognitive behavioural therapy, which would be the best fit for those patients who are depressed, anxious or hopeless as a result of their illness and to assist in optimizing self-management. If depression in the context of ME/CFS should take on specific characteristics of a	other diseases that may be not directly related to the diagnosis of ME/CFS, and for referring to different specialists as appropriate.	**Secondary psychiatric problmes** Mild or moderate secondary psychiatric problems often can be managed by the primary care physician, provided the physician feels comfortable with informal counseling. Giving support and encouragement to the patient can be adequate treatment. When referral to a child psychiatrist or psychologist is needed, it is likely to be more successful if she/he is familiar with ME/CFS. The treatment of other symptoms of ME/CFS such as pain or insomnia can also help to relieve emotional distress. If antidepressant medications are indicated, it should be noted that young patients with ME/CFS often respond to a smaller than expected dosages of these medications and careful follow-up is important. **Joint hypermobility, connective tissue laxity, Ehler’s-Danlos Syndrome** The evaluation and management of these patients often is helped by consultation with a physical	appropriately. Brief psychiatric screening tools can be given and scored in the primary care setting. When the results of such a tool or other assessment suggest possible depression or other psychiatric diagnoses, that condition should be managed. Referrals to mental health professionals may be warranted either alone or in combination with medication. Although treating these comorbid conditions can be helpful, such treatment is for the conditions and does not cure ME/CFS. Some patients with ME/CFS who are clinically depressed may benefit from antidepressants. However, healthcare providers should use caution in prescribing these medications. Some drugs used to treat depression have other effects that might worsen other ME/CFS symptoms and cause side effects, particularly sedation and orthostatic hypotension. If prescribed, medication for depression should be started at a low dose with	may help patients with fibromyalgia, it can make patients with ME/CFS worse. Comorbidities should be treated using the published standard of care […].	practices could help.

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common mental health problems. Discuss cognitive behavioural therapy (CBT) with adults, children and young people with ME/CFS (and their parents or carers, as appropriate). Explain: • its principles, including that it may help them manage their symptoms but it is not curative and • any potential benefits and risks. However, it [CBT] should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness. Only offer CBT to adults, children and young people with ME/CFS if, after discussing it, they would like to use it to support them in managing their symptoms. For children and young people with ME/CFS who would like to use CBT: • involve parents or carers (as appropriate) in the therapy wherever possible	major depressive disorder (MDD) i.e., anhedonia and suicidal thoughts are present, treat as per usual for a major depressive disorder with some considerations such as increased sensitivity to medications. **Pharmacologic treatment** Patients with ME/CFS tend to be more sensitive than primary psychiatric patients to medication side effects. Therefore, it is advised to start at a lower than usual dose and work up slowly. Antidepressant side effects such as specifically sedation and orthostatic hypotension, may exacerbate the symptoms of ME/CFS. The choice of medication should be based on minimizing side effects, maximizing therapeutic effects (e.g., treating more than depression) and antidepressant effectiveness. […] it should be noted that for patients with ME/CFS, CBT may not be sufficient as a stand-alone treatment and other interventions may be required. Therefore, CBT can be		therapist. **Gynecological issues** • Dysmenorrhea: […] menstrual symptoms can improve as ME/CFS symptoms improve. • Endometriosis: The pain is often minimally responsive to oral contraceptive pills (OCPs) and NSAIDs. • Adolescents with dysmenorrhea and/or peri-menstrual symptoms often feel better on an OCP and OI symptoms can also improve. The OCP can be given in monthly cycles, but for peri-menstrual symptoms, patients often do better when the pill is taken continuously for 3 months, e.g., an active pill daily for 84 days then one week of placebo pills to induce a menstrual period every 90 days. Intramuscular Depoprovera (medroxyprogesterone acetate) can also be effective. For menorrhagia, the patient should be tested for the presence of iron	careful monitoring for side effects. As for all patients starting anti-depressants, improvement might not occur for several weeks. Counseling may help to reduce stress and some symptoms of depression and anxiety, like sleep problems and headaches. Some children might benefit from antidepressants and anti-anxiety medications. However, doctors should use caution in prescribing these medications. Some drugs used to treat depression have other effects that might worsen other ME/CFS symptoms and cause side effects. Some children with ME/CFS might benefit from trying techniques like deep breathing and muscle relaxation, massage, and movement therapies (like stretching, yoga, and tai chi). These can reduce stress and anxiety, and promote a sense of well-being.		

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• adapt the therapy to the child or young person's cognitive and emotional stage of development. CBT should only be delivered by a healthcare professional with appropriate training and experience in CBT for ME/CFS, and under the clinical supervision of someone with expertise in CBT for ME/CFS. Explain that CBT for people with ME/CFS: • aims to improve their quality of life, including functioning, and reduce the distress associated with having a chronic illness • does not assume people have 'abnormal' illness beliefs and behaviours as an underlying cause of their ME/CFS, but recognises that thoughts, feelings, behaviours and physiology interact with each other. Explain what CBT involves so people know what to expect. Tell them that it:	helpful in ME/CFS but is rarely if ever curative or sufficient. Other treatment options should be considered based on specific symptoms as well as ongoing monitoring of symptoms and reassessment of treatments.		deficiency anemia and this should be treated if present. The menorrhagia might respond to an OCP or to cyclokapron (tranexamic acid), 1 g tid during the period. For persisting pelvic pain, consultation with a gynecologist is often helpful. **Gastrointestinal issues [comorbidities]** Gastrointestinal conditions which can be present include: gastroesophageal reflux, gastrointestinal motility disorders, celiac disease and non-celiac gluten sensitivity, lactose intolerance, food allergies (e.g., nut, milk, eggs, and wheat), post-infectious or irritable bowel syndrome and constipation. […] if present [these conditions] should be treated appropriately. […] Unless delayed food protein hypersensitivities are adequately addressed, they can obscure any improvements that might accompany otherwise effective treatments. A history of suspected food intolerances should be			

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• takes a non-judgemental, supportive approach to the person's experience of their symptoms and the challenges these present • is a collaborative, structured, time-limited intervention that focuses on the difficulties people are having at that time • involves working closely with their therapist to establish strategies to work towards goals and priorities that they have chosen themselves • takes into account how symptoms are individual to each person, can fluctuate in severity and may change over time. CBT for people with ME/CFS should include the following components: • developing a shared understanding with the person about the main difficulties and challenges they face • exploring the personal meaning of their symptoms and illness, and how this might relate to how they manage their			taken. If the specific symptoms mentioned above are present and intolerance to a specific food is suspected, a trial of strict dietary elimination of the offending food for 2–4 weeks can be undertaken. Provided that the initial food that has been restricted, based on the history is the culprit, and the elimination diet is strict enough, intestinal symptoms usually begin to resolve after 10–14 days (sometimes sooner). If allergic individuals have already been restricting the offending food and then are inadvertently re-exposed, their symptoms will return. This occurrence provides support for the diagnosis. For persisting abdominal symptoms, consultation with a gastroenterologist can be helpful. **Allergies [Comorbidity]** Treatment of MCAS [mast cell activation syndrome] involves antihistamines and medications to stabilize the mast cell membrane such as cromolyn, quercetin and the leukotriene receptor antagonists zafirlukast and montelukast. **Oral and dental issues**			

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symptoms • developing a self-management plan • working together to adapt and refine self-management strategies to improve the person's functioning and quality of life, for example their sleep, activity and rest • reviewing their plan regularly to see if their self-management strategies need to be adapted, for example if their symptoms or functioning change • developing a therapy blueprint collaboratively with their therapist at the end of therapy. Healthcare professionals delivering CBT to people with severe or very severe ME/CFS should adjust the process and pace of CBT to meet the person's needs. This might include shorter, less frequent sessions and longer term goal.			**[comorbidity]** Dry mouth can exist on its own, result from the effects of medications or from co-morbid medical conditions. It can lead to rampant dental caries, exacerbation of periodontal disease, or oral candidiasis. Standard treatment includes increasing oral moistness with regular fluid intake, fluoride supplementation for home use, and professional dental prophylaxis.			
Orientation vers d'autres professionnels						
When ME/CFS is suspected in a child or young person based on the criteria in	Patients who need more guidance on activity management and diet can	Although with good education of primary care physicians, diagnosis and	If there is diagnostic uncertainty and referral is necessary, it should be	Because ME/CFS is a complicated illness, its management may require	A specialty consultation may be helpful in developing a treatment plan and in	Physical therapists may help with energy conservation approaches, pain

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recommendation 1.2.2 and the assessment in recommendation 1.2.3: • refer them to a paediatrician for further assessment and investigation for ME/CFS and other conditions Primary healthcare professionals should consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms at 3 months and whether further investigations are needed. Refer adults directly to an ME/CFS specialist team to confirm their diagnosis and develop a care and support plan. Refer children and young people who have been diagnosed with ME/CFS after assessment by a paediatrician […] directly to a paediatric ME/CFS	be referred to other health care providers such as physiotherapists and dietitians that are knowledgeable about ME/CFS and appropriate management, if available. Identify other health care providers who can offer specific treatments, e.g., kinesiologist, dietitian, sleep specialist, mental health professional – familiar with treating those with ME/CFS	monitoring of people with ME/CFS in primary care are possible and desirable, and referral for specialist services may be indicated in some circumstances : • for may benefit from a multi-disciplinary team with specific confirmation of diagnosis, when there is doubt; • for cases who expertise, including drug treatments or care of those with severe or complicated disease; and • for a range of service offerings, such as occupational therapy, supportive counselling, education on self-management and energy/activity management with "pacing", social services, and advice on access to community support, e.g., for educational, occupational, and social matters, such as benefits (see below on secondary services).	preferably to a specialist familiar with ME/CFS. Young patients can do well when treated in a primary care setting, but given the complexity of this illness, appropriate referral to other health practitioners (preferably those familiar with ME/CFS) is often needed. For young people with complex pain syndromes, referral to a pain clinic (preferably one that is familiar with ME/CFS) might be helpful. When referral to a child psychiatrist or psychologist is needed, it is likely to be more successful if she/he is familiar with ME/CFS. **Orthostatic Intolerance** Patients with [neurally mediated hypotension, …] Tilt table testing requires referral to a specialist center and is costly. **Neuroanatomic Abnormalities** In those with prominent symptoms including headache, evaluation needs to exclude intracranial hypertension and	input from a variety of medical professionals, such as rheumatologists, neurologists, or infectious disease specialists. People [and children] might continue to feel unrefreshed even after the medications help them to get a full night of sleep. If so, they should consider seeing a sleep specialist. For patients with [frequent dizziness and lightheadedness, changes in vision, weakness, feeling like your heart is beating too fast or too hard, fluttering, or skipping a beat], their doctor will check their heart rate and blood pressure, and may recommend they see a specialist, like a cardiologist or neurologist. Rehabilitation specialists or exercise physiologists who know ME/CFS may help patients with adjusting to life with ME/CFS. When healthcare providers are concerned about a patient's psychological condition, they may recommend seeing a mental health professional.	managing those aspects of the disease with which the referring physician is unfamiliar. Referrals to specialists or allied health professionals, such as occupational therapists and physical therapists, may be helpful in securing the needed documentation and support [patients often need help acquiring handicap placards, work or school accommodations, housing, adequate nutrition, disability benefits, and other necessary resources].	management, joint protection to prevent joint contracture, body positioning, and gentle range of motion, stretching, and strength exercises to help address the effects of being inactive and bedbound. The approaches used must be done in such a way that they do not trigger PEM or sensory sensitivities (e.g., to touch). Occupational therapists can utilize modification and adaptation strategies for ADLs to conserve energy and to provide patient and caregiver education on techniques for pacing and nonpharmacological approaches to manage symptoms. Speech language therapists can help evaluate and treat problems with eating/swallowing as well as problems with communication, whether they stem from anatomical or functional abnormalities in the oral/gastrointestinal tract or in the brain. Mental health providers may be able to help patients better cope with the debility of the disease.

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specialist team* to confirm their diagnosis and develop a care and support plan. * Specialist teams consist of a range of healthcare professionals with training and experience in assessing, diagnosing, treating and managing ME/CFS. They commonly have medically trained clinicians from a variety of specialisms (including rheumatology, rehabilitation medicine, endocrinology, infectious diseases, neurology, immunology, general practice and paediatrics) as well as access to other healthcare professionals specialising in ME/CFS. These may include physiotherapists, exercise physiologists, occupational therapists, dietitians, and clinical or counselling psychologists.		Note that some cases may be best served by referral to alternative services, especially where ME/CFS or Complex Chronic Diseases (CCD) Services are not well developed, such as to pain management, rehabilitation, neurology, psychiatry, and rheumatology services.	intracranial hypotension. Referral to a neurologist can be helpful. [Basic supportive therapy] can be carried out by the primary care physician if she/he is comfortable doing so. If not, or if the patient's situation is complex or severe, a social worker, psychologist, or child psychiatrist, preferably one who is knowledgeable about ME/CFS, can be consulted.			

Sources : [CDC, 2022; Bateman *et al.*, 2021; Montoya *et al.*, 2021; Nacul *et al.*, 2021; NICE, 2021; US ME/CFS CC, 2021a; US ME/CFS CC, 2021b; US ME/CFS CC, 2020; Rowe *et al.*, 2017; TOP ME/CFS Working Group, 2016]

[1] Site Web consulté le 23 août 2022.

Tableau E-4 Recommandations et information clinique concernant les modalités de bonne pratique clinique pour soutenir les personnes atteintes dans la gestion de leurs symptômes et l'impact de l'EM/SFC sur leur vie (Question 3c)

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Généralité						
Give families and carers information on how to access training and resources about caring for the person with ME/CFS.	The patient should be educated about the illness […] and be an active participant in determining a care plan. For patients who wish to try CAM, they should be informed about the lack of strong evidence of benefit. If they choose explore CAM treatments regardless, the physician should assist patients to avoid harm.	Support for self-management, education, and work activities may require further contacts with the patients and their carers/families, as well as with educators and employers. […] Organization of care for people with ME/CFS and in particular the severely affected may be complex and requires communication by primary care professionals with others from various disciplines. Education of patients in advance of, during, and following consultation may be useful, and reliable educational materials should be recommended, e.g., booklets, videos, or other online information materials. […] A main goal of educational activities is to empower the patient for self-management and to be in control of their disease and healing process.	Educating the patient, the parents, the wider family and school personnel about the illness is important, e.g. providing handouts […]. A patient's needs early in the illness might differ from her/his needs in later years, as health improvement is being achieved. Helpful strategies to support the family can include: • Participation of both parents in the evaluation and management of the patient. • Educating the immediate family about the illness and ensuring that siblings receive age-appropriate information. • Enabling extended family members to also be informed about ME/CFS, with the goal of fostering their support of the nuclear family. • Encouraging communication between family members about management of the illness. • Having the treating physician serve as an advocate for the patient with	Other important aspects of care are: • Educating patients and their caregivers about ME/CFS. This can promote support and understanding. These patients [severely ill] often cannot make office visits, and require in-home assistance and management plans specifically adjusted to their needs by a coordinated care team of providers.	Aucune information présentée.	Educate the patient, family, and caregiver about helpful behavioral measures.

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			her/his school system.			
Gestion de l’énergie						
Recognise that symptoms of severe or very severe ME/CFS may mean that people: • need a low-stimulus environment, for example a dark quiet room with interaction at a level of their choice (this may be little or no social interaction) • are housebound or bedbound and may need support with all activities of daily living, including aids and adaptations to assist mobility and independence in activities of daily living (for example, a wheelchair) When ME/CFS is suspected, give people personalised advice about managing their symptoms. Also advise them: • not to use more energy than they perceive they have − they should manage their daily activity and not 'push through' their symptoms • to rest and convalesce as needed (this might mean making changes to their daily routine, including work, school and other	Pacing is a strategy of staying within the range of activity required to avoid exacerbating fatigue and post-exertional malaise. Individuals need to learn how much they can do at a given time without exacerbating their symptoms. One must remember that the effects of activity are often cumulative over days to weeks and onset of post exertional malaise can be delayed for several days. This requires self-awareness and self-evaluation. Activities of daily living use energy and therefore are considered exercise. These activities may be enough exercise for some patients or excessive exercise for others. The ideal range is very individual and is often referred to as the “energy envelope.” Staying within one’s energy envelope is associated with a better outcome than frequently pushing beyond. To stay within the energy envelope, some patients need to decrease their activity while others need to increase activity. An individual's energy envelope is discerned by noting the	**Support measures** • “Pacing” and activity management to work with the “energy envelope” These should cover concepts and practical recommendations for “pacing” (pacing is a self-management tool to implement a strategy designed to help people live within their energy envelope, minimise PEM, and improve quality of life) with adequate rest periods or breaks in activity, sleep hygiene, and pain management strategies. Both mental and physical activities should be taken in such a way to avoid over-exertion, which may trigger post-exertional aggravation of symptoms or “crashes”, and as a key strategy to optimise chances of recovery. Wearables can assist objective measurement of activity and sleep patterns, and in some cases heart rate variability. They may be combined with a symptom diary, which will help the interpretation of symptoms and management.	Adequate rest and activity management are the mainstays of treatment. Premature resumption of activity or attempts to return to school can result in a relapse or increased severity of symptoms. Guidance needs to be given on an activity plan that helps the young person to function. Adolescent patients are encouraged to propose a personal, optimal balance of social, physical, and academic activities (and include something pleasurable outside of the home). The unpredictable level of function from day-to-day can interfere with planning ahead for school attendance, social outings, or family obligations. The unequivocal advice for careful avoidance of overexertion can help to both avoid deterioration and facilitate improvement. Activities can be planned by the young patient over a weekly period. She/he	Other important aspects of care are: • Encouraging patients to find enjoyable, low-effort activities to engage in with family or loved ones. • Encouraging patients to consider using energy-saving devices, which many patients have found to be helpful. For example, using a wheelchair to cover longer distances in grocery stores or enjoy family events or trips. **Severely ill ME/CFS** The treatment plan for these patients usually includes: • Creating a very quiet, darkened environment, as this is often helpful to severely affected patients. • Modifying or limiting physical and mental activity. An important strategy for patients to learn is how to manage their activities to avoid triggering post-exertional malaise (PEM). This is often referred to as activity management (also sometimes called pacing)	Referrals to physical therapists and occupational therapists familiar with ME/CFS, education about pacing, and use of energy-saving/monitoring devices (eg, shower chairs, motorized scooters, pedometers, heart rate monitors) are often beneficial, as are diaries to help patients identify when they are exceeding their limits. Even with such aids, pacing is challenging and some setbacks are inevitable, especially because tolerance for activity can vary from day to day. *Nonpharmacologic approaches to conserve energy and to minimize postexertional malaise* • Pacing of physical and cognitive activity • Assistive devices, such as motorized scooters, handicap parking stickers, shower chairs to conserve energy • Home health aides for those who are more severely ill • Ear plugs, eye masks, perfume-free	For example, space out caregiving tasks to avoid overstimulation of the patient […]. *Recommendations for Minimizing Post-Exertional Malaise and Sensory Sensitivities* • Ensure the patient and caregiver understand post-exertional malaise. Educate them about energy conservation strategies, such as pacing, to minimize the physical, mental, orthostatic, and emotional stressors that could trigger post-exertional malaise with its consequent worsening of symptoms and functioning. • Minimize those stimuli to which the patient is sensitive, such as light, noise, touch, movement, chemicals, and odors, Exposure to these could increase pain and other symptoms. The most severe patients may not be able to tolerate any touch, light or noise. • Accommodate the

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activities) • to maintain a healthy balanced diet, with adequate fluid intake. Discuss with people with ME/CFS the principles of energy management, the potential benefits and risks and what they should expect. Explain that it: • is not curative • is a self-management strategy led by the person themselves with support from a healthcare professional in an ME/CFS specialist team • includes all types of activity (cognitive, physical, emotional and social) and takes into account overall level of activity • helps people learn to use the amount of energy they have while reducing their risk of post-exertional malaise or worsening their symptoms by exceeding their limits • recognises that each person has a different and fluctuating energy limit and they are experts in judging their own limits • can include help from a healthcare professional to recognise when they are	response to changes in activity level. To pace effectively, an individual may divide tasks into smaller parts with rest periods between each task. For patients with orthostatic symptoms, horizontal rests are especially helpful. Patients should remain as active as possible while avoiding fatigue-worsening over-exertion. Keeping an activity log helps to determine the best combination of activity and rest.	"Pacing" refers to breaking up physical or mental activities with periods of rest, before a significant level of tiredness or exacerbation of symptoms is achieved or is expected following exertion, e.g., PEM, which may manifest many hours after the effort. A general rule of thumb is the recommendation to keep the activity at 2/3 of the duration and of the intensity that is expected (based on previous experience) to cause post-exertional symptoms, though flexibility should be exercised in order to reflect the particular needs and circumstances of individual patients.	should be encouraged to balance intellectual, social and physical activities, and to make a commitment to undertake segments of each component regularly. This allows the patient and family members to regain some control over their lives. It must be remembered that activity levels fluctuate from day-to-day and patients sometimes experience set-backs in their available energy reserves. Family members need to recognize that set-backs can occur and any activity plan needs to be flexible. **Very severely ill patients** ○ Protect the patient from undue physical, cognitive, and emotional stress. ○ A very quiet environment that might include a darkened room.	and requires that patients learn to "listen to their bodies" to be aware of their individual exertional limits, aiming to remain as active as possible without exceeding them. Clinical experts have observed that this process requires "trial and error." Patients need to determine their individual limits for mental and physical activity, and plan activity and rest to stay within these limits. Some patients and healthcare providers refer to staying within these limits as staying within the "energy envelope." Limitations may be different for each patient. Keeping individual activity and symptom diaries may be helpful to patients in identifying their personal limitations, especially early on in clinical care. Healthcare providers need to keep in mind that when patients with ME/CFS exceed their individual capacities, PEM and serious deterioration of function may result. In general, patients should not push themselves beyond their capacities as this may exacerbate the symptoms and trigger PEM. When patients experience	environments to decrease sensory stimulation; may need to maintain low sensory environment for the most severely ill • School or work accommodations, such as flexible hours, shortened days Patients may also be helped by ear plugs, eye masks, and sunglasses to minimize light and noise intrusion […].	patient's restricted energy. In the most severe patient, specialized beds, wheelchairs, bedpans, feeding tubes, and catheters may be needed to conserve their extremely limited energy. **Grooming/Washing** • Provide shower chair and grab bars. A transfer board can be used to transfer patients from the chair to the tub. Eliminate bathroom mats and rugs that pose a fall risk. • Use a tub with a pillow/neck support. Elevate feet and begin with lukewarm water temperatures. • Perform sponge bath bedside or in bed to conserve energy. • Wash body parts at separate times (e.g., face one day, hair another). • Use soaps with low fragrance and that are hypoallergenic. • Use dry shampoo. Consider short hair. • Examine skin integrity

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approaching their limit (children and young people in particular may find it harder to judge their limits and can overreach them) • uses a flexible, tailored approach so that activity is never automatically increased but is maintained or adjusted (upwards after a period of stability or downwards when symptoms are worse). Help people with ME/CFS develop a plan for energy management as part of their care and support plan. Support them to establish realistic expectations and develop goals that are meaningful to them. Discuss and record the following in the plan along with anything else that is important to the person: • cognitive activity • mobility and other physical activity • ability to undertake activities of daily living • psychological, emotional and social demands, including family and sexual relationships • rest and relaxation (both quality and duration)				improvement, activities can be cautiously increased with monitoring for any negative effects. Patients need to be advised about "push and crash" cycles: patients sometimes respond to having a "good day" by subsequently doing too much to make up for "lost time," and then relapsing. For some patients, even daily chores and activities such as cleaning, preparing a meal, or taking a shower can be difficult and may need to be broken down into shorter, less strenuous pieces. Helping patients manage PEM should be one of the first actions healthcare providers take. One of the best options to minimize or prevent PEM is to help patients learn to keep all energy expenditures, physical, cognitive and emotional, within limits that can be tolerated by planning when and how to use their limited energy. This approach is known as pacing. Minimizing PEM can lead to stabilization or improvements in pain, sleep, fatigue, cognition, and other symptoms. It can also		and look for any lesions while bathing. • Rest immediately after washing and before dressing if needed. Wrap in blankets, dry towel, or robe and return to bed. • Consider bathing every few days instead of daily. • Consider remodeling bathrooms to increase accessibility **Grooming/Tooth Brushing** • Conserve energy by performing activity in bed if needed. • Use mild flavor paste or just water. • Use a soft-bristle brush. If an electric toothbrush is used, choose one with control for vibration and • intensity. **Grooming/Dressing** • Perform activity in bed, if needed to conserve energy. • Use fragrance/chemical free laundry detergents. • Wear loose fitting clothing made of soft, lightweight, breathable materials. Wear solid colors (no patterns) as

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• sleep quality and duration • effect of environmental factors, including sensory stimulation. Work with the person to establish an individual activity pattern within their current energy limits that minimises their symptoms. For example: • agree a sustainable level of activity as the first step, which may mean reducing activity • plan periods of rest and activity, and incorporate the need for pre-emptive rest • alternate and vary between different types of activity and break activities into small chunks. Make self-monitoring of activity as easy as possible by taking advantage of any tools the person already uses, such as an activity tracker, phone heart-rate monitor or diary. When agreeing energy management plans with people with severe or very severe ME/CFS (and their family or carers, as appropriate), take into account the need to make				prevent worsening of these symptoms. Activity pacing may improve quality of life considerably and even increase function. • Ask patients to keep a daily diary for 1-2 weeks of symptoms and the activities they engage in, including type, intensity, frequency, and duration. Such a diary can help recognize energy limits and the links between activities and episodes of PEM (e.g., walking a short distance one day and then experiencing PEM hours or days later). • Review the diary with the patients and ask whether they see any patterns. For example, a patient may find reading for 30 minutes is fine but reading for an hour continuously leads to PEM. Thus, this patient's energy limit for reading is 30 minutes. • Brainstorm techniques with patients to adjust the activity to avoid or minimize PEM. For example, patients could set a timer for 30 minutes to stop reading,		these may be less stimulating. • Consider adaptive clothing—e.g., slip on, no closures or buttons as these are easier to don (put on)/doff (take off). • Don garment on the affected side (e.g., weakest, sorest) first, doff garment on the affected side last. • Dress in stages. May not be able to complete all at once. • Assess the cause of any sensitivity to clothes—e.g., small fiber neuropathy, contact dermatitis, etc. • Change clothes for comfort/cleanliness, not necessarily daily. **Toileting** • Use a raised toilet seat and install handrails near the toilet. If needed, a bedside commode can conserve steps for meaningful activity. • Use adult diapers, bedpan or catheter when unable to transfer or maintain upright posture. If a catheter is needed, try condom

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any changes in activity smaller and any increases (if possible) much slower. **Rest and sleep** Advise people with ME/CFS: • about the role of rest in ME/CFS • that rest periods are part of all management strategies for ME/CFS • how to introduce rest periods into their daily routine, including how often and for how long, as appropriate for each person • that relaxation techniques at the beginning of each rest period could be helpful. Flare-up • A worsening of symptoms, more than would be accounted for by normal day-to-day variation, that affects the person's ability to perform their usual activities. Flare-ups may occur spontaneously or be triggered by another illness, overexertion or other triggers. Flare-ups usually occur as part of post-exertional malaise but it is possible for other symptoms, such as pain, to flare-up without post-				switch to audiobooks occasionally, read during the time they have most energy, or schedule a time to rest after reading for 1 hour. Inactivity can result in muscle deconditioning. Providers should individualize a threshold level of activity for each patient. The challenge is to not overdo it and learn to adjust to less activity than before (e.g., going from easily walking a few miles to struggling to climb a flight of stairs). Some people use heart rate monitors to avoid going over the anaerobic threshold and activity monitors to avoid overexertion.		catheters and/or intermittent catheterization first before using long-term in-dwelling catheters. • Ask about and plan toileting on a scheduled basis. This can help decrease urgent visits and bladder/bowel accidents. **Environment/Room Setup** To protect the patient from undue physical, cognitive, or emotional exertion: • Provide a low sensory environment: o Hang black-out shades and/or plain curtains (no patterns); o Control room temperature and humidity; o Limit sounds from inside and outside the home to the extent possible; o Do not use products, such as cleaning supplies or perfumes, that have a strong smell. • Provide assistive technology such as call buttons; remotes for light, fan and tv control; smart light bulbs (dim/color changing)

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exertional malaise. The worsening of symptoms is transient and flare-ups typically resolve after a few days, either spontaneously or in response to temporary changes in energy management or a change in treatment. A relapse lasts longer than a flare-up. Relapse • A sustained and marked exacerbation of symptoms lasting longer than a flare-up and needing a substantial and sustained adjustment to the person's energy management. It may not be clear in the early stages of a symptom exacerbation whether it is a flare-up or a relapse. Relapses can lead to a long-term reduction in the person's energy limits. Advise people with ME/CFS how to manage flare-ups and relapses. Agree with the person how to adjust their physical activity during a flare-up or relapse. This should include: • providing access to review						with remotes; and wireless remote-control electrical outlet switches for fan/lights. • Utilize a bedside table with adjustable height, tilt, and swivel top. • For ease of reach, use “hook and loop” or similar technology to attach items to the wall and • headboard and to position baskets with supplies/snacks/tools within reach. • Use magnetic boards, bulletin boards or boards with symbols that people can point to as a communication aid. • Assess balance issues, fall risks and hazards (stairs, rugs, home entry, etc.). Remove obstacles to keep pathways open and recommend other mitigation strategies as needed. • Provide blankets, fans, and other warming and cooling devices if patients experience poor temperature regulation. • If the patient needs to prepare their own meals, organize the

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and support from a physiotherapist in an ME/CFS specialist team • stabilising their symptoms by reducing physical activity to within their current energy limits • only once symptoms stabilise and the person feels able to resume physical activity, establishing a new physical activity baseline. Advise people with ME/CFS after a flare-up that the time it takes to return to the level of physical activity they had before varies from person to person. Explain that flare-ups and relapses can happen in ME/CFS even if the person's symptoms are well managed. Tell people with ME/CFS that: • they are likely to be having a flare-up if they experience a worsening of their symptoms beyond their normal day-to-day variation, which lasts a few days • a relapse is when there is a sustained and marked exacerbation of ME/CFS						kitchen for safety and energy conservation, e.g., provide a stool, position most commonly used dishes and utensils for easy access, etc. **Mobility and Transfers** • Provide transfer and mobility devices (e.g., Hoyer lift, slide boards, other assistive devices, wheelchairs, canes, walkers) as required. • Use planned, controlled, and slow position changes, especially for people affected by orthostatic intolerance or hypersensitivity to touch. • Consider installing a stairlift and/or moving the patient to a more accessible room. • Use a wheelchair for transitions between rooms if required and possible. • Teach caregivers how to move patients safely. • Ask private (e.g., taxi, ride-share) and public (e.g., paratransit, ambulance, fire department) transport services about transport options.

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symptoms lasting longer than a flare-up and needing substantial and sustained adjustment of energy management. Include guidance on managing flare-ups and relapses in the person's care and support plan. Discuss and agree self-management strategies with the person with ME/CFS to help them respond promptly if they have a flare-up or relapse, and record these in their care and support plan. This should include: • For a flare-**up:** o identifying possible triggers, such as acute illness or overexertion (in some cases, there may be no clear trigger) o temporarily reducing their activity levels o monitoring symptoms, recognising that although flare-ups are transient, some will develop into a relapse o not returning to usual activity levels until the flare-up has resolved. • For a relapse: o reducing, or even stopping, some activities						**Support and Socialization** • Ensure the patient has adequate caregiver support. Help facilitate access to needed community resources. • Consider the patient's desire and need for socialization when recommending energy management approaches.

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o increasing the frequency or duration of rest periods o reassessing energy limits to stabilise symptoms. If a flare-up or relapse cannot be managed using the person's self-management strategies outlined in their care and support plan or they are worried about new symptoms or a change in symptoms, advise the person to contact their named contact in primary care or the ME/CFS specialist team. When a person with ME/CFS has a relapse, review their care and support plan with them (if needed), and discuss and agree a course of action, taking into account: • possible causes of the relapse, if knwn • the nature of the symptoms • the severity and duration of the relapse (bearing in mind this can be years). Once a flare-up or relapse has resolved or stabilised,						

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discuss with the person: • whether their care and support plan needs to be reviewed and adjusted to reflect their current symptoms and energy limit if this is different from before the flare-up or relapse • their experience of the flare-up or relapse to determine whether strategies can be put in place to manage potential triggers in the future.						
Maintien de la capacité physique et prévention des complications dues à l'immobilité						
Include strategies to maintain and prevent deterioration of physical functioning and mobility in the care and support plans of people with ME/CFS. These strategies may need to be carried out in small amounts and spread out throughout the day. Think about including the following: • joint mobility • muscle flexibility • balance • postural and positional support • muscle function • bone health • cardiovascular health. Give people with ME/CFS and their family or carers (as	Aucune information présentée	Aucune information présentée	Very severely ill patients o Prevention of venous thrombosis by passive physiotherapy. […] movement is important to help reduce stiffness, maintain range of motion and prevent contractures. In very severely affected patients who are confined to bed, movement is limited to tolerated activities of daily living. For those who can tolerate touch, a knowledgeable physical therapist can provide gentle, passive range-of-motion activity and gentle, passive stretching for brief periods of time (1 min at a time followed by a rest).	A realistic goal with severely ill patients is focusing on reducing stiffness and maintaining joint range of motion by passive range-of-motion exercises and gentle stretching (if touch can be tolerated). Hand stretches and picking up and grasping small objects may be all that can be managed by some patients. Help with regular repositioning may be needed to prevent pressure sores in patients unable to turn over in bed. Movement can help maintain range of motion, prevent contractures, and decrease stiffness. Osteoporosis risk can also be a long-term concern. For these and other clinical	Aucune information présentée	For example, […] adjust/turn the patient occasionally to decrease pressure ulcers […]. **Positioning and Range Motion** To protect the patient from pressure sores, joint contractures, skin and joint irritation, and poor alignment: • Utilize wedges, bolsters, pillows for support and positioning or consider a specialized/adjustable bed to provide needed support. • Switch the head/foot of bed (if needed and possible) to decrease repetitive movements

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appropriate) information, advice and support on how to recognise and prevent possible complications of long-term immobility. This may include: • bed mobility • moving from lying to sitting to standing • transferring from bed to chair • using mobility aids • walking • joint mobility • muscle stretching • muscle strength • balance • going up and down stairs.				reasons, it is important to note that complete bed rest, while sometimes necessary, should be reserved for patients with the most severe symptoms		and reaches. • Utilize a reclining chair with footrest. Maintain proper neck and lumbar support for proper alignment (e.g., zero gravity chair, lounge chair). • Educate caregivers about the need for regular, scheduled re-positioning as tolerated. • Utilize passive or active range of motion to help avoid contractures and maintain some flexibility. This must be done in a way that it does not trigger PEM.
Alimentation						
Recognise that symptoms of severe or very severe ME/CFS may mean that people: • are unable to eat and digest food easily and may need support with hydration and nutrition Emphasise to people with ME/CFS the importance of adequate fluid intake and a well-balanced diet according to the NHS eat well guide. Work with the person and their family or carers (as appropriate) to find ways of	[…] there is no evidence to date that supports a special diet for ME/CFS. In the absence of evidence, a common sense approach of ensuring adequate nutrition from a balanced diet is recommended while avoiding high fat foods, sugars and caffeine. Eating small frequent meals/snacks may be helpful for some individuals. An appropriate daily multivitamin and/or additional specific vitamin or mineral supplements (e.g., vitamin D and calcium if restricting dairy products)	**Diet** • Healthy and balanced diet • Anti-inflammatory diet • Reduce ingestion of simple carbohydrates • Adequate fluid intake • Adequate ingestion of protein • Increase unsaturated fatty acids and omega-3 fatty acids • May try exclusion diets with support from dietician, especially for	**Very severely ill patients** ○ Maintain fluid and nutritional intake by early recourse to tube feeding.	Balanced diet. A balanced diet is important for everyone’s good health and would benefit a person with or without any chronic illness.	[…] avoidance of certain foods to decrease gastrointestinal disturbances.	Oral feeding and hydration are preferred and should be tried first. However, tube feeding may be required to ensure nutrition and to conserve the patient’s energy. Intravenous saline may be needed for hydration. If necessary, intravenous feeding may be required as a last resort. **Feeding and drinking** • Assess whether a patient has food insecurity due to financial, transportation, preparation, or other

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minimising complications caused by gastrointestinal symptoms (such as nausea), changes to appetite, swallowing difficulties, sore throat or difficulties with buying, preparing and eating food. Encourage people with ME/CFS who have nausea to keep up adequate fluid intake and advise them to try to eat regularly, taking small amounts often. Explain that not eating or drinking may increase their nausea. Give advice to support people with severe or very severe ME/CFS, which could include: • eating little and often • having nourishing drinks and snacks, including food fortification • finding easier ways of eating to conserve energy, such as food with softer textures • using modified eating aids, particularly if someone has difficulty chewing or swallowing • oral nutrition support and enteral feeding. Refer people with ME/CFS	may be required to ensure that recommended nutrient intake is obtained. Getting nutrition from food sources is preferred to taking supplements. Referral to a dietitian, preferably knowledgeable in ME/CFS, may be necessary if dietary guidance is needed. For reasons that are not understood, a large percentage of patients with ME/CFS become intolerant of alcohol. As a result alcohol addiction is rare in ME/CFS. Because of the sleep disturbing and sedating effects of alcohol, its use should be avoided or minimized.	food with reported intolerances by the patient. It may be worth trying to avoid gluten, lactose, or fructose during a few weeks to test if there is any improvement in symptoms.				problems and address as needed. If preparation is the issue, home delivery of meals and/or a supply of frozen or canned foods requiring minimal preparation can be critical, particularly when patients experience bad days. Prepare large quantities of food when able and store for future use. • Provide foods that are nutritionally dense and do not need any/much preparation, such as shakes, bars, soft or liquid foods. Referral to a nutritionist may be needed. • Provide a variety of snacks that can be easily accessed by the patient. • Eat or drink in bed, if needed, to conserve energy. Less severely ill patients may prefer to have a meal(s) with their family for social interaction. • Assist with feeding and managing the meal setup if needed. • Use lightweight bowls, plates, and utensils (e.g., plasticware,

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for a dietetic assessment by a dietitian with a special interest in ME/CFS if they are: • losing weight and at risk of malnutrition • gaining weight • following a restrictive diet. Refer children and young people with ME/CFS who are losing weight or have faltering growth or dietary restrictions to a paediatric dietitian with a special interest in ME/CFS. Monitor people with severe or very severe ME/CFS who are at risk of malnutrition or unintentional weight loss because of: • restrictive diets • poor appetite, for example linked with altered taste, smell and texture • food intolerances • nausea • difficulty swallowing and chewing.						bamboo or other lightweight materials). • Use a small, lightweight cup. Use a short straw for less effort to suck. Use a non-spill water bottle or a hydration pack or bag (cut the length of the straw). • May require tube feeding for nutrition and hydration or intravenous saline for hydration if oral nutrition and hydration is not adequate.
Altérations du sommeil						
Rest and sleep Advise people with ME/CFS: • how to introduce rest periods into their daily routine, including how	Aucune information présentée	Wearables can assist objective measurement of activity and sleep patterns, and in some cases heart rate variability. They may be combined with a symptom	Aucune information présentée	Aucune information présentée	[…] sleep hygiene measures (tailored as needed for patients who are bedbound or have orthostatic intolerance) […].	Aucune information présentée

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often and for how long, as appropriate for each person.		diary, which will help the interpretation of symptoms and management.				
Difficultés cognitives et fatigue mentale						
Aucune information présentée	Managing cognitive difficulties: • Use a "memory book or device " to document important activities, tasks, events, appointments etc. (and keep the book in an open location where it can't be misplaced). • Develop habits such as leaving keys or glasses or always parking in the same spot. • Try to avoid situations where multisensory bombardment and fast-paced activity is likely to occur. • Limit time and intensity of cognitive effort (similar to pacing physical activity). • Limit or discontinue (i.e., take a break from) cognitive effort with exacerbation of cognitive symptoms.	Aucune information présentée	Many patients self-medicate with caffeine in coffee and popular energy drinks. While this can be useful, patients should be cautioned against consuming excessive amounts of caffeine as this can cause tachycardia and agitation.	Aucune information présentée	[…] memory aids (notebooks, calendars) may help with cognitive issues.	Aucune information présentée
Acceptation et adaptation aux changements de vie imposés par la maladie						
Aucune information présentée	Aucune information présentée	**Support measures** • Supporting therapies that could help with coping and adapting to changes in life	Likewise, the patient and the family might need to adjust their expectations to very modest levels.	Other important aspects of care are: • Encouraging patients to find enjoyable, low-effort activities to	Aucune information présentée	For example, […] lower expectations such as the need for a daily bath. Be alert to caregiver stress.

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		due to symptoms, within the "energy envelope", and counselling or psychotherapy	The young person with ME/CFS needs to learn to adapt to the reality of the illness, and integrate it into a meaningful life despite sometimes severe physical limitations. Above all, the young patient needs to develop a sense of achievement in her/his life, however, small. Young patients with ME/CFS benefit from practical suggestions for coping with chronic illness. We recommend: • A private space at home, so that the young patient's rest will be undisturbed and she/he is able to work without being distracted. • Developing a daily routine, especially for patients who are housebound. • Attempting to achieve a normal day/night cycle, to help the patient fit in with the family's daily schedule and make school possible. • Encouraging participation in education, however minimal, but without undue pressure. • Providing time for meeting with friends and for family treats. • Incorporating rewards for achievements.	engage in with family or loved ones. • Helping patients to develop effective coping skills to help ease worry, anger, hopelessness, or other feelings. This may include a referral to counseling or support groups if available and possible. Professional counseling with a trained supportive counselor will help most patients with any kind of chronic illness to build effective coping skills to lessen the grief, anger, and guilt that may accompany chronic illness and help empower patients to seek comprehensive care. Chronic illnesses like ME/CFS affect entire families, not just patients. Consulting a behavioral health professional may be helpful to address changes in family dynamics that often occur when living with ME/CFS. Counseling may also help family members to provide better care for their loved ones suffering from ME/CFS. To reduce stress and anxiety without medication and promote a sense of well-		Community resources, local support groups, and respite services for those caring for people with ME/CFS or other chronic diseases may be helpful.

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			• Joining a local patient support group (if available, and if it has competent leadership). • The use (when appropriate) of stress reduction techniques such as music, visualization, self-hypnosis and/or mindfulness-based cognitive therapy Our experience suggests that the following elements of basic supportive therapy can be helpful: • Exploring what the patient and her/his parents already know about the illness. • Teaching the patient and her/his family about ME/CFS and correcting any misinformed notions about cause, course of the illness and forms of management. • Making it clear that ME/CFS is a medical/biological illness, but that often there can be understandable, secondary, emotional reactions. • Clarifying and discussing the patient's and family's particular anxieties and mood changes. • Discussing strategies such	being, less severely affected patients with ME/CFS might benefit from trying techniques like deep breathing and muscle relaxation, massage, and movement therapies (such as stretching, yoga, and tai chi). While methods that involve physical activity might be beneficial for some patients with ME/CFS, initiating or resuming these or other movement therapies requires careful consideration to avoid post-exertional malaise. **Severely ill ME/CFS** The treatment plan for these patients usually includes: • Providing or referring to counseling to help adjust expectations and deal with feelings of anger, frustration, and despair that can accompany any debilitating illness, including ME/CFS. Caregivers, who provide ongoing management and the majority of care for patients, are subject to substantial stress and may need additional support.		

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			as pacing of activities that enable the patient to live within the limitations of the illness. • Ensuring the medical management of symptoms. • Making clear that you (as the treating physician and/or therapist) will be available as new questions arise and setting up follow-up appointments.			
Services sociaux						
Recognise that symptoms of severe or very severe ME/CFS may mean that people: • are housebound or bedbound and may need support with all activities of daily living, including aids and adaptations to assist mobility and independence in activities of daily living (for example, a wheelchair). If a person with ME/CFS needs support at home, carry out a social care needs assessment. As a minimum, record and provide information and support on: • activities of daily living • mobility, including transferring from bed to chair, access to and use of toilet and washing	Identify community resources available to assist with self-management, e.g., in-home assistance with ADLs, cooking, cleaning, support for family members, financial disability support as needed.	**Support measures** • Occupational therapy provided by professionals with experience in ME/CFS patients • Social workers who could help with social welfare This includes facilitating the provision of emotional, social care, and occupational health support, and medical advice to teachers, employers, and caregivers, in response to the specific needs of patients. This could involve access to resources in the community, such as to physiotherapy, occupational therapy, dietician, or home visits by the primary care	In addition to medical supervision they [young serverely ill] might require support from home health services and aides perhaps overseen by a nurse manager. **Very severely ill patients** ○ General nursing care to consist of gentle help with turning, skin care and toileting, diapers might be necessary.	The subset of severely ill ME/CFS patients who are bedbound requires special attention, including in-home visits and phone/online check-ups, and a modified approach to activity management. Some accommodations for those severely ill from ME/CFS include recumbent wheelchairs, portable cook surfaces, shower chairs and bedpans. For example, they can consider sitting instead of standing when cooking or showering, using a bed-side commode in lieu of walking to the restroom, and taking frequent breaks during activity. **Severely ill ME/CFS** The treatment plan for these patients usually includes: • Referring for physical	Patients often need help acquiring handicap placards, work or school accommodations, housing, adequate nutrition, disability benefits, and other necessary resources. Conduct a careful assessment of the patient's needs and provide information, documentation, referrals, equipment, and accommodations to address these needs. Documenting how symptoms affect function during every appointment can save time in documenting disability later. Patients should assist by documenting such information before the visit.	Encourage the patient and family to establish a living will, appoint a healthcare proxy, and consider a power of attorney to manage finances if needed. Additionally, encourage them to establish a contingency plan and maintain a summary of their health issues and medications in the event that hospitalization is necessary, or an emergency issue arises. Examples of emergency issues include a fire, loss of a caregiver (e.g., through death or illness), or a very severe relapse in which the patient can no longer communicate their needs. Be aware of any regulatory or insurance requirements

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facilities, use of stairs, and access to outside space • dexterity and balance, including avoiding falls • their home, including environmental controls to reduce light levels, sound levels and temperature fluctuations • the feasibility of equipment and adaptations • access to technology, including internet access • where to get financial support and advice, for example signposting to advice on money management and making personalised arrangements with banks or the Post Office to access personal finances, and how to claim carers' and disability benefits and grants. Enable prompt assessment for funding for home adaptation. If the person is not eligible for funding, continue to offer information and support in arranging home adaptations. For people with moderate ME/CFS or severe or very severe ME/CFS, consider providing or recommending aids and adaptations (such		team (especially for the more severely affected), e.g., by district nurses.		therapy and other home health services when possible. Referrals to specialists or allied health professionals, such as occupational therapists and physical therapists, may be helpful in securing the needed documentation and support [aide technique, aide à la mobilité,…].		for providing home visits. Document ADLs and IADLs to demonstrate the need for home care. Engage a targeted set of other professionals as necessary and as tolerated by the patient. These could include physical therapists, occupational therapists, nurses, home health aides, social workers, and mental health experts. Home visits by optometrists/ophthalmologists and dentists may be required. Ensure these other professionals are knowledgeable about ME/CFS. While providing access to essential healthcare providers, care must be taken not to overwhelm the patient with too many providers or too many visits. Where feasible, leverage the caregiver to save the patient's energy. For example, capitalize on the caregiver's intimate knowledge of the patient's needs, preferences, and status. Teach them to provide certain services to minimize the need for additional healthcare

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as a wheelchair, blue badge or stairlift) that could help them maintain their independence and improve their quality of life, taking into account the risks and benefits. Include these in the person's care and support plan. Provide aids and adaptations identified in the person's social care needs assessment without delay, so that people with ME/CFS can carry out activities of daily living and maintain their quality of life as much as possible.						providers. Reserve patient visits for those times where patient input is required or there is a need to examine the patient in-person. Some severely ill ME/CFS patients may not have caregivers. Be alert to their nonmedical needs, such as their ability to obtain and prepare food. For patients who do not have caregivers, the provider will also need to evaluate IADLs such as shopping, cooking, managing medications, and doing laundry and housework to assess the level of support needed. **Medical Management and Emergency Preparadness** • Recommend the patient or caregiver create and maintain a summary of their health issues (e.g., symptoms, sensitivities/allergies, cautions for medical services, etc. Tas), current medications (including over-the-counter drugs, supplements, vitamins, etc.), and physician contact information. • Recommend advanced

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						directives and a health care proxy for when the patient is unable to convey their intent. • Assess emergency preparedness including emergency alert, fire extinguishers, safe exit route. • Recommend the patient or caregiver maintain a pack with essential medicine, clothes, and supplies. • Recommend emergency alert technology (iWatch, Life Alert, Alexa, etc.) and a cell phone with programmed numbers. • Notify emergency services (fire department, police) of resident's mobility concerns and identify the location as high priority for utility services.
Accommodements étude ou travail						
When ME/CFS is suspected in a child or young person […]: • start to work with the child or young person's place of education or training to support flexible adjustments or adaptations.	For students with ME/CFS who need accommodation due to the illness, a resource entitled: "Teach ME" is helpful and can be found on the ME-FM Action Network website.	**Support measures** • Educational needs: welfare and educational sectors should be involved in the planning and care for affected patients, particularly children, adolescents, and young adults	Educating the patient, the parents, the wider family and school personnel about the illness is important […]. Adequate rest and activity management are the mainstays of treatment. Premature resumption of activity or attempts to return	A particularly important aspect of illness management for the pediatric patient population is to help children continue their education and stay connected with their friends. Healthcare providers can work with young patients and their school	Patients often need help acquiring […] work or school accommodations, […]. Conduct a careful assessment of the patient's needs and provide information, documentation, referrals, equipment, and accommodations to address these needs.	Aucune information présentée

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Offer to liaise on the person's behalf (with their informed consent) with employers, education providers and support services. Give them information about ME/CFS and discuss the person's care and support plan and any adjustments needed. Advise and discuss with people with ME/CFS that: • they may be able to access reasonable adjustments or adaptations (in line with the Equality Act 2010) to help them continue or return to work or education • there may be times when they are unable to continue with work or education • some people find that going back to work, school or college worsens their symptoms. Health and social care professionals should work with training and education services to: • provide information about ME/CFS and the needs		This includes facilitating the provision of emotional, social care, and occupational health support, and medical advice to teachers, employers, and caregivers, in response to the specific needs of patients. Support for self-management, education, and work activities may require further contacts with the patients and their carers/families, as well as with educators and employers.	to school can result in a relapse or increased severity of symptoms. It is helpful for school personnel to be aware of the following. • The illness is very unpredictable. Symptoms vary widely between patients and wax and wane. • Large fluctuations in illness severity can occur making planning and school attendance a challenge. Some students are able to attend school daily, others can only manage a part-time schedule, while others are homebound or bedbound. Early in the illness, students might be too ill to attend school and this situation can sometimes persist for months or years. Sometimes a student who is able to go school might appear fine one day and the next day they may be unable to go to school, and that inability to attend might continue for several weeks.	administrators to create a study plan that will accommodate the needs of individual patients. Healthcare providers can play critical roles in ensuring that schools provide optimal support for students with ME/CFS. This support needs to begin while children are being evaluated for ME/CFS. Some children with extreme fatigue and cognitive dysfunction might need accommodations such as part-time schooling or home tutoring. The occasional patient might need to withdraw from school until symptoms have improved enough to tolerate part-time classwork.	*Nonpharmacologic approaches to conserve energy and to minimize postexertional malaise* • School or work accommodations, such as flexible hours, shortened days	

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and impairments of children and young people with ME/CFS, including the need for a balance of activities in their life • discuss the child or young person's care and support plan so that everyone has a common understanding of their priorities, hopes and plans • discuss a flexible approach to training and education – this could include adjustments to the school day, online learning or education at home and using assistive equipment. Advise children and young people with ME/CFS and their parents or carers (as appropriate) that: • training or education should not be the only activity they undertake • they should aim to find a balance between the time they spend on education or training, home and family life, and social activities.			Sometimes the student may be able to attend school in the early part of the week, but can't manage Thursday and Friday. • A common pattern of absence is that following the summer break, students with ME/CFS are able to start the school term enthusiastically, but are incapable of keeping up with the increased activity involved in maintaining their school schedule over time. They "run out of steam" and this can result in a prolonged absence from school. While this might raise suspicions of truancy, or school refusal in some school personnel, the student usually wants to attend school, but is too ill to do so. The physician might need to take an active role in supporting young people with ME/CFS and ensure that they receive an education that is appropriate for their physical condition. Students experience mental			

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			confusion, forgetfulness, difficulty concentrating, a short attention span and a slowing of mental processing speed. Working memory can be significantly reduced and there is often increased distractibility, which can be exacerbated by noise in the classroom. […] Cognitive problems can sometimes mimic attention deficit disorder without hyperactivity. For those with more severe illness, cognitive problems are very limiting. Generally, if students are homebound, the most that they can manage are one or two essential or core subjects. Although not easy and requiring a real commitment, completing school work can give the student a real sense of achievement, which is important. The homebound student usually needs regular help from someone such as a Visiting/Homebound Teacher. Students with ME/CFS are often unable to handle simple math calculations. They might be able to complete the steps to solve			

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			a complex problem correctly, but can make simple addition, subtraction, or multiplication mistakes. Teachers should be aware of this problem when grading tests. Many young people with ME/CFS also experience orthostatic intolerance. Educators need to be aware that it is difficult for these students to stand or even sit for prolonged periods of time. These students might need to move around during lessons. They might also need access to drinks and salty snacks especially during testing. They might also be physically unable to complete long exams in one sitting. Returning to school after a long absence can be a challenge. […] If the student needs to travel long distances to school, this is very tiring. The situation needs to be handled with understanding and patience. Students with ME/CFS often need a personalized school schedule. Ideally, young people with ME/CFS will undergo an			

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			evaluation process and an educational plan should be developed by the school after consultation with the student, the student's parents and the student's physician. Neuropsychological testing is not routinely recommended to investigate the cognitive symptoms of ME/CFS […].At a practical level, the testing usually does not alter the suggested management, which most often is to decrease the volume of academic work. Because ME/CFS symptom severity varies widely, clinicians should, whenever possible, recommend specific educational accommodations (see later) that are appropriate for the severity of symptoms. Regular communication with the school is helpful. Any of the following [educational accommodations] can be recommended, depending on the student's physical condition: *In the school:* • A person designated as a single point of contact for both teachers and			

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			the family. • A shortened day/shortened week; the student might arrive late, leave early, attend school for only part of the day and/or only 2or 3 days a week; students with sleep reversal might not be able to manage morning classes. • A reduction in course load and flexible scheduling where only classes in selected subjects are attended. • A quiet place to rest if fatigue is evident to the student or the teacher. • Use of the elevator to access different floors. • Exemption from or modification of, the physical education program. • Provide homebound instruction or Distance Education for students who are partly or completely homebound. *In the classroom:* • Provide two sets of textbooks—one for school and one for home. • Use the buddy system, so that someone can take notes in class,			

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			allow taping of classes, and/or give the student an outline of material taught. - Permit the use of electronic devices such as a laptop or tablet and allow work to be completed and submitted online. - Permit a student with orthostatic intolerance to move around during classes. - Allow salty snacks and a water bottle for use in the classroom and especially during long tests. - Provide tutorial or homebound instruction for work missed or if the student is too ill to attend school. *Assessments/Testing:* - Allow flexibility with assignments and deadlines as well as modifications of the number of problems and/or assignments to be completed. - Significant extended time might be needed for testing as well as adjusted time of day for assessments, depending on the time when the student			

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			functions best. • Tests/Final Exams might need to be given over several days and/or sessions with water and snacks available. **Sports** The student needs to be able to recognize when she/he is experiencing the onset of fatigue and inform the teacher. When this occurs, the student *must* stop and rest. Students with ME/CFS should never be pressured to push themselves to their limits. **Social development** When possible, these [classroom and school lunchroom] opportunities [to socialize] should be facilitated. Access to extra-curricular activities is also important for social reasons.			

Sources : [CDC, 2022; Bateman *et al*., 2021; Montoya *et al*., 2021; Nacul *et al*., 2021; NICE, 2021; US ME/CFS CC, 2021a; US ME/CFS CC, 2021b; US ME/CFS CC, 2020; Rowe *et al*., 2017; TOP ME/CFS Working Group, 2016]

[1] Site Web consulté le 23 août 2022.

Tableau E-5 Recommandation et information clinique concernant les modalités de bonne pratique clinique pour effectuer le suivi de l'EM/SFC (Question 3d)

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
Généralité						
Recognise that people with ME/CFS need: - regular monitoring and review, particularly when their symptoms are worsening, changing or are severe.	- Monitor progress and assess for any other emerging conditions with regular patient follow-up.	When a diagnosis is suspected in primary care, regular reviews are warranted […]. […] it may be helpful to ask the patient to record their symptoms and other health parameters using standard instruments in advance of follow-up consultations […].	Regular monitoring can support the young patient and uncover a change of symptoms, or the emergence of a new illness.	Since ME/CFS can be unpredictable and can change over time, evaluation of each patient's condition at scheduled intervals is warranted.	Schedule regular follow-up visits.	The health status of a severe or very severe ME/CFS patient can change over time, sometimes rapidly and potentially requiring hospitalization. The primary care provider should schedule regular visits, be prepared to provide guidance to hospital staff, and encourage patients to maintain advance directives and contingency plans […].
Fréquence						
Offer children and young people with ME/CFS a review of their care and support plan at least every 6 months, and more frequently if needed, depending on the severity and complexity of their symptoms. Agree how often to review the person's energy management plan with them and revise it if needed. Offer adults with ME/CFS a review of their care and support plan in primary care at least once a year. Arrange more frequent	Aucune information présentée	Aucune information présentée	Frequent monitoring of the patient once every 1–3 months, depending on the level of illness severity is important. Young patients who are ill appreciate continuing care.	As with many chronic illnesses, the length of intervals between visits might vary from patient to patient and depends on the severity and degree of symptom improvement and control. In addition, regular (every 1-2 months) visits with a healthcare provider can help keep track of ongoing and new symptoms, particularly at the beginning of the disease. Extensive testing and frequent healthcare provider visits may exacerbate the symptoms of patients with	Aucune information présentée	Aucune information présentée

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NICE 2021 **Angleterre**	**TOP 2016** **Canada**	**EUROMENE 2021 - Nacul et al. 2021** **International**	**Rowe et al. 2017** **International**	**CDC[1] 2018 à 2022 selon les sections** **États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web** **États-Unis**	**Montoya et al. 2021** **États-Unis**
primary care reviews for children, young people and adults with ME/CFS as needed, depending on the severity and complexity of their symptoms, and the effectiveness of any symptom management. When deciding how often reviews or reassessment might be needed for children and young people with ME/CFS, take into account: • their developmental stage • transitions, such as changing schools or exams • the severity and complexity of symptoms • the effectiveness of any symptom management				ME/CFS, so when follow-up visits are needed, they need to be scheduled thoughtfully.		
Modalité						
Health and social care organisations should ensure that people with ME/CFS can use their services by: • adapting the timing, length and frequency of all appointments to the person's needs • taking into account physical accessibility, such as how far the person has to travel, whether there is	Aucune information présentée	Health services need to be prepared to attend to the specific needs of the severely affected, including home visits or virtual health consultations. Virtual healthcare or virtual support from the specialist to the primary care team may have an important role.	Reassurance that medical advice from the treating physician will continue to be available can help the patient and family cope with the disease. Telephone or Skype contact can serve the same purpose for those who are more severely affected and unable to travel, or those who are geographically remote. If the patient is cared for at	Aucune information présentée	Aucune information présentée	Partnerships with the patient, the caregiver and a targeted network of providers along with use of enablers such as telemedicine and remote monitoring are key to providing the needed care without overwhelming either the patient or the busy provider. Leverage a combination of home visits, telemedicine,

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suitable transport and parking, and where rooms are for appointments - taking into account sensitivities to light, sound, touch, pain, temperature extremes or smells - providing care flexibly to the person's needs, such as by online or phone consultations or making home visits. If a person with ME/CFS misses an appointment: - do not discharge them for not attending because it could be due to their symptoms worsening - discuss why they could not attend and how the multidisciplinary team can support them. Service providers should be proactive and flexible in delivering services to people with severe or very severe ME/CFS, who may have particular difficulty accessing services and articulating their needs. This could include home visits, online or phone consultations, supplying written communication, and			home, home visits are necessary. Further advice can also be given by telephone consultations or by e-mail. **Management of the Very Severely Affected** • Protect the patient from undue physical, cognitive, and emotional stress. • A very quiet environment that might include a darkened room. • The use of patient eye pads can allow the physician to examine the patient in a low ambient light. • Maintain fluid and nutritional intake by early recourse to tube feeding. • General nursing care to consist of gentle help with turning, skin care and toileting, diapers might be necessary. • Prevention of venous thrombosis by passive physiotherapy.			written communications, partnerships with home health care services, partnership with the caregiver if one exists, and emerging remote monitoring technologies to best manage both the needs of the patient and the demands on your time.

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supporting their applications for aids and appliances						
Suivi à réaliser						
Review the use of rest periods and sleep management strategies regularly as part of the person's care and support plan. Assess at every contact people with severe or very severe ME/CFS or those with prolonged periods of immobility for: • areas at risk of pressure ulcers (see the NICE guideline on pressure ulcers) • deep vein thrombosis (see the NICE guideline on venous thromboembolic diseases) • risk of contractures. Evaluate and investigate any new symptoms or a change in symptoms and do not assume they are caused by the person's ME/CFS. When carrying out a review in primary care, ensure you have access to the person's care and support plan and any clinical communications from the ME/CFS specialist team (including their	Assess progress toward treatment goals including: • Self-management – any barriers to adherence to treatment plan? • Intervention efficacy and adverse effects – medication and other treatments? • Co-morbidities – new, improved, getting worse? • Make adjustments to treatment plan as required.	[…] when the possibility of alternative diagnoses is explored at the same time as initial management, strategies are put in place. **The ME/CFS Specialist Consultation** […] when progress should be assessed, and the possible development of new diagnoses and co-morbidities considered, as the management plan is reviewed. Regular follow-ups are opportunities for education, including on self-management, assessment of usefulness of medications and other treatments and side-effects. Follow-up should include monitoring of symptoms, using similar instruments to those used at or before the initial consultation.	At each visit, the activity plan can be adjusted, in relation to symptom severity or improvement. The young patient should be encouraged to report any changes or additional symptoms as symptoms of ME/CFS wax and wane. The physician might need to determine whether new or changing symptoms represent an altered ME/CFS symptomology, the onset of common co-morbid conditions, or whether new symptoms are suggestive of an alternative diagnosis. Changes to medications and/or their dosages might be required. The practitioner must be alert for the emergence of new symptoms. They might not be related to ME/CFS, but due to another illness. In patients who are improving, fatigue can be one of the last symptoms to subside. Young people often expand their activity level as they start to improve,	Re-assess symptoms and their duration, frequency, and intensity. The scheduled re-evaluations serve as opportunities to adjust the treatment strategies as needed based on patient status**.** While it may take some time to experience an improvement and not all patients may improve significantly, it is important to communicate to patients that improvement is possible. Since ME/CFS can be unpredictable and can change over time, evaluation of each patient's condition at scheduled intervals is warranted. Patients with ME/CFS should be re-evaluated periodically. Routine age-appropriate health monitoring/screening is important and should continue. In addition, healthcare providers should	Ask patients to report any new or worsening symptoms and confirm that these are not caused by another condition. Instruct patients to report any new drugs, supplements, or complementary approaches and review for potential adverse effects and treatment interactions.	Monitor for emerging comorbidities and complications and whether changes in management practices could help. Do not assume any new issues are caused by ME/CFS or are intractable.

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discharge letter, if relevant). As part of the review, discuss with the person with ME/CFS (and their family or carers, as appropriate) and record as a minimum: • their condition, including any changes in their illness and the impact of this symptoms, including whether they have experienced new symptoms • self-management − ask about their energy management plan and (if relevant) their physical activity or exercise programme • who is helping them and how they provide support psychological, emotional and social wellbeing • any future plans − ask if the person is considering any changes or if they have any challenges ahead. Refer the person with ME/CFS to their named contact in the ME/CFS specialist team if there are any new or deteriorating			preferring to tolerate some symptoms rather than remain on restricted activities so as to experience less fatigue. Thus, measuring improvement by asking solely about fatigue can underestimate progress. Functional improvement can be judged by determining how much activity it takes to provoke post-exertional worsening of symptoms. It can be helpful to use questionnaires/forms which measure activity, cognitive function, and mood to quantify the severity of the illness, and document progress. Brief questionnaires used in some pediatric ME/CFS studies include the Functional Disability Inventory, PedsQL, and Wood Mental Fatigue Inventory. Progress should be measured over months or years, rather than at a single clinic visit. During regular appointments with the young patient, the physician should ask how school is going. The clinician needs to be sensitive to the relationship between the young person, her/his parents, and the	remain vigilant for illnesses that have symptoms similar to ME/CFS.		

Guides de pratique clinique retenus		Sources d'information clinique retenues				
NICE 2021 Angleterre	**TOP 2016 Canada**	**EUROMENE 2021 - Nacul et al. 2021 International**	**Rowe et al. 2017 International**	**CDC[1] 2018 à 2022 selon les sections États-Unis**	**US ME/CFS CC – Bateman et al. 2021 et documents du site Web États-Unis**	**Montoya et al. 2021 États-Unis**
aspects of their condition. Consider seeking advice from an appropriate specialist if there is uncertainty about interpreting signs and symptoms and whether a referral is needed. Ensure reviews are carried out or overseen by a paediatrician with expertise in ME/CFS. Involve other appropriate specialists as needed.			school. Students who have understanding teachers, a flexible program, and assistance from sympathetic advocates often need less help from medical and psychological professionals.			

Sources : [CDC, 2022; Bateman *et al.*, 2021; Montoya *et al.*, 2021; Nacul *et al.*, 2021; NICE, 2021; US ME/CFS CC, 2021a; US ME/CFS CC, 2021b; US ME/CFS CC, 2020; Rowe *et al.*, 2017; TOP ME/CFS Working Group, 2016]

[1] Site Web consulté le 23 août 2022.

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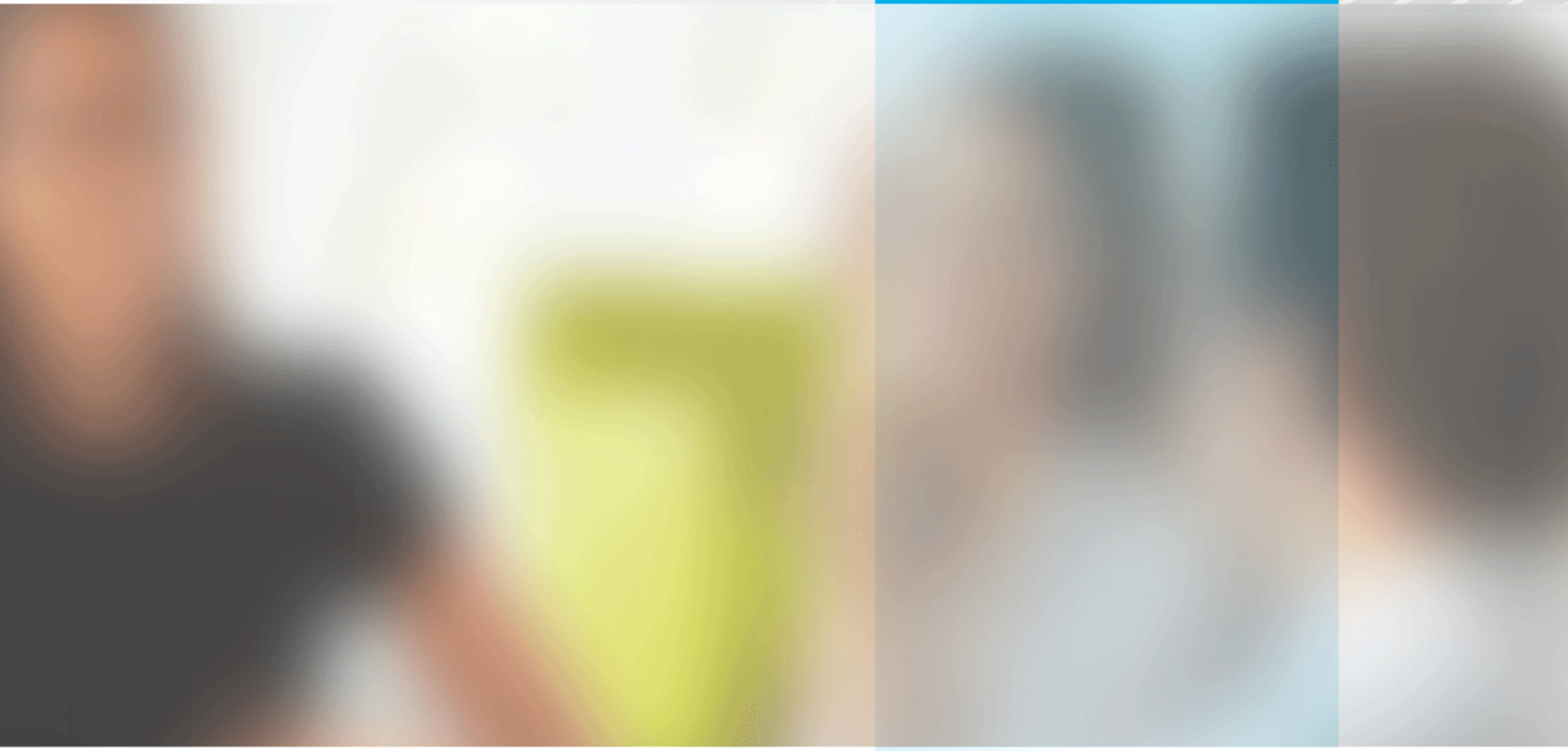

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