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Canadian Association of MAiD Assessors and Providers

Association canadienne des évaluateurs et prestataires de l'AMM

Medical Assistance in Dying (MAiD) Assessments for People with Complex Chronic Conditions

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Canadian Association of MAiD Assessors and Providers (CAMAP)

The Canadian Association of MAiD Assessors and Providers (CAMAP) is a unique association of professionals involved in the assessment and provision of MAiD in Canada. Founded in 2016, their mission is to support MAiD assessors and providers in their work, educate the public and the health care community about MAiD, and to provide leadership on determining the highest standards and guidelines of practice in MAiD provision. CAMAP members strive to achieve the highest level of care for our patients and to model this care for a national and international audience. They aim to work with governments in Canada at all levels, provincial medical and nursing licensing bodies, national medical and nursing colleges, national professional groups, medical and nursing, and national advocacy groups.

Process

Medical Assistance in Dying (MAiD) Assessments for People with Complex Chronic Conditions (CCCs) was first drafted by the CAMAP Working Group on Complex Chronic Conditions. The Working Group included MAiD providers who specialize in (1) psychiatry, (2) treatment of chronic pain, and (3) chronic complex conditions. The CAMAP Committee on Standards and Guidelines suggested amendments to this initial draft which were incorporated by the Working Group. The next draft was circulated to national stakeholders for comment and further amendments were made by the Working Group. The resultant draft was re-examined by the Committee on Standards and Guidelines and the resulting final draft has been approved by the CAMAP Board of Directors for publication on the CAMAP website. It is a working document and will be amended as experience is gained in the provision of MAiD to patients with CCCs and those whose natural death is not reasonably foreseeable.

Terminology

MAiD Provider or Provider: the physician or nurse practitioner who will carry out MAiD if the person is found eligible and chooses to have MAiD.

Assessor: the other physician or nurse practitioner who determines the eligibility of the person for MAiD.

Assessors: in almost all cases, this means the Provider and the Assessor together. On occasion it may mean two or more physicians or nurse practitioners who have assessed the patient other than the Provider. The context will make it clear if this is the meaning.

Clinician: any physician or nurse practitioner. This term, therefore, includes a physician or nurse practitioner discussing MAiD with a person, whether or not the clinician will be one of the Assessors.

It should be noted that in some literature, the Assessor is referred to as the “second assessor”. This term is not used here as there is no requirement in the law that the Assessor must assess the person only after the Provider has done so.

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Executive summary

Purpose

To provide information and tools to help clinicians assess eligibility for medical assistance in dying (MAiD) and fulfill procedural safeguards for individuals with complex chronic conditions.
Note: This document does not constitute legal advice.

Key Recommendations

1. Clinicians should be aware that amendments made to Canada's assisted dying legislation in March 2021 by the passing of Bill C-7 changed eligibility criteria in two ways that have a potential impact on individuals with complex chronic conditions. First, C-7 removed the requirement that a person must have a reasonably foreseeable natural death (RFND). Since most individuals with CCCs do not have an RFND, most were previously ineligible. Many more individuals with CCCs may now be eligible. Second, C-7 excluded mental illness from the criterion of serious and incurable illness, disease, or disability. Therefore if, in the clinical judgement of the assessors, a person's CCCs is a mental illness and is their sole underlying medical condition, the person is ineligible for MAiD (until the law changes).

2. People with CCCs often feel marginalized and disregarded by the health care system. Clinicians should approach all patients with an open mind and consider the best environment for any discussion to help the patient feel at ease.

3. During an assessment for eligibility for MAiD, a clinician should gather evidence by investigating (1) whether a natural death has become reasonably foreseeable and (2) whether all appropriate investigations have been done to rule out curable illness, disease, or disability, reversible decline in capability, and suffering that can be relieved by means acceptable to the person. For those cases where natural death is not reasonably foreseeable, a clinician should gather evidence about whether the patient has (3) been informed of the means available to relieve their suffering, (4) been offered consultations with relevant professionals who provide those services or that care, and (5) given serious consideration to the reasonable and available means of alleviating their suffering.

5. Documentation should include the reasons the assessors are of the opinion that all the eligibility criteria have been met and that the provider is of the opinion that the relevant procedural safeguards have been satisfied. For patients who do not have a RFND, the documentation should indicate which assessor has expertise in the condition causing the person's suffering, which is a requirement of the law. If neither assessor has this expertise, it should confirm that a medical or nurse practitioner with the necessary expertise was consulted and that their opinion was shared between the assessors. Documentation should expressly state that the two assessors agree with the patient that the patient has given serious consideration to the reasonable and available means of alleviating their suffering.

6. Clinicians should be aware of any College Practice Standards that address the issue of whether one or both assessors need to be specialists or have expertise in the primary motivating condition for the request. This is particularly relevant to complex track two cases in which there is uncertainty regarding incurability and irreversibility. In the absence of specific College guidance, clinicians should ensure that they are operating within their

scope of practice (i.e., they have sufficient competencies, training, experience, and qualifications to conduct an assessment for eligibility for MAiD in the particular circumstances of the patient either independently or following supplemental consultation with other clinicians).

Introduction

In this paper, clinicians who carry out eligibility assessments for MAiD are provided with information and tools which may help with the assessment of people with CCCs such as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Chronic Pain Syndromes (CPSs), and Fibromyalgia (FM).

The legal requirements for MAiD are outlined. Patients must have a serious and incurable illness, disease or disability, be in an advanced state of irreversible decline in capability and have enduring and intolerable suffering that cannot be relieved by any means acceptable to them.

Basic information on several CCCs is given along with references. Guidelines to consider when carrying out MAiD assessments of persons with these conditions are presented. These guidelines are of particular importance since the passage of Bill C-7 on March 17, 2021, as it is no longer required that patients seeking eligibility for MAiD have a RFND. Many people with a CCCs do not have an RFND. It should be noted that this paper concerns only patients with CCCs. It does not cover all patients who do not have an RFND.

It is not uncommon that patients with CCCs have concurrent mental health conditions. With the passage of Bill C-7, the Criminal Code contains an explicit exclusion from eligibility for MAiD for individuals whose *sole* underlying medical condition is a mental illness (this exclusion was scheduled to be lifted in March 2023 but the timing on the lifting is now uncertain). The issue of *concurrent* mental illness is addressed below.

Appendix A provides basic information about some CCCs including diagnostic criteria, epidemiology, possible etiologies, physiological changes, and prognosis, or natural history. It is a representative but not exhaustive list of such conditions. It provides a framework to help assessors approach patients with these conditions.

Challenges

There are three main challenges with respect to assessing people with CCCs for MAiD under Canadian law.

1. Whether complex chronic conditions are themselves “mental illnesses”

There is a lack of consensus among experts as to whether CCCs are psychiatric or neurobiological in origin. There is additionally a lack of consensus as to whether any such distinction exists at all. The law does not define “mental illness” although it is clear that not everything in the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5) is to be considered a mental illness for the purposes of excluding individuals from MAiD eligibility. For example, the DSM-5 includes the diagnoses of dementia and intellectual disability, yet the government was clear that it did not intend for these patients to be said to have a “mental illness” for the purposes of the mental illness exclusion. In its response to the Truchon case the government stated:

> Despite the absence of a single clear definition of mental illness, in the context of Canadian discussions on MAID, this term has come to be understood as generally referring to those conditions which are primarily within the domain of psychiatry, and which raise specific types of concerns as set out above, when it comes to eligibility for MAID. In the context of the federal MAID legislation, the term 'mental illness' would not include neurocognitive or neurodevelopmental disorders, or other conditions that may affect cognitive abilities, such as dementias, autism spectrum disorders or intellectual disabilities, which may be treated by specialties other than psychiatry (such as neurology for neurodegenerative or neurodevelopmental conditions) or specialties outside of medicine (such as education specialists for intellectual disabilities) and do not raise the specific concerns outlined above" (1).

It is therefore up to the judgement of the assessors to determine, on a case-by-case basis, whether the person's underlying serious and incurable illness, disease, or disability is a mental illness or not. If the clinicians involved are of the opinion that it is, then, until such time as the exclusion of those with mental illness is lifted, the person should be found to be ineligible for MAiD unless they have a second serious and incurable illness, disease, or disability that is not a mental illness, and which might qualify them for MAiD.

2. <u>The "incurable" and "irreversible" aspects of the "grievous and irremediable" criterion</u>

Since there are no accepted biomarkers to diagnose these CCCs, only the history and clinical symptomatology can be used to make a diagnosis. Chronic complex conditions are heterogenous, sometimes making the assessment of prognosis or remediability more difficult. While full cure may be difficult or impossible to achieve, there are many treatments of varying effectiveness. The responsibility of assessors is to determine whether the patient has been made aware of the treatment options available to relieve their suffering and whether the patient has given serious consideration to them, as the law requires.

Although the May 2022 report by the Expert Panel on MAiD and Mental Illness does not relate to CCCs directly, the comments on incurability are useful here:

> "MAiD assessors should establish incurability with reference to treatment attempts made up to that point, outcomes of those treatments, and severity and duration of illness, disease, or disability.
>
> "It is not possible to provide fixed rules for how many treatment attempts, how many kinds of treatments, and over what period of time as this will vary according to the nature and severity of medical conditions the person has and their overall health status. This must be assessed on a case-by-case basis."

3. <u>The requirement that the person be "capable of making decisions with respect to their health"</u>

There are often concurrent mental health disorders, such as post-traumatic stress disorder (PTSD), anxiety, or depression in people diagnosed with CCCs. These may compromise decision-making capacity and/or make the assessment of capacity challenging. It is important to emphasize that having a mental health disorder does not mean that a person necessarily lacks capacity to make their own health care decisions – indeed, most often such patients have capacity. Furthermore, under Canadian law, patients are presumed to be capable. Clinicians must start from the presumption that the person requesting MAiD is capable but should explore and question this

presumption whenever there are reasonable grounds to think otherwise.

Treatment of Complex Chronic Conditions

By definition, all of these conditions have persisted, usually for a long time, despite any treatment provided thus far. It is important that MAiD assessors are aware of treatments for CCCs in general.

Individuals with CCCs may experience high levels of physiological and psychological distress. Some of this distress is a reaction to their physical suffering and to the losses they have experienced (career, independence, etc.). Some of their distress may be due to a history of trauma, particularly adverse childhood experiences. Each condition and each patient is unique, but as well as providing some details of common treatments available for specific CCCs (see Appendix A), this paper presents information on general treatments applicable to many CCCs (see Appendix B).

Assessment

All patients being assessed for MAiD eligibility must satisfy each of the legal criteria. They must have a serious and incurable illness, disease, or disability, be in an advanced state of irreversible decline in capability, and have enduring and intolerable suffering that cannot be relieved by means acceptable to them. Of note, in particular, is the importance of the requirement for the patient to be in an advanced state of irreversible decline in capability. It is for the assessors to decide whether this criterion has been satisfied. For patients with an RFND, it is common for them to already have developed such an advanced state of decline in capability that examination of this criterion is simple. For some patients who do not have an RFND, however, an advanced state of decline in capability may be less obvious. Assessors might consider assessing an individual's current capability in relation to their capability prior to the onset of their chronic illness. Some patients may be declining in their capability and others may be living in a state of decline. A patient who previously ran marathons and who can now only walk a mile might perhaps be considered to have developed an advanced state of decline whereas a person who previously would never have attempted to walk more than a few miles might not, while exhibiting the same degree of restriction of mobility. Similarly, a person who was once a voracious reader but who now cannot read, or a person who was multilingual but who can now speak only one language might reasonably be regarded as being in an advanced state of irreversible decline in capability especially if their current state is a significant factor contributing to their intolerable suffering. Also, of note is the fact that "suffering" under the Criminal Code is subjective - the person decides whether their suffering is intolerable to them. Assessors in turn must be of the opinion that it is the person's illness, disease, or disability, or advanced state of decline in capability that is the cause of the person's suffering and assessors should explore the consistency of the person's assessment of their suffering with the person's affect, expressed wishes over time, and life narrative.

Assessor competencies, training, experience, and qualifications (scope of practice) regarding MAiD assessments

Any assessment of eligibility for MAiD requires great care. The assessment of some patients with CCCs can be extremely difficult and experience in MAiD assessments in such cases is particularly advantageous.

Not all MAiD assessors will feel that they have the necessary competencies, training, experience, and qualifications to assess patients with the most challenging CCCs. If, after carrying out a pre-assessment chart review of a case that has been referred to them, it is clear to the assessor that a MAiD assessment of the patient falls outside their scope of practice and therefore should be assessed by, e.g., a more experienced MAiD clinician, then the referral should be returned to the referring physician or program promptly with an explanation to this effect.

That said, a MAID assessor need not have training, experience, and qualifications in every illness encountered in the patients for whom they are assessing eligibility for MAiD (e.g., an anesthesiologist may be able to assess MAiD eligibility for a person with multiple sclerosis with proper background information and supplemental consultations). Assessors need to be able to use their professional knowledge and skills to research the condition and gather relevant information, and to know when to consult one or more physicians or nurse practitioners to inform their assessment, as is true in all situations of clinical practice. This is consistent, for example, with the approach taken in situations within which a primary care clinician would seek to fill gaps while treating a patient with an unfamiliar diagnosis. Where that is not possible, clinicians need to exercise their professional obligation to detect when a particular assessment lies outside their scope of practice and to refer the case to another clinician or program.

The issue of the procedural safeguard requiring expertise in the condition that is causing the person's suffering is addressed in the section *Gathering evidence – 3. Consultation with medical or nurse practitioners with expertise* below.

A General Approach to Interviewing Patients

Very often, people with CCCs feel marginalized and disregarded by the health care system. They have often been labelled as Emergency Room "frequent flyers", drug seekers, alcoholics, attention seekers, etc. The assessors should enter the interview with an open mind and trauma-informed approach. A MAiD assessment can be a therapeutic and validating experience for any applicant if they feel that they are being treated fairly, with respect and dignity. Attention to an appropriate environment should be considered e.g., at the patient's home instead of a doctor's office. The applicant should be asked if they want a family member or friend present for parts of the interview. The interview must not be rushed. Adequate time should be reserved for it. The patient might need to take small breaks or have multiple shorter interactions. Although interviews may be done virtually in most jurisdictions, it is preferable to do interviews in person, if practicable.

The assessors should be as familiar as possible about case details. If consent has been given, it is useful to review clinical records ahead of time and to talk with any involved or treating health care practitioners, family, and caregivers. Having a broad understanding ahead of time will be an asset. Alternatively, it may be appropriate to tell the patient it will be necessary to gather additional information in between two or more interviews held over a period of time.

It is important at some point for the assessors to review all available therapeutic options and to determine whether the patient has been made aware of these options. Sometimes therapeutic options need to be researched between interviews leading to supplemental discussion.

Finally, the patient must be informed of the assessors' conclusion. If eligibility is not found, then an explanation must be given. If the patient is found not to be eligible, they should be informed of the process for requesting assessment by another MAiD clinician.

Comorbid mental health conditions

People with chronic complex health conditions very often have comorbid mental health conditions. This association is multidirectional as mental health conditions such as anxiety, depression, and suicidal ideation can variably predate, present simultaneously, or follow the diagnosis of the chronic complex health condition. However, it is important to remember that with the advance of medical knowledge, many conditions not previously understood to have a physical etiology were attributed to a mental health condition such as “hysteria”, resulting in much stigmatization (2). For example, multiple sclerosis and functional neurological disorder are sometimes misdiagnosed as each other. With ongoing research into the etiology of many of these chronic physical syndromes, the evidence increasingly suggests that physical mechanisms either acting singly or in combination with other factors are strong factors in their development. In particular, there is now much better understanding of the complex interplay between peripheral and central neurophysiological mechanisms, so a variety of authors have considered the DSM-5 to over-psychologize, for example, people with chronic pain syndrome, leading to unnecessary stigma and damage to the therapeutic relationship between patient and healthcare provider (3).

In summary, the comorbidity between complex chronic health conditions and mental health conditions is considerable, varies between different conditions, and often requires complex interventions to address these multiple disorders. It is therefore not possible in this document to cover the treatment of every permutation of complex chronic health conditions and comorbid mental health conditions. However, assessors are advised to consider involving multidisciplinary teams including mental health practitioners and other therapies such as physical therapy, occupational therapy, speech therapy and social work, which are often necessary to maximize the functioning and quality of life of people with these complicated comorbidities.

Gathering Evidence

1. Has the diagnosis been established?

For some conditions, such as Lyme disease or degenerative disc disease, there are specific objective tests that can be undertaken. However, most CCCs have diagnostic criteria that primarily concern history and symptoms. Unlike conditions such as metastatic cancer, it is not the objective diagnosis of a CCCs with imaging, lab reports, etc. that is necessary to determine the existence of the eligibility criterion of a serious and incurable illness, disease, or disability, but instead the evidence provided by the symptoms and the history of progression, lack of response to treatment, and of loss of function or developing frailty. Examining these is necessary when exploring treatment options or the management of symptoms, but for MAiD assessment, it is also important to document issues such as increasing cachexia with weight records, or frailty with an objective instrument like the Clinical Frailty Scale (4,5) and to obtain corroboration from others about the need for caregivers to assist with activities of daily living. Some people have several diagnoses, both physical and psychiatric. Others do not have a firm diagnosis. It is necessary to rule out other treatable conditions because there can be misdiagnoses. It is not necessary for all clinicians involved previously or currently to agree as to the patient’s precise diagnostic label, only that the assessors are satisfied that the patient has a serious and incurable illness, disease, or disability (which, until the legislation changes, is not a mental illness), is in an advanced state of irreversible

decline in capability, and that they have identified the cause(s) and extent of the patient's suffering.

2. Has the patient been offered reasonable and available treatments?

Since CCCs are rarely curable, the assessors are searching for evidence of the patient having been offered reasonable and available means to manage their symptoms. In the case of patients who do not have an RFND, the assessors must agree that the patient has given serious consideration to the reasonable and available means of alleviating their suffering. This is where the involvement of a clinician with expertise in the condition causing the patient's suffering is most impactful (whether one or both assessors or a consultant). Ideally, there should have been a multi-disciplinary approach to treatment trials. Clinicians frequently involved may include psychiatrists, physiatrists, psychologists and/or counsellors, physiotherapists, and occupational therapists. Various specific and general treatment modalities are discussed in the appendices.

3. Consultation with medical or nurse practitioners with expertise

Current legislation requires that for a patient without an RFND, if neither of the MAiD assessors has expertise in the condition causing the patient's suffering, then a medical or nurse practitioner who has such expertise must be consulted. It is essential to note that the clinician consulted is not being asked to do a MAiD assessment, nor do they necessarily have to opine on any of the eligibility criteria. Rather, they are being consulted with respect to the condition that is causing the person's suffering, specifically with respect to diagnosis, prognosis, and the reasonable and available treatment options.

The expertise must be in the condition causing intolerable suffering. Therefore, the clinician should have expertise in:

- 1a) the patient's serious illness, disease, or disability so that they can deem whether it is incurable

  and/or
- 1b) the patient's decline in capability so that they can deem whether it is irreversible

  and

2) the cause(s) of the patient's suffering so that they can be sure that all potential treatments have been offered to the patient and seriously considered by them.

It is for an assessor to decide if they have sufficient expertise in the patient's condition including whether they are aware of all reasonable and available approaches to the relief of suffering in the case they are assessing. The possibility of the existence of therapeutic approaches unknown to the assessors must always be borne in mind. If neither assessor has the required expertise, they must consult a medical or nurse practitioner with that expertise.

To gather adequate information, the assessors may seek the advice of an allied professional but cannot record them as the person with expertise in the documentation since the law's requirement is for a "medical or nurse practitioner who has that expertise."

The opinion of the clinician with expertise must be shared between the assessors.

The responsibility for confirming that one of the two assessors has the necessary expertise falls on the clinician who will provide the assisted death. If the practitioner who intends to be the provider of MAiD in a particular case does not have the necessary expertise in the condition that is causing

the patient's suffering, they must ensure that either the other assessor has this expertise or a separate practitioner with expertise has been consulted. A simple assertion by the other assessor that they have the expertise should not necessarily satisfy the MAiD provider particularly if the condition is especially complex or the other assessor is not known personally or professionally by the provider.

While the patient is not required to agree to the consultation with a clinician with expertise other than the two assessors, if the patient refuses, the MAiD assessors will not be able to proceed as it will not be possible to meet the procedural safeguard set out in the legislation.

Reports from a chronic pain clinic or a CCCs clinic documenting adequate investigation to rule out conditions that are reversible using treatments acceptable to the patient and the offering of evidence-based treatment are useful but not a requirement. Similarly, reports from medical specialists such as internists, neurologists, and psychiatrists may be especially helpful but are not mandatory if at least one of the assessors is satisfied that they have the required expertise.

Documentation

For all patients, it is necessary to document that their request is voluntary; that their consent to MAiD is informed, and that they have been given information about the means available to relieve their suffering, including palliative care; that they are eligible for health services funded by a government in Canada; and that they are at least 18 years of age.

1. <u>For patients whose natural death is reasonably foreseeable:</u>

   I. Document their serious and incurable illness, disease, or disability including the investigations and treatments they have tried or been offered, including any discussion around treatments that the patient has declined (serious and incurable illness, disease, or disability).

   II. Document their deterioration including, as appropriate, frailty, weight loss, care requirements, functional losses, etc., (advanced state of irreversible decline in capability).

   III. Document that their suffering is enduring, intolerable to them, and cannot be relieved by means acceptable to them.

   IV. Document that the patient's natural death is reasonably foreseeable, i.e., they are on a trajectory towards death (RFND).

   V. Document the patient's ability to understand their condition and their prognosis, the treatments available, and MAiD (capacity).

2. <u>For patients whose natural death is not reasonably foreseeable</u>

   I. All the above, except the patient, need not be on a trajectory towards death.

II. Document that one of the assessors has the expertise required or that another clinician with expertise was consulted and that the results of that consultation were shared with both assessors.

III. Document that the patient has been informed of all the means available to relieve their suffering including, where appropriate, counselling services, mental health and disability support services, community services, and palliative care, and has been offered consultations with relevant professionals, and that both assessors agree the patient has given serious consideration to the reasonable and available means of relieving their suffering.

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Appendix A

Complex chronic conditions (CCCs)

This appendix contains details of some CCCs. It is not inclusive of all CCCs. It is not possible to make definitive statements regarding whether or not particular CCCs are mental illnesses. For each CCC, a section entitled *Physiological changes* is included for completeness. It should be noted that physiological changes occur in mental illnesses as well and that the existence of such changes does not preclude the possibility of a condition being solely a mental disorder. Nor does it change the fact that both psychological and physical treatments may ameliorate symptoms.

It is for the assessors to determine the extent of any mental illness present and to decide on the patient's eligibility for MAiD, taking into account all parts of the individual case. If the assessors decide that a condition is primarily a mental illness then until the law changes, in the absence of other condition(s) making the patient eligible for MAiD, the patient may not receive MAiD.

Central sensitization

Many of the CCCs involve central sensitization and this can be defined as a state in which the central nervous system amplifies sensory input across many organ systems. Heightened sensitivity results in the perception of pain from non-painful stimuli (allodynia) and greater pain than would be expected from painful stimuli (hyperalgesia) (6,7).

On a cellular level, central sensitization results from multiple processes altering the functional status of nociceptive neurons. These processes include increases in membrane excitability, facilitation of synaptic strength, and decreases in inhibitory transmission (disinhibition). Affected neurons display spontaneous activity, reduced activation threshold, and enlarged receptive fields. Hypersensitivity amplifies the sensory response elicited by normal inputs such as innocuous stimuli and normal body sensations and results in changes in brain activity that can be detected by functional magnetic resonance or positron emission tomographic imaging and electro-physiologic studies (8).

There is also overlap with chronic fatigue, cognitive difficulties (brain fog) and drug or chemical sensitivities (9,10). It is important to consider central sensitization when assessing many of the CCCs.

Chronic pain syndromes (CPSs)

There are many types of CPSs. A general discussion of CPSs is followed by information on a selection of the more common syndromes presented in alphabetical order. None of these conditions leads directly to an RFND.

General

Definition and diagnosis

Chronic pain occurs due to persistent activation of neural pain pathways and often muscle spasm. It can occur as part of degenerative diseases, chronic conditions, or injuries. Pain that lasts for

longer than three months is considered chronic. Some chronic pain, such as pain due to traumatic musculoskeletal injuries, has clear origins while others, such as Burning Mouth Syndrome and Fibromyalgia may not. Whether or not the chronic pain was triggered by a specific event or events, it usually involves central sensitization and many of the diagnostic and treatment strategies are similar.

Epidemiology

Chronic pain is one of the most common reasons individuals seek care from a primary care provider. Worldwide, the prevalence of significant chronic pain is approximately 23% (11). The prevalence increases with age and one third of adults over 65 years of age experience chronic pain. Risk factors include being female, being pregnant, being over 45 years old, having a personal or family history of chronic pain, having a high-risk occupation, and experiencing unemployment or job change.

Etiology

The triggers of chronic pain include musculoskeletal causes such as arthritis, fractures and myofascial diseases; neurological causes such as spinal stenosis and neuropathies; psychological causes such as depression and sleep disturbances; localized disease such as those affecting the gastrointestinal tract or reproductive system; or as part of a generalized disease process such as in some rheumatological conditions, infectious diseases, and cancers (12).

Physiological changes

The transition from acute to chronic pain involves distinct pathophysiological changes in the peripheral and central nervous system (13). A group of cortical and subcortical brain regions, often referred to as the "pain matrix" show differences on functional imaging studies in individuals with chronic pain compared to healthy controls (14). A decrease in grey matter in the pain-transmitting areas has also been observed among individuals with CPSs in structural imaging studies (15). Changes in the motor and sensory homunculus have also been observed (14).

Additionally, neuropathic and inflammatory pain promote persisting adaptations at the cellular and molecular level (16). Injuries can induce changes to chromatin structure, which lead to stable changes in gene expression and neural function (16). There is also evidence of epigenetic changes in the spinal cord and brain in individuals with chronic pain (16).

Treatments

Medications

Patients with chronic pain have usually tried many analgesics. Sometimes their treating physicians have not viewed them as requiring a palliative approach and so have not considered opioids for non-cancer pain or augmenters like gabapentin (17). Methadone is more effective for neuropathic pain than other opioids and could be tried for refractory pain (18–20).

Intravenous or intranasal ketamine has been effective for both intractable pain and for concurrent depression (21,22).

Sleep disturbance is common and may be from pain or from the condition itself and should be managed (23,24). Often a small dose of a tricyclic antidepressant is helpful.

Any concurrent depression should be offered a trial of appropriate antidepressants.

Physical and occupational therapy

Physical activity and exercise is an intervention with few adverse events that may improve pain severity and physical function, and consequent quality of life, but studies showed mostly small-to-moderate effect, and were not consistent (25).

Psychological, Somatic-Based, and Neurophysiological treatments

There are several treatments aimed at changing brain function through words, actions and thoughts.

A. Cognitive Behavioural Therapy (CBT) and Mindfulness

CBT has been shown to be effective in reducing chronic pain and improving function and wellbeing (26). Mindfulness refers to intentional, non-judgmental conscious awareness of the present moment (27). Mindfulness exercises are incorporated into many therapeutic interventions. One review found that mindfulness improves pain, depression symptoms, and quality of life in patients with chronic pain (28).

B. Biofeedback and Neurofeedback

Biofeedback is a self-regulatory therapy that provides feedback on physiological systems. It is used to reduce sympathetic activation (stress response) and to increase parasympathetic activation (relaxation response) of the nervous system, with more conscious control over each response (29). Neurofeedback is a type of biofeedback which teaches self-control of brain functions to subjects by measuring brain waves and providing a feedback signal. Neurofeedback methodology proposes that by learning self-regulation a patient can reduce or even eliminate pain sensations from chronic conditions. Studies suggest that the brain changes its functional organization at the level of the somatosensory cortex in chronic pain patients (30). Both biofeedback and neurofeedback have been helpful in CPSs especially those with concurrent PTSD (31).

Specific CPSs

Burning Mouth Syndrome, Fibromyalgia, and Vulvodynia are described here as representative of the CPSs. Other CPSs include irritable bowel syndrome, interstitial cystitis, chronic headache (including trigeminal neuralgia and migraine), and pelvic pain syndromes. All can be severe and disabling and can involve central sensitization. The BMJ best practice guideline on CPSs provides a good overview on epidemiology, diagnosis, treatment, and prognosis of these syndromes (32).

A. Burning Mouth Syndrome (BMS)

Definition and diagnosis

BMS is characterized by a burning sensation in the oral mucosa and perioral regions. It usually has a bilateral and symmetric distribution and occurs in the absence of relevant clinical and laboratory findings. The pain usually has a sudden onset and constant duration but may vary. Like other CPSs, diagnosis of BMS is primarily based on exclusion. In the International Classification of Headache Disorders-II, BMS is listed under “central causes of facial pain”.
Using this classification system, a diagnosis of BMS requires:

1. a burning-like pain in the mouth that is daily and persists most of the day,
2. normal appearing oral mucosa, and
3. exclusion of local and systemic diseases

Epidemiology

The estimated prevalence of BMS ranges from 0.7-3.6% in men and 0.6-12.0% in women. BMS primarily affects postmenopausal women and prevalence increases with age (33).

Etiology

The etiology of BMS is unclear, but hormones, steroid alterations, and dysregulation may contribute its pathogenesis (34).

Physiological changes

Individuals with BMS have been observed to have reduced serum neurokinin A (35), and increased levels of Interleukin-6 (IL–6) and tumor necrosis factor alpha (TNF-alpha) (36). Cytomorphometric changes in the oral mucosa have also been observed (37).

Prognosis

Some short-term follow-up studies suggest potential symptomatic improvement of BMS symptoms with treatment, but the long-term outcomes are unclear. In a retrospective study of individuals with BMS who did not receive treatment over at least 18 months, approximately 10% of cases had spontaneous remission, 26% had moderate improvement, 37% had no significant change, and 26% had worsening symptoms. The same study reported that therapy may be effective in 29% of cases, with 56% reporting no changes, and 15% reporting worsening symptoms (38). An estimated 50-66% of individuals with BMS will experience improvement in their symptoms after 6-7 years (39).

Treatment

The treatment of burning mouth syndrome is usually directed at its symptoms and is the same as the medical management of other neuropathic pain conditions. Studies generally support the use of low dosages of clonazepam and tricyclic antidepressants (e.g., amitriptyline). Evidence also supports the utility of a low dosage of gabapentin. Studies have not shown any benefit from treatment with selective serotonin reuptake inhibitors or other serotoninergic antidepressants (40).

B Fibromyalgia (FM)

Definition and diagnosis

FM is characterized by chronic widespread pain, fatigue, and sleep disturbances. According to the American College of Rheumatology 2010 criteria, a patient satisfies diagnostic criteria for FM if the following three conditions are met:

1. Widespread pain index (WPI) ≥7 and symptom severity (SS) scale score ≥5 or WPI 3 to 6 and SS scale score ≥9
2. Symptoms have been present at a similar level for at least 3 months
3. The patient does not have a disorder that would otherwise explain the pain.

Epidemiology

The prevalence of FM is approximately 2% in Canada. 80-90% of all cases are among women (41).

Etiology

The etiology of FM is not clear, but the most clearly defined mechanism is the alteration of central pain pathways. Emotional conditions can trigger or worsen symptoms (42). The relationship between the nervous system and inflammation is well-characterized but the mechanism that links the various features of FM, including stress-related manifestations, central sensitization, and dysregulation of the innate and adaptive immune responses is largely unknown (42).

Physiological changes

Mast cells play a role in maintaining pain conditions such as musculoskeletal pain and central sensitization in FM; they can mediate microglia activation through the production of proinflammatory cytokines such as IL-1beta, IL-6, and TNFalpha (42).

Prognosis

One long-term follow-up study found that symptoms of FM are persistent for decades in most individuals without significant deterioration of self-reported functional ability (43). About a quarter of individuals with FM experience periods of time without symptoms during their illness (43). Shorter follow-up studies support these findings; some individuals with FM have reported improved symptoms over a 2–3-year period, but most report stable symptoms over time (44–46).

Treatment

Medications: Only pregabalin and duloxetine have Health Canada approval for management of fibromyalgia symptoms, but acetaminophen, NSAIDs and tramadol are also effective for pain control in fibromyalgia (48).

Concurrent sleep and mood disorders are best treated with tricyclic and other antidepressants. Cannabis can be helpful for both pain and sleep disorders (48). Physical: Graded or pacing exercise can be useful (48).

C. Vulvodynia

Definition and diagnosis

Vulvodynia is a CPS that affects the vulvar area. It occurs without an identifiable cause or visible pathology (49,50). Other terms used include provoked vestibulodynia, vulvar vestibulitis, vulvar vestibulitis syndrome, vulvar dysesthesia and dysesthetic vulvodynia. This syndrome is characterized by severe pain on vestibular touch or attempted vaginal entry, point tenderness to cotton-tip palpation of the vulvar vestibule, and physical findings confined to vestibular erythema and non-specific inflammation (51).

Epidemiology

Vulvodynia may be the main cause of dyspareunia in premenopausal women with reported prevalence rates of up to 15% in general gynecological practice (52).

Etiology

There is no known cause, but it commonly occurs after an infection such as vaginal candidiasis.

Physiological changes

Allele 2 in the interleukin-1β gene has been reported to be more common in women with vulvar vestibulitis syndrome than in other women (53). Sensory nerves that cover the skin surface are peptidergic (protein producing) and when these sensory nerves are irritated, they produce Substance P, which is pain producing, and other unfavorable cytokines such as calcitonin gene related peptide and neurokinin A (54). These proteins are called neuropeptides as they are produced by nerves. A simple definition of neurogenic inflammation is the “release of neuropeptides from nociceptors” (55).

Prognosis

Remission of symptoms after a diagnosis of Vulvodynia is common. However, half of the women with remission end up having a relapse soon thereafter. Persistence of Vulvodynia symptoms happens in the minority. Factors associated with whether the patient will experience relapse, remission or persistence are the characteristics of the pain, pain duration and comorbidities (56). Vulvodynia is a chronic disease, and the data regarding long-term prognosis is limited (57).

Treatment

Pharmacological treatments that may be beneficial but require further research include antinociceptive agents (lidocaine, capsaicin), anti-inflammatory agents (corticosteroids, interferon), neuromodulating medications (anticonvulsants and antidepressants), hormonal agents, and muscle relaxants (e.g., botulinum toxin). There is strong evidence to support and recommend non-pharmacological interventions including psychological therapy, pelvic floor physical therapy, as well as surgery (i.e., vestibulectomy for provoked vestibulodynia) for the treatment of vulvodynia (58,59).

Chronic Lyme Disease (CLD)

Chronic Lyme Disease (CLD) is one example of a bacterial infection that can trigger a CCC. It causes chronic fatigue and other symptoms.

Definition and diagnosis

The International Lyme and Associated Diseases Society defines CLD as a multisystem illness with a wide range of symptoms and/or signs that are either continuously or intermittently present for a minimum of six months. CLD is characterized by symptoms such as fatigue, musculoskeletal pain and cognitive difficulties which may wax, wane, or migrate over time (60,61). CLD includes those with untreated late-stage infection (such as late Lyme neuroborreliosis) and those with symptoms that persist after treatment (post-treatment syndrome) (60,61).

Initial diagnosis of Lyme disease usually involves a two-step serological process, and sometimes PCR or culture (62–64). Objective biomarkers to test for CLD are currently lacking (65).

A diagnosis of CLD can be made if the following criteria have been satisfied:

1. documented clinical and laboratory evidence of previous infection with *Borrelia burgdorferi*;
2. a completed course of appropriate antibiotic therapy;
3. symptoms including fatigue, arthralgia, myalgia, cognitive dysfunction, or radicular pain persisting for at least six months;
4. a plausible chronological association between documented *B. burgdorferi* infection and onset of symptoms; and
5. exclusion of other somatic or psychiatric causes of symptoms (66).

A condition other than CLD is eventually diagnosed in 80% of individuals with persistent and pleomorphic symptoms after documented or suspected Lyme infection (67,68).

Epidemiology

It is estimated that 10% of individuals who have been diagnosed with Lyme disease experience fatigue, musculoskeletal pain, concentration disorders, or short-term memory deficits six months following treatment (65). The neurological manifestations, Lyme neuroborreliosis, are reported in 10-15% of patients with Lyme disease (69–71). The risk of initial infection depends on the geographic distribution of vector tick species, ecologic factors that influence tick infection rates, and human behaviours that promote tick bite. Rates of infection are highest among children 5 to 15 years old and adults older than 50 years (72). Risk factors for CLD following infection include delayed diagnosis, increased severity of symptoms, and presence of neurologic symptoms at time of initial treatment (61).

Etiology

The etiology of CLD remains unclear, but there is strong evidence that CLD is not caused by persistent active infection (67). Prolonged treatment with antibiotics has no benefit in relieving CLD symptoms and carries the risk of serious adverse effects (68–75). Other potential illness-causing mechanisms have been investigated, including immune dysregulation through inflammatory or secondary autoimmune pathways, and altered neural networks, as in central sensitization (76,77). Psychological trauma may also contribute to CLD symptoms (78).

Physiological changes

Neuroimaging studies have shown abnormalities in individuals with CLD compared to healthy adults (65).

Prognosis

One study followed people with documented cases of acute Lyme disease and found that 10-20 years later, 9% had severe fatigue (79). However, in most of these people, their symptoms were not thought to be related to Lyme disease (79).

Treatment

Prolonged courses of antibiotics are sometimes used, but a clinical practice guideline states “The evidence does not support the hypothesis that persistent symptoms should be interpreted as clinical infection, or that antibiotic retreatment is safe and effective” (80). We are left with general treatments for the neuropathic pain, chronic fatigue and other symptoms.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

Definition and diagnosis

ME/CFS is characterized by persistent fatigue that is not alleviated by rest. There are no reliable or specific biological causes, biomarkers or laboratory anomalies that indicate or help to diagnose ME/CFS. Instead, diagnosis is based on self-reported symptoms. Using the 2015 Institute of Medicine criteria (81) a diagnosis of CFS can be made if patients have the following 3 symptoms:

1. Substantial reduction/impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities that:
    a. persists for more than six months;
    b. is accompanied by fatigue that is often profound;
    c. is of new or definite onset;
    d. is not the result of ongoing excessive exertion; and
    e. is not substantially alleviated by rest
2. Post-exertional malaise (PEM)
3. Unrefreshing sleep.

Patients must also have at least 1 of the following symptoms:

1. Cognitive impairment
2. Orthostatic intolerance

Symptoms must be present at least half of the time and have moderate, substantial, or severe intensity.

The DePaul symptom questionnaire, the 36-question short form of the DePaul questionnaire (SF-36) (82) the functional capacity scale (83), and the CFS-activities and participation questionnaire (CFS-APQ) (84,85) may be useful tools when assessing individuals with ME/CFS.

Epidemiology

A comprehensive review of prevalence studies estimated the prevalence to be 0.89% (86). ME/CFS has been found to be 2 to 3 times more prevalent among women than men, and onset has been observed to peak during adolescence and between 30 and 50 years of age.

Etiology

Viral and bacterial infections and immunological, neuroendocrine, genetic, gastrointestinal, and psychological factors have been investigated as triggering factors of chronic fatigue syndrome, but the etiology of ME/CFS remains unclear. Epstein Barr virus (EBV) is an example of a virus that can lead to post-infectious fatigue syndrome. The lifetime prevalence of EBV infection is 90-95% (87,88), and infection in adolescents and young adults can lead to infectious mononucleosis (IM) in up to 50% of cases. Evidence suggests that there may also be an inflammatory component to ME/CFS (89).

Physiological changes

Although there is insufficient data to identify a unique biomarker of ME/CFS, there are abnormal metabolic patterns in peripheral blood of individuals with ME/CFS (90). Numerous studies investigating ME/CFS using neuroimaging techniques have reported neurological or cognitive differences in adults with ME/CFS compared to healthy adult controls. Differences include changes in grey and white matter volumes, cerebral blood flow, brain structure, sleep, EEG activity, functional connectivity, and cognitive function (91). Additional brain area recruitment and sluggish functional MRI signal response suggest abnormal neurovascular coupling in adults with ME/CFS (92).

Individuals with ME/CFS have also been observed to have elevated ss2 adrenergic receptor (ss2AdR) and M3 acetylcholine receptor antibodies (93); different methylation patterns of genomic DNA and noncoding RNA profiles of immune cells (94); reduced mitochondrial function (96); reduced glycolysis (95); difference in blood values of creatine kinase; difference in the count, size and zeta-potential of plasma extracellular vesicles (94,96); increased levels of GDF15, a circulating biomarker of cellular stress (97); difference in expression of protein kinase genes (98); increased hypermobility, signs of intracranial hypertension, and craniocervical obstructions (99); increased proportion of mucosal associated invariant T cells (100); and elevated levels of LncRNAs NTT, MIAT and EmX2OS (101).

Prognosis

Measures of disability, fatigue, support, optimism, and coping have been observed to remain stable over a 10-year period among individuals with ME/CFS (102). In one small study of 56 deceased individuals with ME/CFS, researchers found that individuals with ME/CFS had an increased risk of earlier all-cause and cardiovascular-related mortality, and a lower age of death for suicide and cancer compared to the overall US population (103).

Treatment

Sleep disturbance is common and should be managed (23,24). Often a small dose of a tricyclic antidepressant is helpful. Fatigue and cognitive difficulties may be treated with stimulants such as methylphenidate and Modafinil and these are effective in about 30% of people (104,105). Any

concurrent depression should be offered a trial of appropriate antidepressants. Concurrent chronic pain should be managed as discussed above.

Pacing, where the patient exercises as much as possible within the constraints of their symptoms, is a useful approach and better than graded exercise (106).

The use of CBT in ME/CFS has become controversial and the US Centers for Disease Control and Prevention have removed CBT from the recommended treatments for the condition (48). A systematic review of mind-body interventions (MBIs) including CBT and mindfulness found that fatigue severity, anxiety/depression and physical and mental functioning were improved in patients receiving MBIs. However, small sample sizes, heterogeneous diagnostic criteria, and a high risk of bias may challenge these results (107).

Appendix B

General treatments of CCCs

In addition to the treatments that are described for specific CCCs in Appendix A, the following treatments can be considered as appropriate for patients with CCCs. The possibility of the existence of therapeutic approaches unknown to the assessors must always be borne in mind. It is for an assessor to decide if they or the other assessor have sufficient expertise in the condition that is causing the patient's suffering (with respect to diagnosis, prognosis, treatment options (currently available and under study).

Medications

Patients with chronic pain who are seeking MAiD should be viewed with a palliative approach. Consider opioids for non-cancer pain or augmenters like gabapentin (17). Methadone is more effective for neuropathic pain than other opioids and could be tried for refractory pain (18–20).

Intravenous or intranasal ketamine has been effective for both intractable pain and for treatment-resistant depression (21,22).

Sleep disturbance is common and may be from pain or from the condition itself and should be managed (23,24). Often a small dose of a tricyclic antidepressant is helpful.

Fatigue and cognitive difficulties may be treated with stimulants such as methylphenidate and Modafinil and these are effective in about 30% of people (104,105).

Any concurrent depression should be offered a trial of appropriate antidepressants.

Physical and occupational therapy

Graded exercise therapy (GET) has been effective in managing some cases of ME/CFS though it remains controversial particularly among some sufferers. Pacing, where the patient exercises as much as possible within the constraints of their symptoms, is an alternative approach (106). GET has been removed from the recommendations for treatment of ME/CFS by the US Centers for Disease Control and Prevention and health agencies in some other countries.

Stretching, yoga and Tai Chi have been used in many CCCs and in concurrent mental disorders with some effects.

Many chronic conditions decrease mobility and there may be adaptive and mobility devices to help (66,108).

Psychological, Somatic-Based, and Neurophysiological treatments

There are several treatments aimed at changing brain function through words, actions and thoughts.

a. Cognitive Behavioural Therapy (CBT)

CBT is one of the most evidence-based therapies for patients with concurrent depression and anxiety associated with CCCs. In CBT, people are assessed for cognitive errors (distortions), maladaptive behavioural patterns, and socio-occupational and interpersonal impairments (109). The assessment of several other psychological factors that might be useful from the psychotherapy point of view include attribution style, coping skills, and perceived stress. Patients are guided through exercises to practice more adaptive thoughts and actions.

b. Mindfulness

Mindfulness refers to intentional, non-judgmental conscious awareness of the present moment (27). Mindfulness exercises are incorporated into many therapeutic interventions. One review found that mindfulness improves pain, depression symptoms, and quality of life in patients with chronic pain (28).

c. Somatic Psychotherapy

Somatic psychotherapies may be helpful when there is also a history of trauma. They are supported by Polyvagal Theory and have the underlying neurophysiological premise that some people suffer dysregulation of the autonomic nervous system (ANS). The ANS is responsible for neuroception – the ability to detect safety, danger, and life-threat. Dysregulation is evinced by maladaptive sympathetic activation of fight or flight and/or parasympathetic shutdown of freeze/collapse/submit/detach.

Somatic Experiencing® (SE®; www.traumahealing.org) and Sensorimotor Psychotherapy (www.sensorimotorpsychotherapy.org) - two leading somatic therapies - involve interoceptive and proprioceptive awareness and can include the imagined “playing out” of the successful resolution of an original traumatic experience. Rather than use re-exposure to the memory of the original trauma, or suppression of those memories (as in cognitive-focused therapies), somatic therapy is a re-working of the traumatic experience, on a felt, subcortical level (110,111).

d. Eye Movement Therapies

Eye movement therapies, such as Eye Movement Desensitization and Reprocessing (EMDR), modulate cognitive and emotionally painful aspects of traumatic experiences. As these facets are bound to the somatic experience of pain, EMDR can reduce or abolish the intensity of physical discomfort (112). Recognized eye movement modalities include EMDR, Eye Movement Integration (EMI), Observed & Experiential Integration (OEI), and Brainspotting.

Somatic psychotherapy and eye movement modalities use directed, conscious awareness to thoughts, feelings, emotions, sensations, images, impressions, and sounds to help to regulate the autonomic nervous system. Somatic psychotherapy focuses on the autonomic nervous system; the emotional motor system (113); portions of the basal ganglia, red nucleus, and periaqueductal gray matter involved in emotion-specific movements and postures which can occur outside voluntary cortical control; the reticular arousal systems (114,115); and the limbic system (116). These treatments have been used successfully in PTSD and have also been used for CCCs with or without concurrent PTSD (2,3,111,117-121).

e. Biofeedback and Neurofeedback

Biofeedback is a self-regulatory therapy that provides feedback on physiological systems. It is used to reduce sympathetic activation (stress response) and to increase parasympathetic activation (relaxation response) of the nervous system, with more conscious control over each response (29). Neurofeedback is a type of biofeedback, which teaches self-control of brain functions to subjects by measuring brain waves and providing a feedback signal. Neurofeedback methodology proposes that by teaching self-regulation, a patient can reduce or even eliminate pain sensations from chronic conditions. Studies suggest that the brain changes its functional organization at the level of the somatosensory cortex in chronic pain patients (30). Both biofeedback and neurofeedback have been helpful in CPSs especially those with concurrent PTSD (31).

Other treatments

There are some treatments that do not fit easily into the categories of medication, physical treatment, or psychological/psychiatric treatment. One example is surgery which has been used in combination with other treatments for Vulvodynia (58).

The possibility of the existence of therapeutic approaches unknown to the assessors must always be borne in mind. It is for an assessor to decide if they or the other assessor have sufficient expertise in the condition causing the patient's suffering that they are aware of all reasonable and available approaches to the relief of suffering; or whether instead consultation with a physician or nurse practitioner with that expertise might be necessary to determine if treatments not known to the two assessors might be available.

Financial and other barriers to treatment

Treatments that have been shown to be useful in some conditions, including CBT, somatic experience therapy, and intranasal ketamine, are not covered financially by most patient's provincial or private insurance and may be unavailable to them. In addition, access to some treatments may be difficult due to local issues of availability, for example in more rural areas. This may lead to the ethical dilemma of patients seeking MAiD instead of treatment they cannot afford (which might be effective) or which is difficult to access in their area. This is, of course, not a problem unique to patients who do not have an RFND; it has been an issue for some patients and their assessors since MAiD became legal for patients with an RFND in 2016. For example, a patient with an RFND who decides to choose MAiD because they are not able to access 24-hour home care making admission to a care facility their only other obvious option, one which they find unacceptable. However, in certain situations it may be appropriate for the assessors to suggest to the patient's family physician or specialist that efforts need to be made to secure treatment or support for the patient, especially if the assessment has revealed gaps in management. Referral to a social worker, to geriatric specialty services, or to palliative care may also need to be suggested.

Appendix C

Canadian Law

Canadian law on MAiD is contained within the *Criminal Code of Canada* as first amended in 2016 by *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* (usually called Bill C-14 or simply C-14) and then amended in 2021 by *An Act to amend the Criminal Code (medical assistance in dying)* (usually called Bill C-7 or simply C-7).

It should be noted that this Appendix only covers federal legislation. The province of Quebec has its own law on medical assistance in dying; clinicians in Quebec must act in accordance with both laws or, where they are inconsistent (as they are currently with respect to MAiD where mental disorder is the sole underlying medical condition), with instructions from their professional regulatory body and/or the director of criminal and penal prosecutions.

Eligibility for MAiD

> ***Eligibility criteria***
>
> 241.2 (1) A person may receive medical assistance in dying only if they meet all of the following criteria:
>
> (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;
>
> (b) they are at least 18 years of age and capable of making decisions with respect to their health;
>
> (c) they have a grievous and irremediable medical condition;
>
> (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
>
> (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.
>
> ***Grievous and irremediable medical condition***
>
> (2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:
>
> (a) they have a serious and incurable illness, disease or disability;*
>
> (b) they are in an advanced state of irreversible decline in capability; and
>
> (c) that illness, disease, or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable.

* For the purposes of this legislation, until the law changes, a mental illness is not considered to be an illness, disease, or disability.

It is important to note that that Bill C-7 removed one of the Bill C-14 eligibility criteria – that a person's natural death had to have become reasonably foreseeable. However, it retained the concept of reasonably foreseeable – it now serves as the determining factor as to which procedural safeguards the individual must meet.

Procedural safeguards

There are two different sets of procedural safeguards that apply to individuals depending on whether their natural death has become reasonably foreseeable or not.

Natural death reasonably foreseeable

For patients who meet the eligibility criteria set out above and whose natural death has become reasonably foreseeable, *the following procedural safeguards must be met:*

> (3) Before a medical practitioner or nurse practitioner provides a person with medical assistance in dying, the medical practitioner or nurse practitioner must
> (a) be of the opinion that the person meets all of the criteria set out in subsection (1);
> (b) ensure that the person's request for medical assistance in dying was
> (i) made in writing and signed and dated by the person or by another person under subsection (4), and
> (ii) signed and dated after the person was informed by a medical practitioner or nurse practitioner that the person has a grievous and irremediable medical condition;
> (c) be satisfied that the request was signed and dated by the person — or by another person under subsection (4) — before an independent witness who then also signed and dated the request;
> (d) ensure that the person has been informed that they may, at any time and in any manner, withdraw their request;
> (e) ensure that another medical practitioner or nurse practitioner has provided a written opinion confirming that the person meets all of the criteria set out in subsection (1);
> (f) be satisfied that they and the other medical practitioner or nurse practitioner referred to in paragraph (e) are independent;
> (g) if the person has difficulty communicating, take all necessary measures to provide a reliable means by which the person may understand the information that is provided to them and communicate their decision; and
> (h) immediately before providing the medical assistance in dying, give the person an opportunity to withdraw their request and ensure that the person gives express consent to receive medical assistance in dying.*

* This requirement does not need to be met if the conditions set out in the provisions regarding final consent – waiver [section (3.2)] or advance consent – self-administration [section (3.5)] are met.

Natural death NOT reasonably foreseeable

For patients who meet the eligibility criteria set out above and whose natural death has not become reasonably foreseeable, *the following procedural safeguards must be met*:*

> (3.1) Before a medical practitioner or nurse practitioner provides medical assistance in dying to a person whose natural death is not reasonably foreseeable, taking into account all of their medical circumstances, the medical practitioner or nurse practitioner must
> (a) be of the opinion that the person meets all of the criteria set out in subsection (1);

(b) ensure that the person's request for medical assistance in dying was
(i) made in writing and signed and dated by the person or by another person under subsection (4), and
(ii) signed and dated after the person was informed by a medical practitioner or nurse practitioner that the person has a grievous and irremediable medical condition;
(c) be satisfied that the request was signed and dated by the person — or by another person under subsection (4) — before an independent witness who then also signed and dated the request;
(d) ensure that the person has been informed that the person may, at any time and in any manner, withdraw their request;
(e) ensure that another medical practitioner or nurse practitioner has provided a written opinion confirming that the person meets all of the criteria set out in subsection (1);
(e.1) if neither they nor the other medical practitioner or nurse practitioner referred to in paragraph (e) has expertise in the condition that is causing the person's suffering, ensure that they or the medical practitioner or nurse practitioner referred to in paragraph (e) consult with a medical practitioner or nurse practitioner who has that expertise and share the results of that consultation with the other practitioner;
(f) be satisfied that they and the medical practitioner or nurse practitioner referred to in paragraph (e) are independent;
(g) ensure that the person has been informed of the means available to relieve their suffering, including, where appropriate, counselling services, mental health and disability support services, community services and palliative care and has been offered consultations with relevant professionals who provide those services or that care;
(h) ensure that they and the medical practitioner or nurse practitioner referred to in paragraph (e) have discussed with the person the reasonable and available means to relieve the person's suffering and they and the medical practitioner or nurse practitioner referred to in paragraph (e) agree with the person that the person has given serious consideration to those means;
(i) ensure that there are at least 90 clear days between the day on which the first assessment under this subsection of whether the person meets the criteria set out in subsection (1) begins and the day on which medical assistance in dying is provided to them or — if the assessments have been completed and they and the medical practitioner or nurse practitioner referred to in paragraph (e) are both of the opinion that the loss of the person's capacity to provide consent to receive medical assistance in dying is imminent — any shorter period that the first medical practitioner or nurse practitioner considers appropriate in the circumstances;
(j) if the person has difficulty communicating, take all necessary measures to provide a reliable means by which the person may understand the information that is provided to them and communicate their decision; and
(k) immediately before providing the medical assistance in dying, give the person an opportunity to withdraw their request and ensure that the person gives express consent to receive medical assistance in dying.**

* Safeguards in bold font are new for MAiD in Canada
** This requirement does not need to be met if the conditions set out in the provisions re: advance consent – self-administration [section (3.5)] are met.

Interpretations of key provisions of current Canadian law on MAiD

There has been confusion and controversy over the meaning of some of the key provisions in Canada's MAiD law.

There have not been any judicial interpretations of any of the terms other than "reasonably foreseeable." When there is no judicial interpretation available, clinicians must look to their regulators and experts. In this section, we identify first judicial interpretations (where they exist), then those from regulators (where they exist), and then interpretations from groups of experts. The first expert group (the Halifax Group) consisted of 15 independent experts drawn from academia, the law, MAiD clinicians, provincial and territorial regulators, and individuals who hold senior posts within professional representative organizations (though present in an individual capacity) (122). The second (the Federal Expert Panel on MAiD and Mental Illness) consisted of members reflecting "a range of disciplines and perspectives, including clinical psychiatry, MAID assessment and provision, law, ethics, health professional training and regulation, mental health care services, as well as lived experience with mental illness" (127). The third (the MAiD Practice Standard Task Group) consisted of individuals drawn from clinical psychiatry, MAiD assessment and provision, law, ethics, and health professional training and regulation (128). Note: The MAiD Practice Standard Task Group content is in italics to emphasize the fact that it is from a draft version. It will be replaced with the final version once available.

Incurable

1. Court

Not litigated.

2. Regulators

An Inquiry Committee for the College of Physicians and Surgeons of British Columbia (CPSBC) found that BC physicians who conclude that a patient's condition is incurable even though the patient has declined a potentially effective treatment, will not be in breach of the College's standard (123).

3. Expert groups

<u>Halifax Group</u>

"Incurable" means that, in the professional opinion of the medical or nurse practitioner, the person cannot be cured by means acceptable to that person. This does not mean that the professional opinion substitutes for the person's assessment of whether the means are acceptable; rather it means that professional opinion holds that there are no clinical options that would accord with the person's own assessment of acceptable means (122).

<u>Federal Expert Panel on MAiD and Mental Illness</u>

MAiD assessors should establish incurability with reference to treatment attempts made up to that point, outcomes of those treatments, and severity and duration of illness, disease, or disability.

It is not possible to provide fixed rules for how many treatment attempts, how many kinds of treatments, and over what period of time as this will vary according to the nature and severity of medical conditions the person has and their overall health status. This must be assessed on a case-by-case basis.

The Panel is of the view that the requester and assessors must come to a shared understanding that the person has a serious and incurable illness, disease, or disability. As with many chronic conditions, the incurability of a mental disorder cannot be established in the absence of multiple attempts at interventions with therapeutic aims (127).

MAiD Practice Standard Task Group

When there is uncertainty in the natural history of the illness, disease or disability (typically complex Track Two cases), incurability cannot be established in the absence of multiple attempts at interventions with therapeutic aims. In such circumstances, MAiD Providers and Assessors should establish incurability with reference to treatment attempts made prior to the request, outcomes of those treatments, and severity and duration of illness, disease, or disability. (Footnote: The number of treatment attempts, the treatment modalities, and the duration of treatment required to establish incurability will vary according to the nature and severity of medical conditions the person has and their overall health status. Therefore, this must be assessed on a case-by-case basis.)

A person who requests MAiD may believe that they have a serious and incurable illness, disease, or disability. However, it is the Provider and Assessor who must be of the opinion that the person has a serious and incurable illness, disease or disability (128).

Advanced state of irreversible decline in capability

1. Court

Not litigated.

2. Regulators

No professional standards or committees of inquiry have addressed this.

3. Expert groups

Halifax Group

"Advanced state of irreversible decline in capability" includes declines in cognitive as well as physical functions; sudden as well as gradual losses of capability; and ongoing as well as stabilized declines in capability. It is assessed by the medical or nurse practitioner, and it is assessed relative to the patient's prior capability (122).

Federal Expert Panel on MAiD and Mental Illness

MAiD assessors should establish irreversibility with reference to interventions tried that are designed to improve function, including: recognized rehabilitative and supportive measures that have been tried up to that point, outcomes of those interventions, and the duration of decline.

It is not possible to provide fixed rules for how many attempts at interventions, how many types of interventions, and over how much time, as this will vary according to a requester's baseline function as well as life goals. Therefore, this must be assessed on a case-by-case basis.

The Panel is of the view that the requester and assessors must come to a shared understanding that the person is in an advanced state of irreversible decline in capability (127).

When there is uncertainty about the evolution of functional status (typically complex Track Two cases), irreversibility cannot be established in the absence of multiple attempts at treatment and rehabilitation. In such circumstances, MAiD Providers and Assessors should determine irreversibility with reference to interventions tried that are designed to improve function, including: recognized rehabilitative and/or supportive measures that have been tried prior to the request, the outcomes of those interventions, and the duration of decline. (Footnote: The number of intervention attempts, the modalities used, and the duration required to establish an advanced state of irreversible decline will vary according to a person's baseline function as well as life goals. Therefore, this must be assessed on a case-by-case basis.)

Functional status should be assessed independently of incurable illness, disease or disability related symptoms. (Footnote: Persons may experience chronic symptoms of an illness, disease or disability but have potential for functional improvement or recovery when they receive appropriate rehabilitative and/or supportive measures including housing, social and income support programs.)

A person who requests MAiD may believe that they are in an advanced state of irreversible decline in capability. However, it is the Provider and Assessor who must be of the opinion that the person is in an advanced state of irreversible decline in capability (128).

Intolerable

1. Court

Not litigated

2. Regulators

No professional standards or committees of inquiry have addressed this.

3. Expert groups

Halifax Group

"[I]ntolerable to them" means extreme, in the opinion of the patient (124).

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MAiD assessors should come to an understanding with the requester that the illness, disease or disability or functional decline causes the requester enduring and intolerable physical or psychological suffering.

The third element of the definition of grievous and irremediable medical condition refers to the suffering experienced by a MAiD requester and states: "that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable" (129). Suffering is a personal experience, and this part of the definition also indicates that it is subjective.

A person's interpretations of the persistence and permanence of their suffering resulting in a request for MAiD should reflect a realistic appraisal of their situation.

The second part of the suffering sub-criterion is that the requester's suffering cannot be relieved under conditions they consider acceptable. Consistent with existing laws and norms concerning

consent and capacity, capable persons are usually entitled to refuse interventions they do not wish to receive (Gilmour, 2017; Robertson, 2017, pp. 53-58).

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For the purposes of forming the opinion that the suffering criterion for MAiD is met, Providers and Assessors:

- *must be of the opinion that it is the person's illness, disease or disability or state of decline in capability that is the cause of the person's suffering;*
- *must respect that "suffering" under the Criminal Code is subjective; and*
- *should explore the consistency of the person's assessment of their suffering with the person's affect, expressed wishes over time, and life narrative (128)*

Reasonably foreseeable

1. Court

In 2017, the Ontario Superior Court of Justice heard the case of the applicant AB who wished to establish that her own natural death was reasonably foreseeable (required to be eligible for MAiD under C-14 which was in force at the time) (124). The trial judge, Justice Perell, stated in his decision:

> "[77] The application before the court is not about interpreting what it means for a medical practitioner "to be of the opinion that the person meets all of the criteria." Rather, the application arises because Physician-1 is uncertain about the meaning of "natural death has become reasonably foreseeable" in s. 241.2 (2)(d).
>
> [78] There is and there ought not to be any uncertainty or misunderstanding about the meaning of those words.
>
> [79] In this regard, those words are modified by the phrase "taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining." This language reveals that natural death need not be imminent and that what is a reasonably foreseeable death is a person-specific medical question to be made without necessarily making, but not necessarily precluding, a prognosis of the remaining lifespan.
>
> [80] Although it is impossible to imagine that the exercise of professional knowledge and judgment will ever be easy, in those cases where a prognosis can be made that death is imminent, then it may be easier to say that the natural death is reasonably foreseeable. Physicians, of course, have considerable experience in making a prognosis, but the legislation makes it clear that in formulating an opinion, the physician need not opine about the specific length of time that the person requesting medical assistance in dying has remaining in his or her lifetime.
>
> [81] In referring to a "natural death" the language denotes that the death is one arising from causes associated with natural causes; i.e., the language reveals that the foreseeability of the death must be connected to natural causes, which is to say about causes associated with the functioning or malfunctioning of the human body. These are matters at the core if not the whole corpus of medical knowledge and better known to doctors than to judges. The language reveals that the natural death need not be connected

to a particular terminal disease or condition and rather is connected to all of a particular person's medical circumstances.

[82] The Attorney General, in introducing Bill C-14, described the meaning of the words in s. 241.2 (2)(d), and in my opinion, she correctly said that the language does not require that people be dying from a terminal illness, disease or disability.

[83] As the Attorney General said, the language of s. 241.2 (2)(d) encompasses, on a case-by-case basis, a person who is on a trajectory toward death because he or she: (a) has a serious and incurable illness, disease or disability; (b) is in an advanced state of irreversible decline in capability; and (c) is enduring physical or psychological suffering that is intolerable and that cannot be relieved under conditions that they consider acceptable.

[84] These criteria or factors are all matters with which Physician-1 and all physicians are, on an everyday basis, capable of forming opinions on. Physician-1 and all other physicians are equally capable of determining whether the criteria or factors are not satisfied because a natural death is not reasonably foreseeable.

[85] During 2015-2016 in the run up to the enactment of Bill 14, some of these factors or criteria were considered in the case law about what was formerly described as physician-assisted death and what is now described as medical assistance in dying.
In A.B. v. Canada (Attorney General), 2016 ONSC 1912 and in I.J. v. Canada (Attorney General), 2016 ONSC 3380, I held that a grievous medical condition connotes that the person's medical condition greatly or enormously interferes with the quality of that person's life. In I.J. v. Canada (Attorney General), supra, I held that in determining whether a person satisfies the criteria for a physician-assisted death, the proximity or remoteness of death and the duration of suffering are relevant factors that must be considered in the unique and special circumstances of any applicant. In Canada (Attorney General) v. E.F., 2016 ABCA 155, the Alberta Court of Appeal held that the constitutional exemption granted in Carter v. Canada (Attorney General) (124), does not require the applicant's medical condition to be terminal."

A definition of "reasonably foreseeable" was also provided to the BC Supreme Court by an expert who appeared for the Attorney General of Canada during the initial stages of the case of Lamb v. Canada. The Attorney General of Canada accepted this interpretation. Dr. Madeline Li said that Julia Lamb would meet the "reasonably foreseeable" criterion because:

> If Ms. Lamb were to be assessed now, and she indicated an intent to stop BiPaP [a machine similar to a CPAP machine, which helps a person breathe better while sleeping] and refuse treatment when she next developed pneumonia, it is likely that she would be found to meet the threshold for having a reasonably foreseeable natural death … She would not be required to develop an episode of pneumonia before being approved for MAiD. Most would consider it sufficient that she expresses certain intent to refuse treatment when this occurs, as she will inevitably develop a chest infection in the near future.

In other words, to meet the "reasonably foreseeable" criterion, all Julia Lamb had to do was express certain intent to stop preventive care and refuse treatment for the inevitable ensuing infection. Thus, it can be concluded that patients can meet the "reasonably foreseeable" criterion if they have demonstrated a clear intent to take steps to make their natural death happen soon or to cause their death to be predictable (125).

2. Regulators

a. College of Physicians and Surgeons of Nova Scotia

> 13.15 “Reasonably Foreseeable” means that:
>
> (a) “natural death need not be imminent and that what is a reasonably foreseeable death is a person-specific medical question to be made without necessarily making, but not necessarily precluding, a prognosis of the remaining lifespan”.
>
> (b) In formulating an opinion, the physician need not opine about the specific length of time that the person requesting medical assistance in dying has remaining in his or her lifetime (126).

b. College of Physicians and Surgeons of British Columbia (CPSBC)

An Inquiry Committee for the CPSBC found that it was not a breach of the College standard to find a patient’s natural death reasonably foreseeable on the grounds that she had stopped eating and drinking (123). (The patient had advanced multiple sclerosis).

3. Expert groups

<u>Halifax Group</u>

“Natural death has become reasonably foreseeable” does not mean that eligibility is limited to fatal conditions, that the person is “terminally ill” or “at the end of life”, or that death is imminent or anticipated within six months. Temporal proximity - the nearness of natural death - can be sufficient for concluding that natural death is reasonably foreseeable. However, temporal proximity is not necessary for reasonable foreseeability. Indeed, it is not necessary for the medical or nurse practitioner to have predicted or to be able to predict the length of time the patient has remaining. Similarly, a predictable cause of natural death can also be a sufficient condition for concluding that natural death is reasonably foreseeable, but it is also not necessary for reaching this conclusion. In other words, natural death will be reasonably foreseeable if either condition exists - a predicted death in “a period of time that is not too remote” or a predictable cause of natural death - but it is not necessary for both conditions to exist for the patient to meet this eligibility criterion” (122).

* Note this interpretation was developed before the *Lamb* case. It is not known whether this expert group would have added “certain intent to stop preventive care” to the definition of “natural death has become reasonably foreseeable.”

<u>Canadian Association of MAiD Assessors and Providers (CAMAP)</u>

According to the CAMAP guidance document (https://camapcanada.ca/):

1. Clinicians may interpret “reasonably foreseeable” as meaning “reasonably predictable”. This may mean that there is sufficient temporal proximity to death (it is coming soon), and/or that the trajectory towards death is predictable from the person’s combination of known medical conditions and potential sequelae. In clinical circumstances this would include the consideration of a person’s individual circumstances such as age and frailty.

2. Clinicians need not employ or support rigid timeframes in their determination of whether a person has a reasonably foreseeable natural death (RFND). The law does not require a prognosis to be given as to the length of time the person has remaining. For greater clarity, "natural death

has become reasonably foreseeable" does not mean that the person must be terminally ill or expected to die within a set period such as 6 or 12 months.

3. A person may meet the "reasonably foreseeable" criterion if they have demonstrated a clear and serious intent to take steps to make their natural death happen soon or to cause their death to be predictable. Examples might include stated declarations to refuse antibiotic treatment of current or future serious infection, to stop use of oxygen therapy, to refuse turning if they have quadriplegia, or to voluntarily cease eating and drinking.

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Not addressed.

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References AB decision and CAMAP guidance document (see above).

The implications of the recent changes to Canada's MAiD law for CCCs

Two issues will be of great significance in determining the implications of the recent changes to Canada's MAiD law for CCCs.

First, whether CCCs are considered a "mental illness" for the purposes of the Criminal Code (affecting eligibility). Second, whether, for the person with CCC, natural death has become reasonably foreseeable (affecting which procedural safeguards must be met).

1. ***Temporary (until unknown date)*** "***mental illness" exclusion***

There is a lack of consensus among experts as to whether CCCs are psychiatric or neurobiological in origin. There is additionally a lack of consensus as to whether that distinction even exists. The law does not define "mental illness" although it is clear that not everything in the DSM-5 is to be considered a "mental illness" for the purposes of excluding individuals from MAiD eligibility. The Legislative Background document to Bill C-7 provided some clarification:

> Despite the absence of a single clear definition of mental illness, in the context of Canadian discussions on MAiD, this term has come to be understood as generally referring to those conditions which are primarily within the domain of psychiatry, and which raise specific types of concerns as set out above [e.g., disagreements about irremediability, challenges with capacity assessments, difficulties establishing the trajectory of a condition], when it comes to eligibility for MAiD. In the context of the federal MAiD legislation, the term "mental illness" would not include neurocognitive or neurodevelopmental disorders, or other conditions that may affect cognitive abilities, such as dementias, autism spectrum disorders or intellectual disabilities, which may be treated by specialties other than psychiatry (such as neurology for neurodegenerative or neurodevelopmental conditions) or specialties outside of medicine (such as education specialists for intellectual disabilities) and do not raise the specific concerns outlined above (1).

Bearing this in mind it is up to the judgement of assessors to determine on a case-by-case basis, whether the person's **sole** underlying serious and incurable condition is a mental illness. If the assessors are of the opinion that it is, then the person must be found to be ineligible (until the law changes). If they are of the opinion that it is not, then the person may be found to be eligible (contingent on meeting the other eligibility criteria).

2. Removal of "reasonably foreseeable" as eligibility criterion

People with CCCs will no longer face the potential eligibility barrier of the requirement that their natural death be reasonably foreseeable.

That said, reasonable foreseeability will remain as the variable that determines which procedural safeguards track the person must follow (see above).