



Case # 2

You are a general medicine resident working on the floor. You meet Mr. D, a 68 year old male with **advanced COPD**. He has had COPD for approximately 9 years. His respirologist started referring to it as advanced about 3 years ago when he started requiring home oxygen and more recently the patient heard the term “end-stage COPD”. He was recently admitted to ICU with pneumonia and COPD exacerbation and required intubation for a short period.

Mr. D has stabilized and is being transferred from ICU to the floor. His son and daughter are present during admission. Mr. D tells you that he is more fatigued and less mobile than he was prior to admission. He also starts to talk with you about how he hates coming to hospital and doesn't want to “ever “come back. He knows this upsets his children, but he wants to know “how to just get this over with!” His children tell you that he has been talking more about wanting to “not go on” and has been asking how to get the doctors to help him “end his life”.

1. When a patient asks about MAID what is your initial gut reaction?

- This can be an emotionally challenging question and can impact residents in different ways. MAID is a controversial topic and physicians have varying viewpoints. These viewpoints are often based on the moral or religious beliefs that we acquire throughout a lifetime and can be deeply ingrained.
- When a patient asks a question that is so controversial and touches on our core beliefs, we can be quick to respond before understanding the entirety and complexity of a situation.

2. When a patient like Mr. D. asks about MAID: How would you initially respond?

Consider: The most important initial response is to validate the patient's emotions.

For example: “I can only imagine how difficult it is not wanting to go on and knowing that your children are upset by this.”

Caution: It may be tempting to answer in a factual way.

For example: “Mr. D, Medical Assistance in Dying is now legal. Do you want a referral for an assessment?”

This may, for some patients be appropriate, but for most patients this is a premature statement without a better understanding why they are asking for hastened death.

Consider: That when initially responding to a request for MAID, it is an excellent opportunity to ask questions and explore what lead to the patient's request.

For example: “Mr. D. I was wondering if you can help me to understand what made you ask me about assistance in dying.”

Caution: Even though as a physician you may not agree with MAID, it is still important to respond in a manner that invites the patient to tell you more about why they are asking about MAID.

- i. Remember that as physicians, we cannot abandon our patients
- ii. This does not mean we have to act against our conscience
- iii. This does mean we have an obligation to respond to a request and provide care and information in a non-judgmental manner

3. What are the reasons that people request a hastened death?

A desire for hastened death is a complex, multifactorial phenomenon usually triggered by a physical or psychological exacerbation of symptoms which leads to emotional distress or suffering. The literature has described possible driving factors¹ which can be grouped into “loss of self” and “fear”^{2,3,4}.

A sense of “Loss of self” can occur when people feel that they can no longer define themselves or what they were proud of due to various losses, such as loss of:

- Bodily functions
- Mobility
- Control
- Meaning
- Dignity
- Independence
- Quality of life

This “loss of self” could extend to them withdrawing from family/friends which can increase the risk of depression and anxiety.

“Fear” can be of:

- The dying process
 - > worsening symptoms
 - > progressive dependency and burdening loved ones
- Imminent death
 - > no treatment options
 - > feeling hopeless

When ‘Loss’ or ‘Fear’ drives a wish for hastened death, the actual request may represent one of three things:

- a. a way to “end suffering”
- b. a “cry for help” – a desire to live, just not in the current way
- c. “an ace up one’s sleeve” – an exit plan in case the situation becomes intolerable

4. How would you evaluate the reason why Mr. D is expressing a desire for hastened death? What are some questions you can ask?

It is essential to understand the nature of the request and what this means to the patient. Encourage patients to share their reasons for making the request by gently inviting patients to talk about what's going on in their lives.

For example: *“Mr. D, there are many reasons why people ask for Medical Assistance in dying. Can you help me to understand what led you to make this request?”*

The suffering a patient experiences can be physical, psychosocial, existential or a combination of some or all of these domains. Acknowledging the suffering and actively listening in a non-judgmental manner will help you to better understand the request and the needs of the patient.

For example: *“Patients can experience suffering in many ways. For some it may be physical, for others emotional and for some both. How would you describe your suffering?”*

Back to the case...

Through your conversation with Mr. D, you discover that he was a successful businessman who owned 4 hotels and is financially well off. He is widowed: his wife of 42 years died two years ago of ovarian cancer. They were very close. They have 2 children (Kelly 41 years old and Tom 39 years old) and 5 grandchildren ranging in ages from 5-12. After his wife's death, Mr. D required 24 hour caregiving. His family lives close and visit regularly. His daughter manages his caregiving needs. He's a fiercely independent and private person and hates having to depend on strangers for most of his care.

Prior to his wife's illness, they would spend 4 months in Florida to avoid cold weather. The worsening of his COPD coincided with his wife's cancer diagnosis and he hasn't been able to go to Florida for 3 years. This is his 4th hospitalization over the past 3 years for exacerbation of his COPD, the last 2 requiring ICU admissions including intubation.

During your discussion with Mr. D and his children, you check in and ask them if they have any questions or concerns they want to have addressed. Mr. D states that he needs time to think and talk with his family.

Three days later, you are rounding on Mr. D; he asks you more about MAID. He tells you that he is really struggling with making this decision. One day he thinks he wants it and the next he doesn't. He tells you that his daughter understands why he wants MAID and has shared that she thinks she would make that decision for herself and his son feels that he could never make that choice for himself but is supportive if his dad wanted MAID.

Discussion Questions

1. Are you surprised and/or worried by his uncertainty?

It is not unusual for patients to vacillate between wanting and not wanting MAID. It is important to realize that this is almost never a one-time conversation and that you may have to go over the same information many times as you help patients and families navigate the complex decision regarding a request for MAID.

It is important for patients to understand that in order to have MAID, they need to be able to consent on the day that MAID takes place and that it is not something that can be done through advanced care planning and a living will with substitute decision makers.

2. What are the eligibility criteria and do you feel that Mr. D qualifies?

In accordance with federal legislation, for an individual to access medical assistance in dying, he/she must:

Eligibility Criteria	Does Mr. D qualify?
Be eligible for publicly funded health services in Canada	Yes , he has publicly funded health services in Canada through OHIP.
Be at least 18 years of age and capable of making decisions with respect to their health	Yes, he is 68 years old and capable of making decisions with respect to his health. Through your discussions with him, you feel that he is able to understand the information that is relevant to making this decision (cognitive element of capacity) and is able to appreciate the reasonably foreseeable consequences of that decision (ability to exercise reasonable insight and judgment)
<p>Have a grievous and irremediable medical condition</p> <ol style="list-style-type: none"> 1. They have a serious and incurable illness, disease or disability 2. They are in an advanced state of irreversible decline 3. 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 4. Their natural death has become reasonably foreseeable, taking into account all the medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining. 	<p>Yes, he has a grievous and irremediable medical condition</p> <ol style="list-style-type: none"> 1. His end-stage COPD is a serious and incurable illness. 2. He is in an advanced state of irreversible decline; there are no treatments to improve his breathing and functional status. He will continue to deteriorate. 3. His illness causes him enduring physical suffering (dyspnea, low energy, decreased mobility) and psychological suffering (decreased independence and control, fear of being a burden to his family) that is intolerable and cannot be relieved. 4. His natural death has become reasonably foreseeable.
Make a voluntary request for medical assistance in dying that is not the result of external pressure	Yes , if he were to make a voluntary request for MAID, you have not seen any evidence of external pressure.
Provide 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	Yes , if he were to make a voluntary request, he would be able to provide informed consent and he has been informed of the means available to relieve his suffering, including palliative care.

Back to the case...

After speaking with Mr. D and answering all of his questions you have a sense that he is still not certain about his decision. Two days later, you see the patient with his children for discharge planning. He has decided that he would like to return home with 24 caregiving and with a palliative care referral for now with the proviso that he could still change his mind. Mr. D thanks you for all of your time, patience and help. He has one more question. He wants you to describe for his daughter and son the difference between MAID and palliative sedation therapy.

3. How would you describe the difference between MAID and palliative sedation therapy?

Palliative sedation therapy is a palliative treatment using pharmacological agents to reduce consciousness for patients with intolerable and refractory symptoms in the last days to weeks of life. The intent of the treatment is to decrease a patient's level of consciousness to a level where they appear comfortable...usually until they die of their underlying illness.

In MAID, a substance is administered or prescribed with the intent of causing the patient to die, and death is usually immediate upon administering the medication.

Although the end result is the same (the death of the patient) the intent is different. In Palliative Sedation therapy, the intent is to alleviate suffering until a patient dies and in MAID, it is to alleviate suffering by causing the death.

The doctrine of double effect [which states that if doing something morally good (relieving the patient's suffering) has a morally bad side-effect (potential to hasten death) it's ethically OK to do it providing the bad side-effect (patient's death) wasn't intended] is often used to help describe the difference.

Palliative sedation therapy is often used in the last days to weeks of life mostly for symptoms of delirium, dyspnea or pain. There is controversy around its use for psychological/spiritual-existential suffering. All suffering whether physical, psychosocial or spiritual may be present well before the last days or weeks of life which makes palliative sedation therapy unavailable for some. For MAID, psychological suffering is an accepted criteria and MAID can be earlier than the last days/weeks of life since the criteria are more vague and state that "**natural death has become reasonably foreseeable... without a prognosis necessarily having been made as to the specific length of time that they have remaining.**"

References:

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