Medical Aid in Dying (MAiD)

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- Professor of Clinical Psychiatry, HMS

Disclosures

I hold stock in various healthcare industry companies.

Objectives

- Understand how MAiD has evolved worldwide
- Identify ethical considerations
- Appreciate the psychiatrist's role in MAiD
- Understand guidelines for discussing MAiD with patients

Outline

- Background: Traditional Options in EOL Decision-making

  - refusal of life support
  - unilateral DNR/DNI

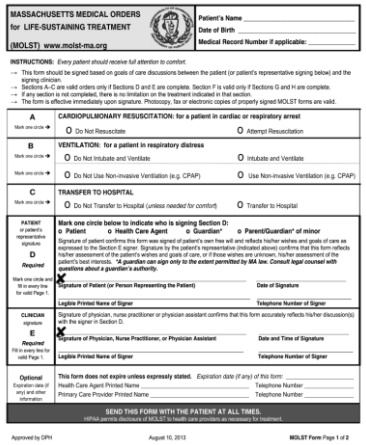
- Medical Aid in Dying (MAiD)

  - historical and legal context
  - ethical considerations
  - the psychiatrist’s role in assessing capacity for MAiD

- DFCI Study Guide for Discussing MAiD with Patients

Refusal of Life Support

- Is this suicide?
- The Nancy Cruzan case (1883-1990) affirmed the right to withdraw/withhold Rx, and highlighted the need for advance directives (ADs)
- About 1/3 of US adults have advance directives
- Two types of AD: living wills (e.g. Medical Order for Life-Sustaining Treatment, MOLST) and durable power of attorney for health care (HCP)


MASSACHUSETTS MEDICAL ORDERS for LIFE-SUSTAINING TREATMENT (MOLST) www.molst-ma.org

Patient's Name
Date of Birth
Medical Record Number if applicable:

INSTRUCTIONS: *Every patient should receive full attention to comfort.*
→ This form should be signed based on goals of care discussions between the patient (or patient's representative signing below) and the signing clinician.
→ Sections A–C are valid orders only if Sections D and E are complete. Section F is valid only if Sections G and H are complete.
→ If any section is not completed, there is no limitation on the treatment indicated in that section.
→ The form is effective immediately upon signature. Photocopy, fax or electronic copies of properly signed MOLST forms are valid.

A (Mark one circle →)	**CARDIOPULMONARY RESUSCITATION: for a patient in cardiac or respiratory arrest** O Do Not Resuscitate O Attempt Resuscitation
B (Mark one circle →)	**VENTILATION: for a patient in respiratory distress** O Do Not Intubate and Ventilate O Intubate and Ventilate
(Mark one circle →)	O Do Not Use Non-invasive Ventilation (e.g. CPAP) O Use Non-invasive Ventilation (e.g. CPAP)
C (Mark one circle →)	**TRANSFER TO HOSPITAL** O Do Not Transfer to Hospital (*unless needed for comfort*) O Transfer to Hospital

PATIENT or patient's representative signature D *Required* Mark one circle and fill in every line for valid Page 1.

Mark one circle below to indicate who is signing Section D:
o Patient o Health Care Agent o Guardian* o Parent/Guardian* of minor

Signature of patient confirms this form was signed of patient's own free will and reflects his/her wishes and goals of care as expressed to the Section E signer. Signature by the patient's representative (indicated above) confirms that this form reflects his/her assessment of the patient's wishes and goals of care, or if those wishes are unknown, his/her assessment of the patient's best interests. ****A guardian can sign only to the extent permitted by MA law. Consult legal counsel with questions about a guardian's authority.***

Signature of Patient (or Person Representing the Patient) Date of Signature
Legible Printed Name of Signer Telephone Number of Signer

CLINICIAN signature E *Required* Fill in every line for valid Page 1.

Signature of physician, nurse practitioner or physician assistant confirms that this form accurately reflects his/her discussion(s) with the signer in Section D.

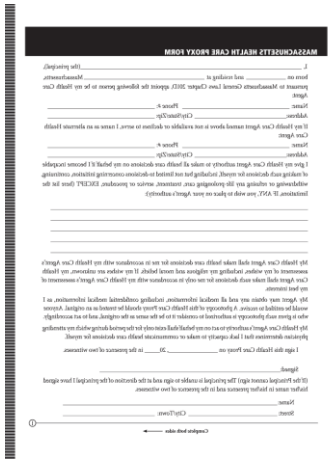
Signature of Physician, Nurse Practitioner, or Physician Assistant Date and Time of Signature
Legible Printed Name of Signer Telephone Number of Signer

Optional Expiration date (if any) and other information

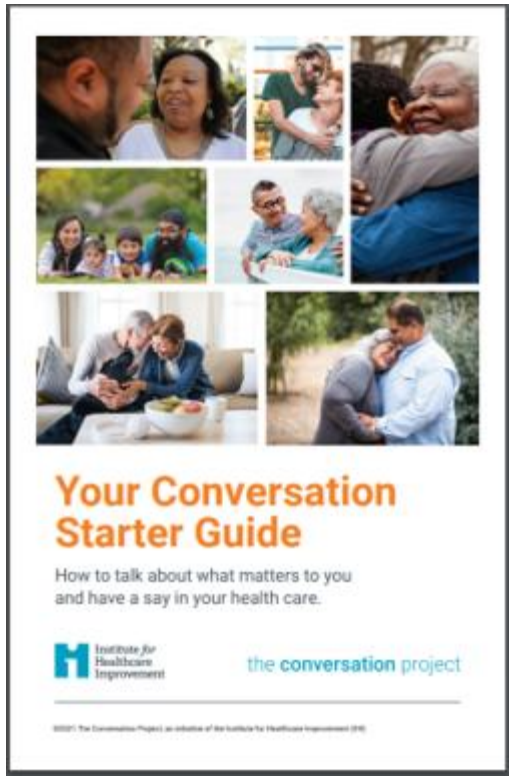
This form does not expire unless expressly stated. *Expiration date (if any) of this form:*
Health Care Agent Printed Name Telephone Number
Primary Care Provider Printed Name Telephone Number

SEND THIS FORM WITH THE PATIENT AT ALL TIMES.
HIPAA permits disclosure of MOLST to health care providers as necessary for treatment.

Approved by DPH August 10, 2013 MOLST Form Page 1 of 2


MASSACHUSETTS HEALTH CARE PROXY FORM

Advance Care Planning



Check for updates

Palliative Care & Social Practice — *Curriculum and Pedagogic Study*

Promoting advance care planning in African American faith communities: literature review and assessment of church-based programs

Jenny McDonnell and Ellen Idler

Palliative Care & Social Practice
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Abstract: Advance care planning is under-used among Black Americans, often because of experiences of racism in the health care system, resulting in a lower quality of care at the end of life. African American faith communities are trusted institutions where such sensitive conversations may take place safely. Our search of the literature identified five articles describing faith-based advance care planning education initiatives for Black Americans that have been implemented in local communities. We conducted a content analysis to identify key themes related to the success of a program's implementation and sustainability. Our analysis showed that successful implementation of advance care planning programs in Black American congregations reflected themes of building capacity, using existing ministries, involving faith leadership, exhibiting cultural competency, preserving a spiritual/Biblical context, addressing health disparities, building trust, selectively using technology, and fostering sustainability. We then evaluated five sets of well-known advance care planning education program materials that are frequently used by pastors, family caregivers, nurse's aides, nurses, physicians, social workers, and chaplains from a variety of religious traditions. We suggest ways these materials may be tailored specifically for Black American faith communities, based on the key themes identified in the literature on local faith-based advance care planning initiatives for Black churches. Overall, the goal is to achieve better alignment of advance care planning education materials with the African American faith community and to increase implementation and success of advance care planning education initiatives for all groups.

Keywords: advance care planning, faith-based program, health disparities, health education

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Introduction

The National Academy of Medicine recognizes advance care planning (ACP) as a key facilitator of high-quality end-of-life (EOL) care.[1] ACP refers to a health care decision process that includes discussing and planning care for the end of life in the event one is unable to communicate care preferences at the time.[2] Informal ACP may involve a conversation with a family member or loved one about EOL care preferences. Formal ACP includes completion of legal documents, such as an advance directive (AD), in which an individual identifies preferences for EOL treatments and designates a durable power of attorney for health care.[2] ACP is positively associated with a better quality death,[3,4] higher rates of hospice use,[5,6] lower medical expenditures,[6,7] and less emotional distress for bereaved family members.[4]

Patients who participate in ACP are more likely to receive care that is less aggressive, to enroll in hospice care, and to experience greater satisfaction with care.[3,7,8] Yet studies show that Black Americans are less likely to participate in ACP than non-Hispanic Whites.[9–12] Evidence suggests numerous reasons for this disparity, including distrust resulting from experiences of discrimination in a medical setting,[9,13–18] cultural values and spiritual beliefs that conflict with ACP,[9,11,15,17,19–22] and lack of understanding or clarity regarding ACP.[9,13,22]

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Unilateral DNR/DNI

- Usually results from a failure of consensus among the team, family and patient
- Reasons often include religious and cultural considerations, collectivist family values, and/or medical mistrust, and clinician factors
- Psychiatry, palliative care and ethics consults may be called to help clarify and resolve the issues

Medical Aid in Dying (MAiD)

- AKA physician assisted suicide (PAS), physician aid in dying (PAD), death with dignity
- Euthanasia (implemented by another person) vs. assisted with a prescription
- Possible Indications
    - terminal illness
    - chronic distressing medical conditions
    - psychiatric conditions

Mr. R.

A 60 year old disabled attorney in remission for a year from an aggressive lymphoma discovers that it has just recurred, in multiple organ sites. Recalling his traumatic initial hospitalization and induction treatment, and wanting to spare his family the burden of dealing with his illness, he says he is “done” and plans to explore MAiD in Vermont. At the same time, he reports considerable pressure from his family to try treatment again.

Ethical Arguments for MAiD

- Self-determination
- Relief of suffering
- Decisions to die from an illness differ from suicide
- A safe medical practice
- Anti-discriminatory (comparisons with animal rights, emotional vs. physical suffering)

Ethical Arguments against MAiD

- Most common reasons for requests [“losing autonomy” (90.6%); being “less able to engage in activities making life enjoyable” (89.1%); a “loss of dignity” (74.4%); becoming a “burden on family, friends/caregivers” (44.8%); “losing control of bodily functions” (44.3%)] are amenable to good palliative and psychiatric care
- Providing MAiD can convey that the end of life lacks intrinsic meaning or purpose, and reneges on the physician’s mandate to “cure sometimes, treat often and comfort always.”
- Slippery slope can lead to euthanizing those who see it as the default option when they are “tired of living” (Netherlands example, erosion of guardrails)
- Depression and demoralization in the terminally ill can be missed
- Irreversibility is difficult to assess in psychiatric euthanasia
- Equity concerns – white and privileged press for MAiD but it also applies to the poor and disabled
- Societal attitudes toward the worth of disabled lives change after MAiD

MAiD and Societal Attitudes

“For those who are most vulnerable to hope on account of lacking relationships of love that could serve as a source of transcendence from trial, society's message that death may be good, that suicide may be rationally chosen on account of sickness, and that one’s society does not need him is a message that creates an experience of despair and that provokes the desire for death.”

Benjamin Parviz, 2023

In a 2023 poll of 1000 Canadians, euthanasia seemed appropriate to

51% for inability to obtain adequate medical treatment

50% for those having a disability

28% for being homeless

27% for living in poverty

https:/tinyurl.com/y4bt79ay

Positions of Professional Organizations

- AMA – “Physician assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.”
- Psychiatric APA – “a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing death” (2016, with a Resource Document approved in 2017)
- Psychology APA – neither supports nor opposes MAiD, and advocates for more research
- Mass Medical Society – moved from opposition to “neutral engagement” with protection of conscientious refusal (2017)

MAiD in the U.S.

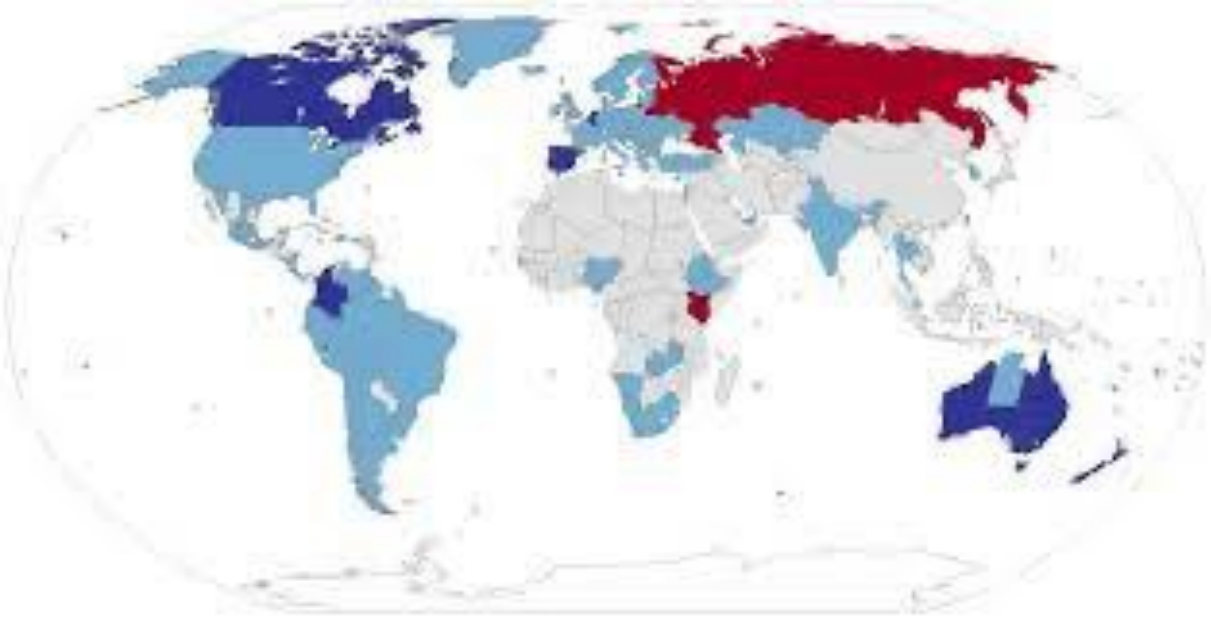
- Washington vs. Glucksberg (1997): no constitutional right to MAiD
- Oregon's Death With Dignity Act (1994,7)
- State laws typically require applicants be a capable/competent adult (18 years of age or older), a resident of the state, determined by medical evaluation as suffering from a terminal disease, and to have made a voluntary expression of the desire to die

US States With Laws Permitting MAID in Certain Circumstances

- California
- Colorado
- Delaware
- Hawai'i
- Maine
- Montana
- New Jersey
- New Mexico
- New York
- Oregon - *Non-resident MAID allowed
- Vermont – *Non-resident MAID allowed
- Washington
- Washington, DC

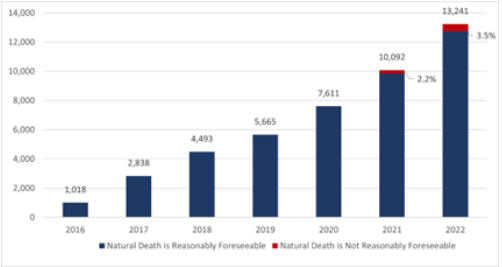
MAiD Worldwide

- Euthanasia is legal in Belgium, Canada, Colombia, Luxembourg, the Netherlands, New Zealand, Portugal (awaiting regulation), Spain and and Australia
- Switzerland allows assisted dying



Euthanasia in Canada

- Legal since 2016 for a “grievous and irremediable medical condition” that is incurable, irreversible, and involves unendurable suffering, in which “natural death has become reasonably foreseeable.”



- “Forseeable natural death” condition was dropped in 2021
- Euthanasia for psychiatric conditions legalized but on hold
- In 2021, over 10,000 deaths by euthanasia (5% of all deaths, 6th leading cause of death)
- MAiD for minors and by advance directives is under consideration
- Canada’s main MAiD-provider organization (CAMAP) has been promoting the practice of bringing up the procedure as a “medically effective care option” unsolicited as a “professional obligation”
- Cases of disabled individuals requesting MAiD for poverty (e.g. inability to find housing) raise the question of whether MAiD compels such individuals who may already fear being a burden to justify their existence.
- In March, 2025 a United Nations committee said it was “extremely concerned” about how Canada’s MAID laws place the lives of people with disabilities at risk, and recommended Canada stop allowing MAID for people whose deaths are not “reasonably foreseeable” and not expand eligibility further.

Euthanasia for Psychiatric Indications in the Netherlands

- Legal since 1994, requiring that:

  the patient's request be voluntary and well-considered

  the patient's suffering be unbearable

  with no prospect of improvement

  reports are published afterwards
- Concerns raised: those who die by suicide and those who request psychiatric MAiD have similar profiles, more that a third of patients referred to the EOL clinic had not tried psychotherapy and only 13% of evaluating MDs were psychiatrists (Nicoloni et al., 2020)

The Psychiatrist’s Role in Assessing Capacity for MAiD

- Oregon’s Task Force described a process that will “usually include” record review, discussion with the referring physician, patient interview and assessment, and collateral interviews with family, caregivers, and other important persons in the individual’s life.
- Werth et al. (2000) advocated deeper exploration of the decision in relation to the patient’s values and how it would affect others
- California’s End of Life Option Act: A mental health specialist may be needed to assess whether a patient “has the capacity to make medical decisions” and is “suffering from impaired judgment due to a mental disorder”
- Appelbaum and Grisso’s criteria focus on understanding, appreciation, rationality and communication of a consistent choice (Bourgeois JA et al., 2018)
- Questions remain about (a) whether the decision to end one’s life is substantially the same as that to accept or reject a procedure, (b) if the evaluating psychiatrist should assess demoralization and the ability to envision alternatives, and try to optimize decision-making capacity and (c) if criteria are well enough established given the complexities involved (Appel JM. Legal and Ethics Considerations in Capacity Evaluation for Medical Aid in Dying. J Am Acad Psychiatry Law. 2024 Sep 3;52(3):311-326. doi: 10.29158/JAAPL.240038-24. PMID: 38981626.)

Three Hypothetical Cases

(1) An elderly woman is told of progressive lung cancer following a year of debilitating courses of chemotherapy and radiation. She discusses with her family the options that remain to her in light of her lifelong values of independence and doing for others. They show a clear understanding of her prognosis and of likely quality of life, weighing her enjoyment of time spent with her grandchildren with the suffering of being unable to care for or play with them. She seems disappointed but not demoralized or depressed.

(2) A previously healthy man in his 50s diagnosed with ALS expresses reluctance to go on because he feels that being unable to control his bodily functions would be intolerable. He says he cannot imagine anyone retaining dignity if they need others to care for them.

(3) A woman in her 60s with newly diagnosed metastatic pancreatic cancer refuses treatment because of what she has read and heard online about its effect on quality of life. She has also been reluctant to accept a Palliative Care consultation for fear of a slow decline in hospice care.

Mr. R (continued)

Mr. R. acceded to his family's wishes for him to try a new treatment for his lymphoma. After he experienced a dramatic response his interest in MAiD lapsed, but he continued to hold the option in reserve.

Questions

- What is legally and ethically appropriate to say to patients about MAID?
- Does one's institution support the availability of information about MAID?
- Is there institutional guidance on how (and how much) MAID information is presented and disseminate
- How, and to what extent, can providers opt out of discussing MAID?
- How and where can they refer their inquiring patients?
- Who should be identified as the source of information about MAID within the institution?
- How public should this identification be?

The DFCI MAiD Study Guide

- The MAID Study Guide project was originally conceived by the MGB Palliative Care Collaborative to assist palliative care clinicians at MGB member institutions in responding to patient and colleague queries about MAID. The original study guide began in late 2023 in response to an increase in questions posed to palliative and psychosocial oncology clinicians by patients and medical colleagues at MGB institutions and DFCI. This attention is a result of the overall increase in public awareness about MAID and the recent change in Vermont's Patient-Choice-at-End-of-Life Law to allow non-residents to participate.
- This version is an adaptation by two of the original authors for DFCI's POPC department with contributions from the DFCI OGC, DFCI Ethics Advisory Committee, and the POPC MAID study group. The document is an advisory, ongoing document that will be reviewed / revisited regularly, and includes information and recommendations for practice with patients and for developing readiness as clinicians. The MGB Collaborative and DFCI POPC maintain positions of neutrality regarding both whether MAID should be legally available in Massachusetts and more generally about whether MAID should be an available option for patients at the end of life.

Legal and Ethical Guidance

 Legal Boundaries of Patient-Clinician Discussion about MAID – DFCI POPC clinicians in Massachusetts can respond to patient inquiries about MAID and provide factual information.

• **Clinician Opt-Out –** Clinicians can opt out of MAID discussions with patients for reasons of personal conscience. These clinicians should facilitate a connection between the patient and a locally accessible clinician who is comfortable responding to such queries.

• **Providing Detail and Referring -** DFCI POPC clinicians may, at the patient's request, informally reach out to physicians who provide MAID in MAID-legal states on a patient's behalf and can refer their patients to websites that provide MAID information. Formal referral, at the patient's request and with their authorization, to an out-of-state clinician who provides MAID, with transmission of protected health information in accordance with privacy rules, is also currently not prohibited by law. *Responsibility for the required medical and biopsychosocial evaluation of a patient pursuing MAID rests solely with the MAID clinician in the selected state.*

• **Avoid Advocacy or Endorsement -** A clear distinction is made between responding to a patient's queries about MAID and advocating for or endorsing MAID for a particular patient. *Clinicians should avoid statements to the patient, to the patient's family or their supporters, or in clinical documentation that could suggest advocacy for MAID or endorsement of the patient's choice to pursue MAID.*

• **Vulnerable Populations –** Clinicians should be aware that MAID is a particularly sensitive topic for patients with disabilities, and those from marginalized and under-resourced groups. One concern is that MAID reflects a societal judgement of the worth (or lack thereof) of the lives of those with disease or disability, coupled with the fear that clinicians, institutions, and payors will steer patients toward MAID to reduce health care costs. A second issue is that some patients may pursue MAID because they lack the resources or services to live well with their disease or disability. Finally, pursuing MAID requires money, transportation, access to information, and assistance in completing the required steps, making MAID less available to those with limited resources. Assessment of and partnership with the patient to understand existing supports – psychosocial, family, cultural, and community - can help mitigate these vulnerabilities.

Preparing Ourselves

- What is legally and ethically appropriate to say to patients about MAID?
- Does one's institution support the availability of information about MAID?
- Is there institutional guidance on how (and how much) MAID information is presented and disseminated?
- How, and to what extent, can providers opt out of discussing MAID?
- How and where can they refer their inquiring patients?
- Who should be identified as the source of information about MAID within the institution?
- How public should this identification be?

Preparing as a Psychosocial Oncology and Palliative Care Team or Practice

It is important for members of the POPC team to have a shared commitment to respond to patient queries about MAID – not to encourage uniformity of beliefs but to foster enough continuity of practice so that a patient's experience will not be uneven between clinicians. We encourage teams and clinics to open a dialogue and develop a shared, neutral approach to patient queries, and to create a culture of mutual support in response to these sensitive requests. A set of discussion questions to guide teams in preparing their approach is provided below.

Clinical Continuity

Documentation in the electronic health record of patient questions about MAID, and the information provided, are essential for continuity of care between clinicians and settings. A patient's questions, level of interest, provider responses, and discussions about MAID can be documented in progress notes. The abbreviation MAID is acceptable and commonly understood. The patient's interest and pursuit of MAID can also be included in the Serious Illness Conversation tool under What's important to patient/family and Recommendations sections. Clinicians should not recommend the pursuit of MAID in this section, but they can recommend further discussions with the care team or other supports at DFCI along with the pursuit of symptom management and quality of life goals.

Clinician Opt-out

Practice groups should discuss a plan to internally refer interested patients to clinicians who are comfortable discussing MAID. Clinicians who opt-out of discussing MAID should re-direct these patients as the need arises.

Visibility

Psychosocial oncology and palliative care practice groups should consider how to communicate their availability as a resource for patients interested in MAID. Communication can be informal among the institution's larger clinical group and included in interdepartmental meetings and teaching activities. Formal or written announcements of such availability, whether in internal or patient-facing material, run the risk of unwanted media attention and being equated with endorsement. Such formal or written announcements should be avoided.

Preparing the Institution

Psychosocial oncology and palliative care leaders at DFCI support their clinicians in engaging in discussions with patients and other clinicians about MAID. Leaders recognize that DFCI patients should have a reliable source of information about MAID within the Institute and believe that POPC clinicians have the communication expertise to navigate such conversations. Institute leaders, the Office of General Counsel, and the Ethics Advisory Council similarly express support for thoughtfully approaching these difficult discussions. Questions about MAID may be posed to non-physician clinicians in the Institute, including nurses, nurse practitioners, physician assistants, social workers, and chaplains. Including these groups in the internal communications described above and providing ongoing updates will facilitate patients' ability to access consistent information from a prepared and sensitive clinician.

Discussion Questions for Practice Groups

1. What individual experiences, ways of identifying, belief systems, cultural influences, or professional lenses do we each bring to this topic?

2. How can we support each other as we encounter challenging clinical cases relating to MAID?

3. Are there certain team members with particular interest or expertise that would be helpful to patients wishing to discuss MAID, or referrals to other services that we should consider?

4. How do we best partner with the patient to understand their psychosocial, community, and cultural needs to identify particular vulnerabilities in the context of a MAID query?

5. How can we ensure that patients wishing to consider MAID have maximal symptom management, attention to psychological and existential distress, resources for optimal care at home or in the setting of their choice, control over decision making through advance care planning, and access to hospice, as appropriate?

6. How shall our team manage when a clinician does not feel comfortable fielding a MAID query? How will the patient's concern be addressed in the moment and lead to a timely visit with a clinician willing to discuss MAID?

7. How will our team manage referrals from other clinicians of patients interested in MAID?

8. What team debriefing or case learning opportunities could we use to work through issues as they arise?

9. Where and how do we want to document patient questions about MAID to provide continuity across clinicians?

10. How should we indicate our availability for answering patient queries about MAID within our institution?

Guidance for Language in Responding to Patient Queries

- **Patient Vulnerability** - When a patient raises the issue of MAID, it is a sign of trust in their clinician's ability to hold their hopes and fears. As such, it is important to respond with compassion and non-judgmental validation of their outreach, regardless of the content discussed or shared. A dismissal of this conversation can be experienced as abandonment or shaming. As in any sensitive conversation, asking permission is an essential first step.
- "Thank you so much for letting me know that this is on your mind. I appreciate you feeling comfortable enough to bring it up. Would it be ok for me to ask about what makes you raise this today?"
- Is the patient asking about MAID? - Sometimes a patient's question is vague and does not directly name MAID: ("I don't want to continue living like this, can you help me?"). Often the most important response by the clinician is, "Can you tell me more about that?" "It sounds like things have been really hard. When you say you don't want to continue living like this, can you tell me what you mean?" "Do you have a sense of what kind of support would be most helpful?"
- Even if the clinician feels certain about the patient's intent, it is still worthwhile to clarify: "I want to make sure I understand your question. Are you looking for information about options like medical aid in dying?"
- **Indicators of Distress** – When patients bring up the topic of MAID, it can be an indicator of broader emotional distress, fear of loss of control, or worry about suffering at end-of-life. It is essential to treat this question as a prompt to perform a thorough psychosocial assessment. Ask permission to proceed first (as above).
- "Do you feel comfortable telling me more about what makes you ask about medical aid in dying?" "As you look ahead, what are the things that worry you most?" "What aspects of your illness have felt hardest for you?" "Have you spoken with your loved ones about any of these questions/concerns?" "Would it be helpful to talk about some of the services that are available to support you with your concerns about X (such as symptom management, palliative/hospice services, mental health support, legacy planning)?""What are you hoping will come out of our conversation today?
- Following the assessment, the clinician should ensure that the patient can access robust support in a cultural and community context, including intensified symptom management, advance care planning, hospice services, mental health supports, or legacy planning.

Suggested responses to specific MAID questions from patients with a consistent interest after a thorough evaluation of their motivation for raising the subject

- **Do I qualify for MAID?**
  - "There are specific eligibility criteria and processes that vary by state. The evaluation process and eligibility decision will need to be performed by a physician in a state where MAID is legal. Generally speaking, the primary qualification in states where MAID is legal is the presence of a terminal illness with a life expectancy of less than six months. Would it help to talk about your diagnosis and prognosis?"
- **I am interested in taking medication to end my life. Can you help me access MAID?**
  - "MAID is not available in Massachusetts, but I can offer information about MAID in general and provide some resources for more information about what is available in other states."
- **For the clinician who elects to opt-out:**
  - "Thank you for raising this important topic. I am unable to counsel you about this, but I will support you by arranging a visit with one of my colleagues who is knowledgeable about MAID."

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- **DFCI Office of General Counsel** – Jamie Flaherty

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