

# End-of-Life Care

Facilitate Early Discussions with Patients

Developed in partnership with



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## How will this module help me?

- 1 Describes four STEPS to help your patients convey their end-of-life decisions.
- 2 Provides answers to common questions about using templates for end-of-life discussions.
- 3 Shares a sample letter end-of-life care for your practice to use.



## Introduction

Approximately 2.7 million Americans die every year<sup>1</sup> and only about one-third of all Americans have any type of advance directive for their end-of-life decisions on file with their health care providers.<sup>2</sup>

Advance care planning is a way to support patient self-determination, facilitate decision making, and promote better care at the end of life. Although often thought of primarily for terminally ill patients or those with chronic medical conditions, advance care planning is valuable for everyone, regardless of age or current health status. Planning in advance for decisions about care in the event of a life-threatening illness or injury gives individuals the opportunity to reflect on and express the values they want to have govern their care, to articulate the factors that are important to them for quality of life, and to make clear any preferences they have with respect to specific interventions. Importantly, these discussions also give individuals the opportunity to identify who they would want to make decisions for them should they not have decision-making capacity.<sup>3</sup>

Without this information, end-of-life decisions may be made by family members and the care team that do not reflect the patient's decisions. Patients may receive unwanted, expensive, high-intensity care that may not improve their quality of life. Families may face greater emotional strain as they struggle to make decisions, not knowing what their loved one would have wanted.

Patients are responsible for preparing their end-of-life care documentation and making their wishes known. While physicians are not required to have end-of-life care discussions with patients, if a physician wants to assist patients to make choices, there are many end-of-life decision tools, templates, and resources available. Patients, in consultation with their physician, should utilize the tool, template, or resource with which they feel most comfortable. In addition, a patient should consult with a qualified attorney.

One resource that your practice may want to consider promoting as an end-of-life letter template has been developed as part of the [Stanford Letter Project](#). It facilitates the important conversation that your patients should have with their families and care team long before an emergency situation arises. The letter covers:

- What matters most to the patient.
- How the patient and family make decisions.
- How the patient and family handle bad news.
- Who the patient wants to have make medical decisions.
- What the patient does and does not want.
- The patient's thoughts about palliative sedation.
- How to resolve conflict about a treatment decision.

The questions and prompts in the guide help patients to think about their end-of-life care plan. The answers that the patient provides can later be transferred into legal documents such as advance directives or living wills. While these letters are not the same as advance directives, they are complementary and can give guidance to the patient and family members as they enter the advance directive process. Patients should execute legally-binding documents such as advance directives to protect their end-of-life decisions.

Table 1.

End-of-life letter vs. advance directive

This table explains the differences between an end-of-life letter and an advance directive.

END-OF-LIFE LETTER	ADVANCE DIRECTIVE
<p>The end-of-life letter is a tool that can help patients communicate their priorities to family members as they prepare to create an advance directive. It asks patients to answer questions about what to do if the designated proxy wants something different than the patient.</p> <p>It does not contain all of the same fields as an advance directive and it is not a legal document.</p>	<p>An advance directive is a legal document that may be in the form of a living will. It allows patients to plan and make their own end-of-life wishes known in the event that they are unable to communicate.</p> <p>It allows patients to document their decisions concerning medical power of attorney, which allows patients to appoint someone who they trust as their health care agent or proxy who is allowed to make medical decisions on their behalf.</p> <p>State law may require that patients sign their advance directive in the presence of witnesses.</p>

## Four STEPS to plan for end-of-life decisions with your patients:

1. Prepare your practice to use a letter, or another planning tool.
2. Invite your patients and their families to have a conversation, and to involve you as appropriate.
3. Discuss each patient's completed letter (or other tool) and add it to the electronic medical record.
4. Remind your patient to periodically update the letter, tool, or advance directive, as appropriate.



### 1 Prepare your practice to use a letter, or another planning tool.

Introduce the goals of the end-of-life discussion tool to your team and practice leadership. Communicate expectations about who will introduce the tool to patients, how to use the end-of-life discussion tool, the advance directive process, and who can answer questions about end-of-life care or the tool itself. Once these expectations are understood, build them into the practice workflows.

You may want to consider sharing this [video](#) to show the importance of advance care planning.

You can [download](#) the Stanford Letter Project end-of-life letter template in English, Spanish, Hindi, Mandarin, Tagalog, Russian, Urdu, and Vietnamese on the Stanford Medicine Letter Project website.

You can also find a letter-to-advance-directive form [here](#); this form allows patients and families to take the contents of the end-of-life letter and use it to complete an advance directive for patients in California.

[End-of-life letter template](#)  
(MS-WORD, 45 KB)

Effective end-of-life conversations should include clear and respectful communication between the physician-led team, the patient and the patient's family. If you would like additional guidance on advance care and end-of-life planning, you may want to consider the following websites and resources:

[Respecting Choices® Advance Care Planning](#)

[The Palliative Care training portal at the Stanford School of Medicine](#)

[The National Institute on Aging's: Understanding Healthcare Decisions at the End of Life](#)

[The Institute of Medicine's Dying in America report](#)

As stated previously, there are many end-of-life decision tools, templates, and resources available; physicians and patients should utilize the tool, template, or resource with which they feel is most effective in your setting. In addition, a patient should consult with a qualified attorney so their wishes are preserved and effective in accordance with state law requirements.

Q&A

[Is it always the physician who should work with the patient on the end-of-life discussion tool?](#)

With the appropriate training, anyone in your practice can have meaningful conversations about how to document end-of-life decisions with patients. The Stanford letter is written in clear and simple language so that patients can fill it out by themselves. This relieves some of the burden on physicians, and gives the family the opportunity to be involved.

However, a majority of patients and their family members are interested in having discussions about their end-of-life decisions, and most expect their physician to initiate the dialogue.<sup>4</sup> It is also important to note that the advance care planning codes are for clinical billable providers (e.g., MD, PA, advanced practice nurse).

[How can I help my patients as they consider whether and how to prepare an advance directive?](#)

You should encourage your patients to consult legal counsel and resources to create the advance directive from their end-of-life letter. Your patient is responsible for preparing his or her own valid advance directive. You may refer patients to the end-of-life letter template, which the patient and their legal counsel can modify based on the advance directive. As a physician, you may provide information and support upon patient request. There are a number of resources for both patients and physicians available on the [AMA website](#) on advance directives.

[How can my workflows reflect the new step in my practice process?](#)

Ideally, conversations about the end-of-life letter should take place over two visits. During the first visit, the nurse or medical assistant (MA) introduces the letter and explains to the patient that they can take the letter home to discuss it with their family and fill it out at their convenience. At the second visit, the MA can ask if the patient brought their completed letter and then enter the appropriate information into the chart. The MA can scan the letter into the chart before the physician enters the room. If requested, the MA can inform the physician that the patient would like to discuss the letter with him or her.

[How should I talk about the end-of-life letter with my patients?](#)

Using a script may provide a guide to beginning the conversation about the letter with your patients, as well as how to answer some of the questions that may come up about the letter and advance care planning. In your practice, if you plan to have patients take the letter template home with them to discuss with their family, start with the explanation of the letter and how to use it.



2

## Invite your patients and their families to have a conversation, and to involve you as appropriate.

You may choose to have the conversation with a subset of your patients, such as older patients or those with a complex medical history or life-threatening condition. Selecting a subset of patients will enable you to automatically flag those who should be encouraged to consider completing a templated letter or advance directive. As your comfort with the conversations increases, you may wish to expand to additional patient groups.

Some of your adult patients who are currently healthy may not know whether they would want a feeding tube, ventilator support, or other interventions at the end of life. Let these patients know they have the option to leave those questions blank and update the letter when they're ready. Other patients may already have completed a version of the letter or advance directive. If patients want more information about the end-of-life letter, refer them to the [Stanford Letter Project resources](#).

### Q&A

[Where do I start with the rollout of an end-of-life tool? Should it be on a small scale or practice-wide?](#)

There is value in starting with a pilot rollout. A physician or pod (a small group of clinicians within your practice) can start the process and learn how the conversation with patients and family members occurs most effectively. Pilot participants can report back to the larger group on their learnings as they refine their process or as the rollout expands.

[Should family members or caregivers be a part of the conversation?](#)

Patients should manage their own end-of-life discussion including answering the questions in the end-of-life letter and discussing their answers with their family and proxy decision makers. This helps ensure that everyone is aware of the patient's decisions, and maximizes the effectiveness of the letter and its use in completing the advance directive template. Family members and caregivers who know what the patient wants can advocate for the patient and ensure that their loved one's decisions are met. Including the family members or caregivers in the conversation may also help prevent situations where a family member, proxy, or caregiver might make a decision that is not in line with the patient's wishes. As a physician, you should provide end-of-life information upon the request of the patient.

3

## Discuss each patient's completed letter or other tool and add it to the electronic medical record.

If requested, discuss any questions the patient has about their end-of-life letter. While the end-of-life letter is useful to identify patient values, preferences for treatment, and designation of surrogate decision maker, the letter is not legally binding. Encourage the patient and their family to use the completed letter as a guide for a healthcare power of attorney or other legally binding document with end-of-life care instructions, with competent legal counsel if necessary. The patient may wish to carry a copy of the document and their physician's contact information with them at all times.

If the patient has an advance directive document or written designation of proxy or other legally-binding document, include a copy (or note the existence of the directive) in the medical record. You may be able to enter

the completed letter directly into the record or scan in the letter using a barcode. Otherwise, the letter should be manually scanned and saved. If the patient has not yet completed a legally-binding document, a completed letter can provide useful guidance but it is not binding.

If the patient has an accident or episode and is taken to another facility, the care team there should have access to the documentation of the patient's decisions, such as an advance directive. If not available when the patient arrives, the receiving facility can reach out to your practice to obtain guidance, so the patient's decisions will still be honored.

Q&A

Who should review the end-of-life letter with the patient?

A trained clinician, such as the physician, nurse, MA, or mid-level provider, should review the completed letter or other document with the patient to answer any questions. If the [letter-to-advance directive template](#) is used, the completed advance directive can be printed, signed by the patient, witnessed, and filed in the EHR during this visit. The patient should keep a copy of the advance directive.



4

Remind your patient to periodically update the letter, tool, or advance directive, as appropriate.

Patients may wish to update their end-of-life plans for a variety of reasons. Check in with patients on an annual basis to ask if they would like to update their preferences. The annual visit could be a consistent time for the practice team to check with patients about any updates they'd like to make to their end-of-life documents, such as an advance directive.<sup>3</sup>

## Conclusion

Your practice team can encourage patients to take an active role in end-of-life planning. The simplicity and accessibility of end-of-life tools means that patients can complete the tools at their convenience, where they are comfortable and in the presence of their family and friends if they choose. Encourage patients to enter legally-binding end-of-life care documents. Your team can provide peace of

mind to patients that their end-of-life decisions will be respected by their care team and loved ones.



## AMA Pearls

### Writing an end-of-life letter can empower patients.

The letter can help patients and their families personalize their end-of-life decisions and ensure that their voice is heard by their care team. End-of-life letters should be used to guide the drafting of legally-binding documents.

### End-of-life letters can empower practices.

Working with your patients on end-of-life letters may make your team feel more confident that they are providing not only the best care, but also emotional support to the patients who need it most.

### Not a lot of effort is needed to make a big impact.

Writing an end-of-life letter and other documents should be done by patients outside of the physician office, freeing you and your staff to answer questions and have critical conversations about patient decisions during the visit.

## STEPS in practice

1

### End-of-Life Care Case Report: Stanford University Department of Medicine

The Stanford University Department of Medicine launched a new approach to advance care planning to empower all adults to take the initiative to talk to their physician about what matters most to them at life's end. With extensive research and the guidance from multi-ethnic, multi-lingual patients and their families, they developed a letter template to guide people through the process of making important advance planning decisions.

The template is a complement to an advance directive that also help patients to:

- talk about what matters to them most on a personal level unrelated to their medical care.
- document how they like to handle bad news.
- describe their preferences for how they make medical decisions.
- give granular input on what treatment interventions they want and do not want at the end of life.
- document their preference for palliative sedation.
- know what to do when the proxy decision maker wants to do something different from the patient.

In addition, the letter format is more personalized and accessible for many patients. It is written in straightforward language that they can understand and is free of medical and legal jargon. Once the template

was tested with hundreds of patients and families from various ethnic and racial backgrounds and in many languages, they began spreading it to different venues. This became the Letter Project.

Participants in The Letter Project included high school students who talked with their families about their end-of-life decisions, older adults who filled out the letter at local community centers, and the patients at Stanford. The Letter Project has received overwhelmingly positive response from everyone involved. Many of the patients who participated said they appreciated the opportunity to convey their decisions. Families and patients developed a greater understanding of what end-of-life care entails, and also developed deeper connections with each other as they talked through what they want and don't want at the end of life. The physicians learned that when patients are given the opportunity to really think about what is important and share the information in a letter format, they feel more confident that their care team will heed their decisions.

The Letter Project's success was measured by patients completing the letter, their satisfaction with the letter, and how their care was personalized and guided by the letter. Over 2000 people have used the online letter tool to complete their letters. Many organizations around the world are also using this simple tool to help their patients. The Letter Project has been featured on PBS, in the New York Times, in the Washington Post, and throughout numerous media outlets.

At Stanford Medicine, a large multi-disciplinary committee is working to implement the letter both in the in-patient and out-patient settings. The letter template is now available in all hospital units and services and can also be ordered in bundles. Each printed letter has a unique barcode that can be scanned into the patient's electronic health record (EHR). The letter is going to be made a part of the "Goals of Care" bundle.

There is a free Letter Project App, available online. There is also a Letter-to-Directive tool that has a simple question which, when answered, will allow the user to print out their auto-filled advance directive form and the letter. Eventually, the Letter Project hopes to create a secure, HIPAA-compliant repository of 100,000 letters that can serve as examples for others interested in writing their own letter.

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**Learning Objectives:**

At the end of this activity, you will be able to:

1. Explain the importance of an end-of-life letter to your staff and describe what is needed to ensure that it is built into your practice workflow;
2. Identify how to approach all patient populations about beginning and completing their end-of-life letter;
3. Discuss with staff the importance of adding your patient's completed end-of-life letter to their patient chart;
4. Describe the need for a practice to check in with their patients to annually update their end-of-life letters.

## Article Information

**About the Professional Satisfaction and Practice Sustainability Group:** The AMA Professional Satisfaction and Practice Sustainability group has been tasked with developing and promoting innovative strategies that create sustainable practices. Leveraging findings from the 2013 AMA/RAND Health study, "Factors affecting physician professional satisfaction and their implications for patient care, health systems and health policy," and other research sources, the group developed a series of practice transformation strategies. Each has the potential to reduce or eliminate inefficiency in broader office-based physician practices and improve health outcomes, increase operational productivity and reduce health care costs.

### Disclosure Statement:

The content of this activity does not relate to any product or services of a commercial interest as defined by the ACCME; therefore, neither the planners nor the faculty have relevant financial relationships to disclose.

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