AMA | STEPSforward™

Planning for End-of-Life Decisions with Your Patients

Empower patients to communicate their end-of-life decisions.

AMA IN PARTNERSHIP WITH Stanford MEDICINE

AMA & MGMA Medical Group Management Association PRACTICE INNOVATION CHALLENGE WINNER

CME CREDITS: 0.5

VJ Periyakoil, MD
Stanford University School of Medicine

How will this module help me plan for end-of-life with the patients in my practice?

1. Four STEPS to help your patients convey their decisions in an end-of-life letter
2. Answers to questions about using the letter and billing for end-of-life discussions
3. A sample letter for your practice to use

Increasing administrative responsibilities—due to regulatory pressures and evolving payment and care delivery models—reduce the amount of time physicians spend delivering direct patient care. End of life decisions are challenging yet necessary (particularly with our advances in medicine today), and physicians must receive training in how to discuss these decisions with patients and families. Yet many physicians do not have training in how to discuss these issues, which may lead to patients' decisions not being reflected in their care.

End-of-life planning with your patients
Release Date: March 2016
End Date: March 2019

Objectives
At the end of this activity, participants will be able to:
1. Prepare your practice to use the letter
2. Share the letter with patients and their families
3. Review and discuss the letter with patients
4. Periodically update the letter with patients

Target Audience
This activity is designed to meet the educational needs of practicing physicians.

Statement of Need
Very few of the nearly 2.6 million Americans who will die this year have their end of life decisions on file with their healthcare providers. 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 then receive unwanted, expensive high-intensity care that does not increase their quality of life or death or families may face greater strain, not knowing what their loved one would have wanted. This module will assist caregivers in starting these important conversations with patients and families.

Statement of Competency
This activity is designed to address the following ABMS/ACGME competencies: practice-based learning and improvement, interpersonal and communications skills, professionalism, systems-based practice and also address interdisciplinary teamwork and quality improvement.

Accreditation Statement
The American Medical Association is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

Credit Designation Statement
The American Medical Association designates this enduring material for a maximum of 0.5 *AMA PRA Category 1 Credit*™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Claiming Your CME Credit
To claim *AMA PRA Category 1 Credit*™, you must 1) view the module content in its entirety, 2) successfully complete the quiz answering 4 out of 5 questions correctly and 3) complete the evaluation.

Planning Committee
Alejandro Aparicio, MD, Director, Medical Education Programs, AMA

Rita LePard, CME Program Committee, AMA

Becca Moran, MPH, Program Administrator, Professional Satisfaction and Practice Sustainability, AMA

Ellie Rajcevich, MPA – Practice Development Advisor, Professional Satisfaction and Practice Sustainability, AMA

Sam Reynolds, MBA, Director, Professional Satisfaction and Practice Sustainability, AMA

Christine Sinsky, MD – Vice President, Professional Satisfaction, American Medical Association and Internist, Medical Associates Clinic and Health Plans, Dubuque, IA

Author(s)
VJ Periyakoil, MD, Director, Palliative Care Education and Training, Stanford University School of Medicine

Faculty
Bruce Bagley, MD, Senior Advisor, Professional Satisfaction and Practice Sustainability, AMA

Christine Sinsky, MD – Vice President, Professional Satisfaction, American Medical Association and Internist, Medical Associates Clinic and Health Plans, Dubuque, IA

Sarah Levy, MD, Medical Director for Continuum of Care, Division of Clinical Excellence and Integration, Group Health Physicians

Jason Fodeman, MD, MBA, General Internist, Board of the Pima County Medical Society

Becca Moran, MPH, Program Administrator, Professional Satisfaction and Practice Sustainability, AMA

Ellie Rajcevich, MPA – Practice Development Advisor, Professional Satisfaction and Practice Sustainability, AMA

About the Professional Satisfaction, 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 of a commercial interest as defined by the ACCME; therefore, neither the planners nor the faculty have relevant financial relationships to disclose.

Media Types
This activity is available to learners through Internet and Print.

Hardware/software Requirements
Adobe Flash 9.0.115 or above
Audio speakers or headphones
Screen resolution of 800X600 or higher
MS Internet Explorer 8.0 or higher, Firefox, Opera, Safari, etc.
Adobe Reader 5.0 or higher

References

1. Centers for Disease Control and Prevention. Deaths and mortality. http://www.cdc.gov/nchs/fastats/deaths.htm. Updated September 30, 2015. Accessed December 14, 2015.
2. Stanford Medicine Letter Project. http://med.stanford.edu/letter.html. Accessed November 20, 2015.
3. American Academy of Hospice and Palliative Medicine. Palliative sedation position statement. http://aahpm.org/positions/palliative-sedation. Accessed February 1, 2016.

4. National Hospice and Palliative Care Organization: CaringInfo. What are advance directives? http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3285. Accessed February 1, 2016.
5. National Institute on Aging. End of life: Helping with comfort and care. https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/planning-end-life-care-decisions. Updated January 22, 2015. Accessed December 14, 2015.
6. Institute of Medicine. Dying in America: improving quality and honoring individual preferences near the end of life. http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx. Released September 17, 2014. Accessed December 18, 2015.
7. Department of Health and Human Services. Centers for Medicare & Medicaid Services. 42 CFR Parts 405, 410, 411, 414, 425 and 495. Medicare Program; Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2016. https://www.federalregister.gov/articles/2015/11/16/2015-28005/medicare-program-revisions-to-payment-policies-under-the-physician-fee-schedule-and-other-revisions. p. 240. Updated November 16, 2015. Accessed December 14, 2015.
8. Periyakoil VJ. Pitfalls for proxies. The New York Times. November 18, 2015. http://opinionator.blogs.nytimes.com/2015/11/18/pitfalls-for-proxies/?_r=0. Accessed November 20, 2015.
9. Periyakoil VJ. The silver tsunami is actually silver brown. How does end-of-life care differ for minorities? The Washington Post. October 28, 2015. https://www.washingtonpost.com/news/in-theory/wp/2015/10/28/the-silver-tsunami-is-actually-silver-brown-how-does-end-of-life-care-differ-for-minorities/. Accessed November 20, 2015.
10. Letter Project *[video]*. https://www.youtube.com/watch?v=vApg3qAn55s. Published April 22, 2015. Accessed November 20, 2015.
11. CPT Code/Relative Value Search. American Medical Association. https://ocm.ama-assn.org/OCM/CPTRelativeValueSearch.do?submitbutton=accept. Accessed February 4, 2016.

Introduction

Very few of the nearly 2.6 million Americans who will die this year have their end-of-life decisions on file with their health care providers. 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 then receive unwanted, expensive, high-intensity care that does not improve their quality of life or death. Families may face greater strain as they struggle to make decisions, not knowing what their loved one would have wanted.

Your practice can use an end-of-life letter template* developed as part of the Stanford Letter Project to facilitate this important conversation that your patients should have with their families and care team long before an emergency situation arises. The letter covers:

- How the patient makes medical decisions
- The type of medical care the patient wants and does not want in their final days
- How to handle palliative sedation ("the intentional lowering of awareness towards, and including, unconsciousness for patients with severe and refractory symptoms")
- Any other information that the patient feels their family and care team should know to make their end-of-life health care experience better

The questions and prompts in the letter guide patients to think about their end-of-life care plan and 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 to them and can give guidance to the patient and family members as they enter the advance directive process.

*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 most comfortable. In addition, a consultation with a qualified attorney may be needed under some circumstances.

How does the end-of-life letter differ from an advance directive?

END-OF-LIFE LETTER	ADVANCE DIRECTIVE
The end-of-life letter template does not contain all of the same fields as an advance directive and it is not a legal document, but it is a tool that can help patients align their priorities with those of their family members as they prepare to create an advance directive. The letter also asks patients to answer questions about what to do if the proxy wants something different than the patient.	An advance directive may be in the form of a living will that allows a patient to document his or her decisions concerning medical treatments at the end of life. Another type of advance directive is a medical power of attorney that allows the patient to appoint a person he or she trusts as his or her health care agent or proxy who is allowed to make medical decisions on his or her behalf. An advance directive is often required to be signed in the presence of witnesses in accordance with state law.[4]

Example scenario:

Mr. Hernandez works with his physician and his family to fill out the letter; he describes how he would like to be present at his granddaughter's wedding in the fall and how he does not want a breathing tube or feeding tube at the end of life. He feels comfortable with the layout of the questions in the letter and how the questions are phrased.

Example scenario:

Mr. Hernandez uses his end-of-life letter to complete an advance directive template; the physician or physician's staff provides information about where to obtain an advance directive, which Mr. Hernandez signs in the presence of witnesses and the document is filed in the electronic health record (EHR).

AMA. Practice transformation series: end-of-life planning with your patients. 2016.

Four STEPS to use end-of-life letters:

1. Prepare your practice to use the letter
2. Share the letter with patients and their families
3. Discuss each patient's completed letter and add it to the chart
4. Periodically update the letter as appropriate

1 Prepare your practice to use the letter

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

DOWNLOAD End of life letter template

Q&A

Where can I find the letter template?

You can find the Stanford Letter Project end-of-life letter template in English in this module's toolkit. The letter is also available in other languages such as 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.

DOWNLOAD End of life letter tools

Is it always the physician who should work with the patient on the letter?

With the appropriate training, anyone in your practice can have meaningful conversations about the letter and end-of-life decisions with patients. The 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. Stanford University's Palliative Care department has trained high school students, undergraduate students and clinic staff to discuss the letter with patients.

Can I help my patients adapt the letter so it can serve as an advance directive in my state?

Yes. You may use the end-of-life letter template and modify it based on the advance directive template that you can access **here**. However, advance directives vary by state; it is recommended that you consult appropriate resources (including qualified legal counsel) about creating a legally binding advance directive in your state. Alternatively, you can encourage your patients to consult legal resources to create the advance directive from their end-of-life letter. There are also a number of resources for both patients and physicians available on the **AMA website** on advance directives.

DOWNLOAD **End of life letter template**

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 who rooms the patient asks if the patient brought their completed letter and then enters 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 informs 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?

You can watch this **video** that shows an undergraduate at Stanford having a conversation with a patient about the end-of-life letter. The student demonstrates how the practice representative might explain the purpose of the letter and guide a patient through the prompts. This downloadable script also provides 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, just start with the explanation of the letter, which can be done by the nurse or MA who rooms the patient. More videos from patients discussing their letters are available **here**.

DOWNLOAD **Introducing the end of life letter**

What other training resources could I use?

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, consider the following websites and resources*:

- **AMA Ethics Resource Center**
- **Online courses from Respecting Choices® Advance Care Planning**
- **The Palliative Care training portal at the Stanford School of Medicine**
- **The National Institute on Aging's End of Life: Helping with Comfort and Care**
- **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 most comfortable. In addition, a consultation with a qualified attorney may be needed under some circumstances.

Which codes can I use to bill for consultations involving the letter and advance care planning?

There are two codes are now payable by Medicare and other payers when the physician or another qualified health care professional provides advance care planning. Providers are required to spend at least 16 minutes of time face-to-face with the patient to report 99497. If the service provided is less than 16 minutes, then the service is considered to be a part of the counseling that is inherent in the Evaluation and Management services codes 99201-99215. To report 99498, a minimum of 46 minutes of service must be provided face-to-face with the patient (30 minutes+16 minutes). CPT codes 99497, 99498 may be reported separately if these services are performed on the same day as another Evaluation and Management service.

99497: Advance care planning including the explanation and discussion of advance directives such as standard forms by the physician or other qualified health care professional; first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate with completion of such forms, when performed.

99498: Advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional; each additional 30 minutes (List separately in addition to code for primary procedure).

Providers can efficiently complete and bill for advance care planning efforts in a way that best suits patient and practice needs. If patients complete the letter at home, the time with the provider can be used towards a focused discussion with the patient about advance care planning.

*It is important to note that the advance care planning codes are for clinical billable providers (e.g., MD, PA, advanced practice nurse). This would not apply for other types of staff members such as practice administration, medical assistants etc.

2 Share the letter with patients and their families

You may choose to give the end-of-life letter to 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 complete the letter. As your comfort with the letter increases, you can start expanding 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 the letter? 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.

Why should I include family members or caregivers in the conversation?

Ideally, patients should answer the questions in the end-of-life letter and discuss their answers with their family and proxy decision makers. This helps ensure that everyone is aware of the patient's decisions and also 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 those of the patient.

3 Discuss each patient's completed letter and add it to the chart

If necessary, discuss any questions the patient has about their end-of-life letter. Encourage the patient and their family to carry a copy of the letter and their physician's card with them at all times. If the patient has an accident or episode and is taken to another facility, the care team there should have access to the letter or other documentation of the patient's decisions (such as an advance directive). If the letter is not available when the patient arrives, the hospital can reach out to your practice to obtain the letter, so the patient's decisions will still be met.

Add the completed letter to the patient's chart. Information from the letter, such as advance directive information and other fields can be entered into the EHR. 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.

Q&A

Who should review the letter with the patient?

Because the completed end-of-life letter can also be used to guide the advance care planning discussion, a trained clinician, such as the physician, nurse, MA or mid-level provider, should review the completed letter 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 Periodically update the letter as appropriate

Patients may wish to update their end-of-life plans for a variety of reasons. Check in with patients who have completed the letter on an annual basis to ask if they would like to update the preferences detailed in their letter. The annual visit could be the time for the practice team to consistently check in with patients about any updates they'd like to make to their letter (such as creating an advance directive based on the letter, if they have not done so already).

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 can empower practices

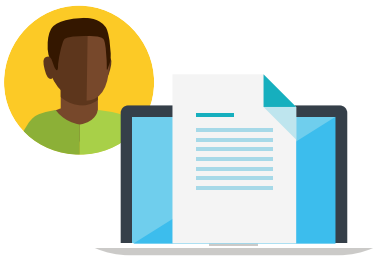
Working with your patients on end-of-life letters may make your team feel more confident that they are providing not only the best care, but also emotional support to the patients who need it most

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

Much of the work of writing the end-of-life letter can be done by patients in the comfort of their own homes, freeing you and your staff to have critical conversations about their decisions during the visit

Conclusion

Your practice team can encourage patients to take an active role in advance care planning. The simplicity and accessibility of the end-of-life letter template means that patients can fill it out at their convenience, where they are comfortable and in the presence of their family and friends if they choose. 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.



STEPS in practice

1

How's it working in Stanford, CA?

In April 2015 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 lets patients:

- Talk about what matters to them most on a personal level unrelated to their medical care
- Allows them to 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
- Helps them document their preference for palliative sedation
- Gives guidance on 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 have 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 that they feel more confident that their care team will heed their decisions.

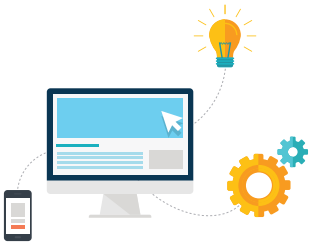
The Letter Project's success was measured by patients completing the letter, their satisfaction with the letter, and ultimately, how their care was personalized and guided by the letter. Over 2000 people have used the online letter tool to complete their letters. Numerous people have printed out the letter and used it. Many organizations are also using this simple tool to help their patients. There is a group in UK using the letter as well. 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 EPIC. Once scanned, it is added to the patient's electronic medical record. The letter is going to be made a part of the "Goals of Care" bundle. There is a free Letter Project App, available in the **Apple Appstore** and **Google Playstore**. 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.

To demonstrate completion of this module and claim *AMA PRA Category 1 Credits*™, please visit:
www.stepsforward.org/EndOfLifePlanning

Get implementation support

The AMA is committed to helping you implement the solutions presented in this module. If you would like to learn about available resources for implementing the strategies presented in this module, please call us at (800) 987-1106 or click here to send a message to StepsForward@ama-assn.org



References

1. Centers for Disease Control and Prevention. Deaths and mortality. http://www.cdc.gov/nchs/fastats/deaths.htm. Updated September 30, 2015. Accessed December 14, 2015.
2. Stanford Medicine Letter Project. http://med.stanford.edu/letter.html. Accessed November 20, 2015.
3. American Academy of Hospice and Palliative Medicine. Palliative sedation position statement. http://aahpm.org/positions/palliative-sedation. Accessed February 1, 2016.
4. National Hospice and Palliative Care Organization: CaringInfo. What are advance directives? http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3285. Accessed February 1, 2016.
5. National Institute on Aging. End of life: Helping with comfort and care. https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/planning-end-life-care-decisions. Updated January 22, 2015. Accessed December 14, 2015.
6. Institute of Medicine. Dying in America: improving quality and honoring individual preferences near the end of life. http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx. Released September 17, 2014. Accessed December 18, 2015.
7. Department of Health and Human Services. Centers for Medicare & Medicaid Services. 42 CFR Parts 405, 410, 411, 414, 425 and 495. Medicare Program; Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2016. https://www.federalregister.gov/articles/2015/11/16/2015-28005/medicare-program-revisions-to-payment-policies-under-the-physician-fee-schedule-and-other-revisions. p. 240. Updated November 16, 2015. Accessed December 14, 2015.
8. Periyakoil VJ. Pitfalls for proxies. The New York Times. November 18, 2015. http://opinionator.blogs.nytimes.com/2015/11/18/pitfalls-for-proxies/?_r=0. Accessed November 20, 2015.
9. Periyakoil VJ. The silver tsunami is actually silver brown. How does end-of-life care differ for minorities? The Washington Post. October 28, 2015. https://www.washingtonpost.com/news/in-theory/wp/2015/10/28/the-silver-tsunami-is-actually-silver-brown-how-does-end-of-life-care-differ-for-minorities/. Accessed November 20, 2015.
10. Letter Project *[video]*. https://www.youtube.com/watch?v=vApg3qAn55s. Published April 22, 2015. Accessed November 20, 2015.
11. CPT Code/Relative Value Search. American Medical Association. https://ocm.ama-assn.org/OCM/CPTRelativeValueSearch.do?submitbutton=accept. Accessed February 4, 2016.