PACE

Pharmaceutical Assistance Contract for the Elderly

Alosa Health

Balanced information for better care

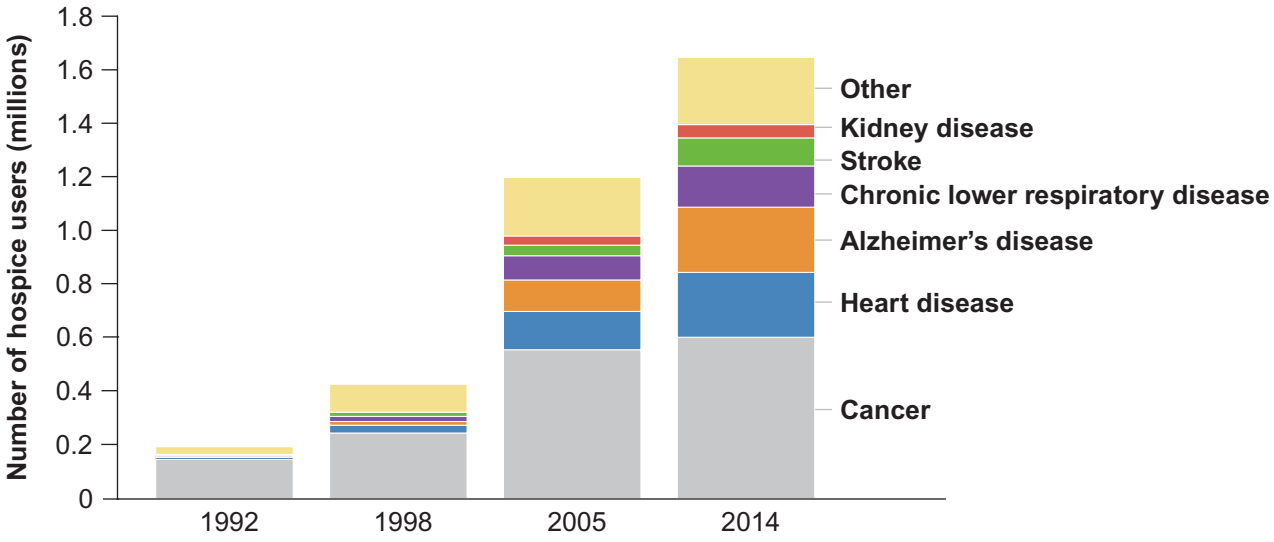
Helping patients and families confront serious illness

Starting difficult conversations, managing transitions

Much can be done to help patients with serious illness facing the end of life

Palliative care can improve quality of life for people with serious illness—those at high risk of death or with impaired daily function. Primary care providers can use palliative care to help patients and their families relieve symptoms and stress, and plan for the future.[1,2]

FIGURE 1. End-of-life services are increasingly used by patients with numerous diagnoses.[3]



Helping patients and families prepare for the end of life can lead to decisions that best reflect the patient's preferences.

TABLE 1. Putting a plan in place does more than respect a patient's wishes.[4]

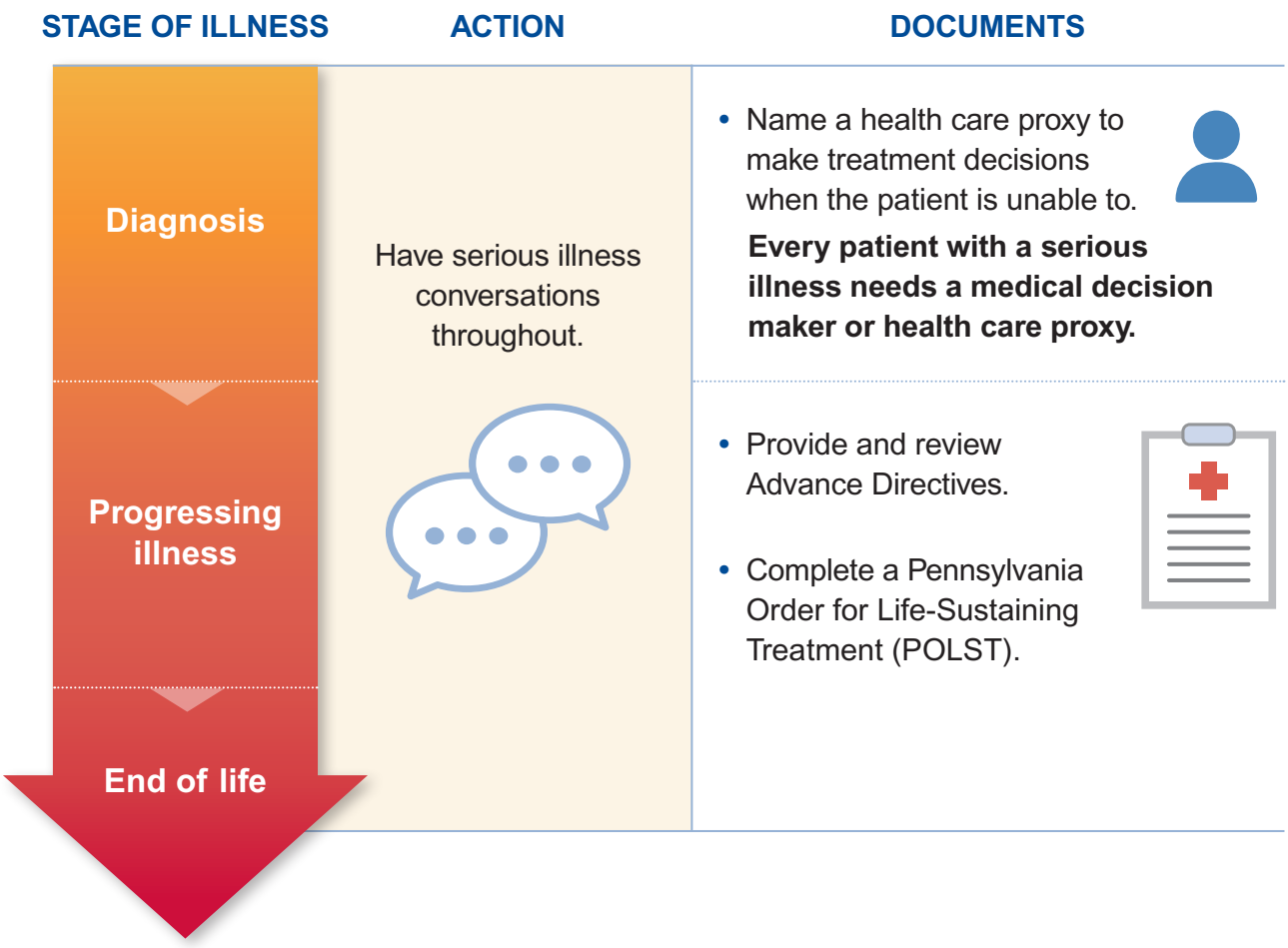
Patient	• Greater sense of control • Decreased decisional regret, peace of mind • Improved quality of life
Surrogate	• Lower caregiver burden and conflict among loved ones • Reduced stress, anxiety, and depression in family members • Increased satisfaction with care
Overall	• Improved communication among patients, surrogates, and clinicians • Better documentation of care preferences

Prepare for progressing illness in advance

Advance care planning (ACP) is a continuous, dynamic process of reflection and communication among patients, those close to them, and health care professionals.

The goal is to provide care that best fits the patient's values, goals, and preferences during serious illness.[5]

FIGURE 2. Continue the conversation as the patient's condition evolves, and use tools to develop and share key decisions.[6]



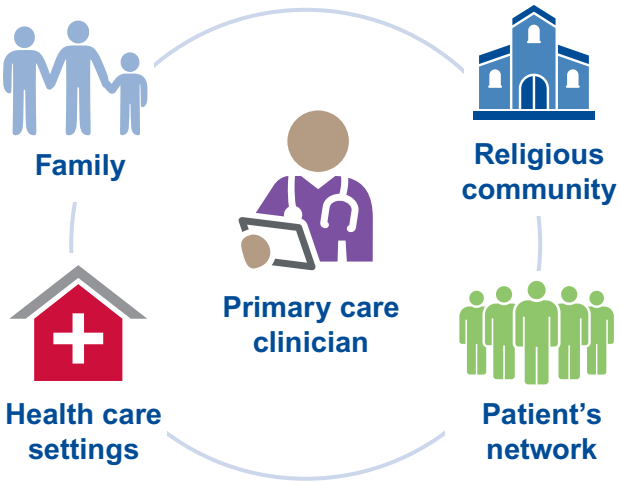
Start talking with patients and surrogates about the patient's preferences

Structure the conversations based on the patient's prognosis.

Asking yourself a simple question can help focus the issue:[7]

"Would you be surprised if this patient died in the next 1 or 2 years?"

ACP can occur in many settings, but should include a patient's primary care clinician.



Getting started can be difficult.

Many patients don't document or discuss their wishes,[8] but field-tested tools can help initiate these conversations. More information is available at **AlosaHealth.org/Serious_illness**.

Prepare patients to think about what they want.

- **PREPARE for your care:** a computer-guided process for ACP documentation[9]
- **"Go Wish":** an interactive approach to help clarify preferences[10,11]
- ***"What Matters to Me" Workbook:*** one of many tools from The Conversation Project to help patients clarify what kind of care they want

Follow up on preferences: Useful tools to talk about ACP.

- ***The Serious Illness Conversation Guide***[12,13]
- **Five wishes:** questions to help prepare and document patient preferences[14]

Begin serious illness conversations

1 Enable the discussion.

Introduce the conversation with a clear and patient-centered rationale to help allay anxiety. ***"I'd like to talk about what is ahead and what is important to you in advance so we can make sure to provide you with the care you want—Is this okay?"***

2 Assess understanding and preferences.

Understand what patients know—and would like to know—so you can tailor information delivery.

3 Share the prognosis.

- Share prognosis using clear, direct language that reflects the patient's stated information preferences.
- Using a framework of "hope/worry" can help patients understand their prognosis while reflecting the uncertainty and promoting planning.[13] ***"It's difficult to predict what will happen. I hope you will continue to live well, but I'm worried that you could get sick quickly, and we should prepare for that possibility."***
- It's important to expect and respond to emotion:

Name the emotion: *"I can see this was really upsetting." "You seem sad."*

Understand: *"How does all this make you feel?"*

Respect: Praise coping; validate emotions. *"I admire the strength you've shown."*

Support: *"This can be frightening. I'll do whatever I can to help you get through this."*

Explore: *"Tell me more"* about…

Silence: Provide silence as a form of non-verbal empathic communication.

4 Explore key topics.

Questions that elicit the patient's goals, fears and worries, strengths, and abilities can help you make recommendations about treatment decisions.

5 Make recommendations and formulate a plan.

Use the information shared by patients and prognosis to formulate a patient-centered recommendation that covers treatment options, additional supports, and/or additional conversations.

When serious illness progresses

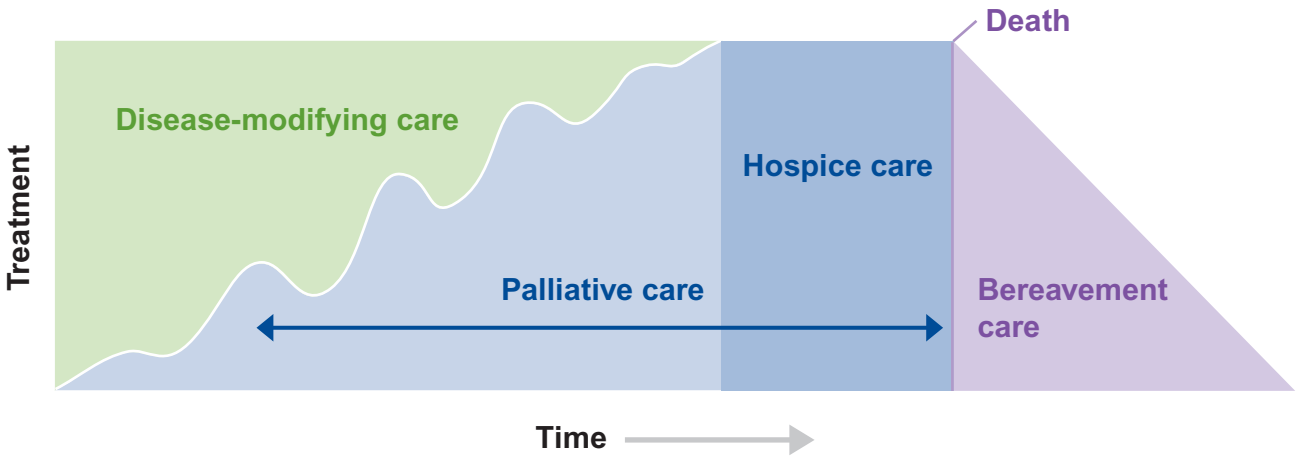
Complete a Pennsylvania Order for Life-Sustaining Treatment (POLST).

- A POLST form can help document a patient's wishes about life-sustaining treatment (e.g., intubation, antibiotics, and feeding tubes) after a conversation with the patient and their family. It is available at **www.bit.ly/POLST_form**.
- Give one or more copies to the patient and file a copy in the medical record.

Involve specialty palliative care or hospice services as needed.

FIGURE 3. The balance between disease-modifying and palliative care will vary over the course of the illness.

Palliative care can begin far in advance of end-stage disease, hospice, or death.[15]



Hospice care

While 'hospice' was originally thought of as a location of care, it is really a kind of care that can occur in multiple settings, including and most commonly the home. All of hospice is palliative care, but not all palliative care occurs in the context of a hospice program.

Decisions about hospice enrollment can be complex and may involve discontinuation of life-prolonging therapies, such as chemotherapy, artificial nutrition, and blood transfusions. Some hospices have "open-access" policies that permit and cover such therapies, but most do not.

Provide evolving support throughout the continuum of care

TABLE 2. The changing roles for primary care as the end of life approaches

Health status	Goal of care	Primary care role
Diagnosis of serious illness	Use disease modifying treatments and manage symptoms.	• Provide overall health care and coordinate specialist input. • Advance Care Planning: Initiate serious illness conversations and identify a health care proxy.
Advancing serious illness	Reassess the risks and benefits of disease-modifying treatments in accordance with the patient's goals and preferences.	• Assess and manage common symptoms. • Link patients and families to additional supports (e.g., social work). • Coordinate with specialists as needed to clarify the prognosis. • Advance Care Planning: Continue serious illness conversations and encourage the patient to complete a POLST.
Hospice	Provide comfort-focused care for the patient and family as the end of life approaches.	• Work with hospice to enroll patient. • Continue to serve as patient's PCP.
Family bereavement	Support family members through their bereavement.	If applicable, screen for complicated grief and refer if necessary. Family members of patients enrolled in hospice care are eligible for bereavement support for one year after death.

Links to hospice in Pennsylvania: www.bit.ly/PA_Healthcare

Manage symptoms adequately

Ease pain as disease advances.

"Total Pain" refers to the multiple and interacting mechanisms of suffering.

FIGURE 4. A multidisciplinary team can help address the constellation of factors contributing to pain.

Managing pain

Use a multimodal approach, including non-pharmacologic options (e.g., yoga, massage, acupuncture, exercise).

Match the pain mechanism to the medication:

- Neuropathic pain responds best to duloxetine (Cymbalta) or anticonvulsants (e.g., gabapentin [Neurontin], pregabalin [Lyrica]).
- Musculoskeletal pain is best managed with acetaminophen or NSAIDs, and any pain with an inflammatory component is best managed with an NSAID. Acetaminophen can be used as an adjunct.

If opioids are needed, use medication agreements, drug testing, and other best practices as appropriate.

For more information on managing pain, visit AlosaHealth.org/Opioids or scan this link to the Dana-Farber Cancer Institute Pink Book:

Reduce symptom burden

TABLE 3. Recommended approaches to managing symptoms other than pain

Symptom	Non-pharmacologic options	Pharmacologic options	Notes
Constipation	• Increase fluids. • Increase activity as tolerated. • Assure privacy for stool evacuation. • Discontinue/taper medications contributing to constipation. • Correct electrolytes (e.g., calcium, potassium).	Before advancing to next option, titrate dose when appropriate. 1. **Senna and/or polyethylene glycol (MiraLAX)** 2. **Lactulose** 3. **Milk of magnesia OR bisacodyl (Dulcolax)** 4. **Magnesium citrate**	Always include a bowel regimen for patients on opioids. Avoid docusate (Colace, and generics); it adds cost and pill burden without additional benefit.[16-18] See page 18 of the Dana-Farber Cancer Institute Pink Book:
Nausea	Frequent smaller meals	• Ondansetron • Metoclopramide • Dronabinol, cannabis • Prochlorperazine • Meclizine • Scopolamine • Lorazepam • Low-dose haloperidol or olanzapine	Preferred agent depends on cause of nausea. See the Dana-Farber Cancer Institute Green Book for more:
Fatigue	• Exercise • Cognitive behavioral therapy	For opioid-related fatigue: • Methylphenidate • Modafinil (Provigil)	
Shortness of breath	• Nasal oxygen • Open a window or use a fan to move air. • Relaxation techniques	Low-dose opioids (e.g., morphine 5-15 mg orally)	

Medicare reimburses clinicians for advance directive conversations

- **Billable conversations may occur as:**
  - an element of a Medicare Wellness Visit.
    - must be delivered by the same clinician on the same day
    - requires the use of a modifier (Preventive services -33)
  - a separate Medicare Part B, medically necessary, service.
- **Services can be delivered via phone, telehealth, or in person.**
- **Meetings may be with surrogates** (i.e., the patient is not required to be present).

CPT codes	Billing code descriptors
99497	Advance Care Planning including the *explanation and discussion* of advance directives such as standard forms (including the completing of such forms, when performed), *by the physician or other qualified health professional;* first 30 minutes, face-to-face *with the patient, family members, and/or surrogate*
99498	(add-on) Each additional 30 minutes 

- Services are performed for a length of time equal to 'one minute past the midway point' of the code, i.e., 16 minutes for each code.
- There are no limits on the number of times a clinician can engage in ACP for a given patient in a given time period—but the copay-free Annual Wellness Visit billing is limited to once per year.

Documentation for billing

- Include a brief summary of the conversation.
- Record who participated in the discussion.
- Document the time spent in the discussion.
- Note whether any forms were completed during the visit.

Key points

- **Engage patients and their surrogates in advance care conversations** early in the course of a serious illness.
- **Create a structure** for discussing prognosis and medical options.
- **Use the tools** listed to facilitate dialog that will clarify the patient's values and preferences.
- **Ensure that the patient has completed the necessary documents** such as naming a health care proxy and advance health care directives.
- **Reduce symptom burden** by managing pain, constipation, nausea, shortness of breath, and fatigue.

Visit AlosaHealth.org/Serious_illness
for links to a comprehensive evidence document and other resources.

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(1) Center to Advance Palliative Care. About palliative care. https://www.capc.org/about/palliative-care/. Accessed February 24, 2021. **(2)** Kelley AS, Bollens-Lund E. Identifying the Population with Serious Illness: The "Denominator" Challenge. *J Palliat Med*. 2018;21(S2):S7-s16. **(3)** Epidemiology And Patterns Of Care At The End Of Life: Rising Complexity, Shifts In Care Patterns And Sites Of Death. *Health Affairs*. 2017;36(7):1175-1183. **(4)** McMahan RD, Tellez I, Sudore RL. Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review. *J Am Geriatr Soc*. 2021;69(1):234-244. **(5)** Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage*. 2017;53(5):821-832.e821. **(6)** Izumi S, Fromme EK. A Model to Promote Clinicians' Understanding of the Continuum of Advance Care Planning. *J Palliat Med*. 2017;20(3):220-221. **(7)** Downar J, Goldman R, Pinto R, Englesakis M, Adhikari NKJ. The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis. *CMAJ*. 2017;189(13):E484-E493. **(8)** Yadav KN, Gabler NB, Cooney E, et al. Approximately One In Three US Adults Completes Any Type Of Advance Directive For End-Of-Life Care. *Health Aff (Millwood)*. 2017;36(7):1244-1251. **(9)** Sudore RL, Schillinger D, Katen MT, et al. Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trial. *JAMA Intern Med*. 2018;178(12):1616-1625. **(10)** Lankarani-Fard A, Knapp H, Lorenz KA, et al. Feasibility of discussing end-of-life care goals with inpatients using a structured, conversational approach: the go wish card game. *J Pain Symptom Manage*. 2010;39(4):637-643. **(11)** Zachariah F, Klein L, Clifton-Hawkins N, et al. "It's about the conversation": A multidisciplinary intervention to support advance-care planning. *J Clin Oncol*. 2014;32(31_suppl):111-111. **(12)** Bernacki R, Paladino J, Neville BA, et al. Effect of the Serious Illness Care Program in Outpatient Oncology: A Cluster Randomized Clinical Trial. *JAMA Intern Med*. 2019;179(6):751-759. **(13)** Paladino J, Lakin JR, Sanders JJ. Communication Strategies for Sharing Prognostic Information With Patients: Beyond Survival Statistics. *JAMA*. 2019;322(14):1345-1346. **(14)** Atherton KN. Project Five Wishes: promoting advance directives in primary care. *J Am Assoc Nurse Pract*. 2020;32(10):689-695. **(15)** Lynn J, Adamson DM. *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age.* RAND Corporation; 2003. **(16)** MacMillan TE, Kamali R, Cavalcanti RB. Missed Opportunity to Deprescribe: Docusate for Constipation in Medical Inpatients. *Am J Med*. 2016;129(9):1001.e1001-1001.e1007. **(17)** McRorie JW, Daggy BP, Morel JG, Diersing PS, Miner PB, Robinson M. Psyllium is superior to docusate sodium for treatment of chronic constipation. *Aliment Pharmacol Ther.* 1998;12(5):491-497. **(18)** Tarumi Y, Wilson MP, Szafran O, Spooner GR. Randomized, double-blind, placebo-controlled trial of oral docusate in the management of constipation in hospice patients. *J Pain Symptom Manage.* 2013;45(1):2-13.

About this publication

These are general recommendations only; specific clinical decisions should be made by the treating clinician based on an individual patient's clinical condition. More detailed information on this topic is provided in a longer evidence document at AlosaHealth.org.

IDIS Independent Drug Information Service

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Alosa Health

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