

Palliative Care Playbook for PACE



Integrating Palliative Care Approaches in PACE

Most participants in the Program of All-Inclusive Care for the Elderly (PACE) face difficulties in their daily functioning and often struggle with distressing symptoms, caregiver burden, and care planning and existential concerns. It is estimated that the majority of individuals eligible for nursing home-level care in the United States are in need of palliative care.ⁱ

Integrating palliative care into the PACE care delivery model can improve participant quality of life while avoiding unnecessary – and potentially harmful – medical interventions. Studies have shown that attention to palliative needs significantly improves quality-of-life measures,ⁱⁱ while reducing emergency department and hospital utilization by as much as 50 percent.ⁱⁱⁱ While PACE programs already focus on optimizing quality of life for their participants, the principles and practices of palliative care can multiply the positive impact of the existing PACE interdisciplinary team. Further, some programs may benefit from integrating specialty palliative care services into their operations.

Recognizing the significant value in integrating palliative care into PACE, the Center to Advance Palliative Care (CAPC), the National PACE Association (NPA), and the West Health Institute (WHI) worked with a group of nine pioneering PACE organizations (referred to below as “the Pioneers”) to integrate palliative care into their care delivery. This report summarizes the best practices collected from these Pioneers, along with the advice collected from these Pioneers, across five parameters:

1. identifying participants in need,
2. conducting conversations about goals of care and advance care planning,
3. equipping staff for effective conversations and appropriate symptom management,
4. using specialty palliative care teams for participants with complex needs, and
5. implementing quality monitoring and improvement.

What Is Palliative Care?

Palliative care focuses on providing relief from the symptoms and stresses of serious illness, including those that impact daily functioning. The goal is to improve quality of life for both the individual and the family.

Palliative care is based on the needs of the patient, not on their prognosis. It is appropriate and beneficial at any age and any stage of illness and can be provided along with curative treatment.

Identifying Participants in Need

Currently, few PACE organizations systematically assess participants for sources of distress, but early recognition and intervention can make a big difference. The programs doing this well incorporate screening for pain, frailty and other symptoms into the initial comprehensive assessment and the semi-annual reassessment, as well as upon a change in the participant's status.

Evidence-based tools that can screen for palliative care needs include the following:

- » Symptom burden: **Revised Edmonton Symptom Assessment System (ESAS-r)**
- » Anxiety and depression: **PHQ-4 Validated Screening Tool**
- » Frailty and risk of death: **Walter Index** or the **Charlson Comorbidity Index**
- » Caregiver burden: **Zarit Burden Interview (ZBI-12)**
- » Spiritual distress: **Spiritual Dimension Screening from the Supportive Care Coalition**

Beyond these formal screenings, the interdisciplinary team (IDT) should be on the lookout for signs of frailty and/or misunderstanding of illnesses and impacts. Staff should take care to note the following:

- » loss of strength, poor endurance, and becoming easily fatigued;
- » unintended weight loss;
- » low activity level, including spending more time sleeping;
- » slowed or unsteady gait;
- » caregiver stress and burnout;
- » misunderstanding of prognosis;
- » unarticulated values and goals;
- » existential worry; and
- » disagreement within family.

There is currently debate about using “the surprise question” to identify individuals in need of palliative care services, meaning asking the provider, “Would you be surprised if this patient died within the next 12 months?” While this does offer a potentially speedy identification process, a recent meta-analysis found that this has a pooled accuracy of only 75 percent, with a sensitivity of 67 percent^{iv}. In other words, there are many patients who die within a year where their treating clinicians did not recognize the risk. Therefore, using the surprise question is not recommended.

Palliative care delivery should be based on participant need, not prognosis. There are many individuals who benefit from symptom management, clarifying goals of care, and making advance care plans, even though they may live for years and years to come.

Tips from the Pioneers

- ▶ This is everyone's job on the PACE IDT. All team members – including drivers, aides, social workers, providers and others – should be looking for signs of distress, and appreciative inquiry is the job of the team itself, rather than automatically making a referral to a specialist.
- ▶ Consider using your therapists to assess for and then address pain. Pain often can be addressed appropriately with physical therapy as an alternative of or complement to pharmacological treatment.

Conducting Goals of Care and Advance Care Planning Conversations

Perhaps the most significant value of a palliative approach in PACE is the emphasis on clarifying goals of care and assisting with advance care planning. PACE is responsible for all care delivery, so clarifying values and what matters most to each individual is essential to the quality of this person-centered care model.

As with the needs assessment, conducting these conversations should begin at intake and can be revisited upon reassessments and significant changes in condition. Many of the successful PACE organizations use their social work team to begin conversations about goals of care and to conduct advance care planning conversations, with the provider team completing the conversation about care goals to create treatment plans aligned with participant values and preferences.

A conversation about goals of care centers around four key topics:

- » What is the participant's **understanding** of their condition, and what should they expect as time goes on?
- » What are their **fears**? Is there any situation that they hope to avoid? For example, someone might be concerned about a loss of independence.
- » What are their **goals**? What is important to them at this time, and what might be important to them in the future? This is where you might hear about hopes to see a grandchild graduate or a favorite niece walk down the aisle.
- » What are the **trade-offs** they are willing to tolerate? For example, someone might be willing to cope with some incontinence if their cognition can remain intact, or they might wish to avoid surgery even if it means less time alive.

Conversations about goals of care are necessary for all participants to guide current care planning. In addition, advance care planning can help the participant plan ahead for things like the following:

- » Who would make health care decisions for them in the event they are unable? This is by far the most important part of advance care planning: **selecting a surrogate decision-maker** and ensuring that they are informed of their role.
- » What they would want (with sufficient explanations of what these things mean and the potential impact they might have) if faced with the need for the following interventions:
 - Mechanical ventilation
 - Artificial nutrition
 - Resuscitation

Goals of Care vs. Advance Care Planning

A conversation about goals of care reviews what the individual values and what makes life worth living, and it helps clinicians make recommendations that align, given their current situation and what is known about their illness trajectory.

An advance care planning conversation is a future-looking plan, asking what health care interventions might be wanted or not in future hypothetical situations.

When appropriate, participant preferences should be documented on the advance directive approved by the state, such as **Portable Orders for Life-Sustaining Treatment (POLST)**.

The PACE team member engaged in advance care planning must make it clear that the conversation is future-facing, hypothetical, and not reflective of any immediate circumstances. It is not uncommon for staff to be uncomfortable starting these conversations, and this guide provides some advice on how to best equip them. There is also comfort in knowing that most people welcome these conversations. A recent study found that 84 percent of adults in the United States would feel comfortable having this conversation with their care team.^v

Tips from the Pioneers

- ▶ Make sure the participant and their family know their condition(s) and what to expect before proceeding with any further conversation.
- ▶ Use an Ask-Tell-Ask approach. Ask for permission to begin such a conversation (and do not proceed if they are hesitant). Then explain what you are hoping to discuss, explain the background of each specific question, and ask them to respond. Allow for silence.
- ▶ The best starting place for advance care planning is to select a surrogate decision-maker. It's the most useful for the care team and is generally a comfortable conversation. If the participant is having difficulty naming someone, setting up an A or B choice makes it easier.

Equipping Staff for Assessments, Conversations and Symptom Management

Knowing what to watch for, performing assessments, conducting conversations about goals of care and advance care planning, and managing pain and other symptoms effectively require some basic knowledge and skill. Meaningful conversations can be strengthened through practice.

All PACE staff should have basic knowledge of what palliative care truly is, along with how to look for and inquire into sources of suffering. Nurses and social workers should have basic competencies in assessment and in serious illness communications, while providers should know the basics of assessment, communications and symptom management. Most of the pioneering PACE organizations required training for certain staff, and others have implemented creative promotions and engagement techniques.

Training and resources are available through the **Center to Advance Palliative Care (CAPC)**, and serious illness communication training programs are available through **VitalTalk, Respecting Choices**, and the **End-of-Life Nursing Education Consortium (ELNEC)**. **Recommended curricula**, both for initial staff onboarding and annual refreshers, are provided at the end of this document. The NPA Palliative and End-of-Life Care Workgroup also has developed training modules and resources to assist PACE organizations in staff education efforts.

Once staff complete their courses, it is important that they practice and debrief on using these skills. Agendas at departmental and IDT meetings can accommodate group discussion and role plays as needed. Consider discussing specific participant cases to help with skill-building.

Tips from the Pioneers

- ▶ It is tremendously valuable to have all staff understand what palliative care is and how participants might be suffering. Leaving the frame of “end of life” allows the PACE program to recognize that most participants have palliative care needs; there’s nothing we need to wait for in order to help them.
- ▶ Hand-outs – such as talking points, conversation prompts and other resources – help staff to integrate more easily conversations about goals of care and advance care planning into their interactions
- ▶ Consider doing a “pre-assessment” of staff knowledge and skills. You may find a lot of misperceptions or concerns, which can help you target your training efforts.
- ▶ Provider training makes them more attuned to look for pain and symptom distress and helps them to be more comfortable with opioids, which some participants definitely need.

Using Specialty Palliative Care Teams

Several of the pioneering PACE programs relied on specially trained palliative care professionals to care for their more complex participants, such as those whose function is declining rapidly. In some cases the palliative care provider co-manages the participant with the interdisciplinary care team, and in others the participant’s care is transferred to the palliative care team. The creation and use of a specialty palliative care team seems to be driven by the culture of the PACE program.

If the PACE program does not maintain its own specialty palliative care team, having a certified palliative care specialist available for consultation can be a valuable contributor to the IDT when warranted. Such a specialist can do the following:

- » manage refractory pain or other symptoms, and
- » assist with conflict resolution regarding goals or services (the conflict may be among family members, among IDT members, or between and among these parties).

If a specialty palliative care provider or team is used, best practices include the following:

- » Clearly define criteria for who will be served by the palliative care specialist(s) based on the assessments conducted to determine palliative needs.

One important point about staff preparation: *Be very careful with the language the team uses when speaking with participants and family members.*

Phrases such as “end-of-life care” or “a good death” can hurt your relationships with the participants and their family, even with good intentions. Non-health care professionals find this language distressing, no matter their circumstances. Instead, talk about how these conversations will help the PACE program optimize quality of life and ensure that any care received is in line with the values of the individual.

Learn more about **palliative care messaging** before proceeding!

- » Consider a relationship with a local hospice. If preferred, the participant can be dis-enrolled in PACE and elect their hospice benefit. If not, the hospice can provide additional supports, including inpatient hospice care, at a negotiated price.
- » Use your palliative care specialists, including your chaplain, to provide grief and bereavement support. This should be not only for family members but for the PACE team members who cared for the participant.

You can find palliative care specialty teams and programs through the [Palliative Care Provider Directory](#). Consider contacting those that serve all settings, even those in acute care hospitals, who may be able to provide consultative services.

Tips from the Pioneers

- ▶ A palliative care specialist can do “rounds” on all participants, helping to not only improve care for those in need as well as continually educate the providers.
- ▶ Having a hospice in your network can help you provide inpatient care without hospital admission, when appropriate. This can be necessary to give the caregivers much-needed relief.

Quality Monitoring and Improvement

The goal of integrating palliative care into PACE is to improve quality of life and quality of care for participants, so monitoring quality is essential to program implementation. The following metrics are useful:

- » Proportion of participants who have a surrogate decision-maker documented in the medical record within a specified number of days from enrollment.
- » Proportion of participants with goals of care documented in the medical record.
- » Proportion of appropriate participants who have a state-approved advance directive in the medical record.
- » Proportion of participants who have an advance care plan.
- » For those patients documented as having palliative care needs:
 - emergency department visit rate
 - hospital days per thousand (or other hospital utilization rate)
- » Proportion of participants who have a documented screening for pain and other symptoms.
- » Proportion of participants who screened positive for pain or symptom burden and who have a documented care plan to address these symptoms.
- » Place of death evaluations:
 - percentage of deaths that occurred in a hospital or skilled nursing facility
 - percentage of participants who died in a setting aligned with their documented preferences
- » Number of days at home during the last 90 days of life.

Two new patient-reported outcome measures relevant to palliative care have been developed. They can help PACE organizations assess how person-centered their care delivery has been. The measure steward is the American Academy of Hospice and Palliative Medicine:

- » How much do participants **feel heard and understood**?
- » Participants' **experience of receiving desired help for pain**.

Under the guidance of the NPA Palliative and End-of-Life Care Workgroup, NPA also has established **quality improvement tools and resources** to assist PACE organizations in assessing the effectiveness of their palliative care services.

Tips from the Pioneers

- ▶ It is important to not only have an advance directive completed but have it be easily available in the EHR so that the team can get it to a hospital or emergency department if needed. Tracking e-POLST completion can address this.
- ▶ Keeping track of the “denominator population” (those that we identified with a high index score) helped us to see if our main quality measures improved in this population. We don't have a firm answer yet, but the screening and attention to these palliative needs seem to be making a difference.

More Information

This playbook can serve as a foundation for PACE organizations working to improve quality of life for their participants by recognizing and addressing potential sources of suffering. Implementation of the strategies and tactics described here will require additional support and resources:

- » The Center to Advance Palliative Care (CAPC) at capc.org provides resources and recommendations on **Clinical Training, Patient Identification and Assessment**, and **Improving Dementia Care**.
- » The National PACE Association at npaonline.org offers **Participant Care Resources**.

Citations

ⁱ Carlson, M.D., Lim, B., Meier, D.E. (2011). Strategies and innovative models for delivering palliative care in nursing homes. *JAMDA*, 12 (2).

ⁱⁱ Kavalieratos, D., Corbelli, J., Zhang, D. (2016). Association between palliative care and patient and caregiver outcomes: A systematic review and meta-analysis. *JAMA*, 316 (20).

ⁱⁱⁱ Scibetta, C., Kerr, K., McGuire, J., Rabow, M.W. (2015). The costs of waiting: Implications of the timing of palliative care consultation among a cohort of decedents at a comprehensive cancer center. *Journal of Palliative Medicine*, 19 (1).

^{iv} Downer, J., Goldman, R., Pinto, R., Englesakis, M., Adhikari, N.K.J. (2017). The “surprise question” for predicting death in seriously ill patients: A systemic review and meta-analysis. *CMAJ*, 189 (13).

^v Kaiser Family Foundation. (2015). Public strongly favors end-of-life conversations between doctors and patients. Sept. 30.

RECOMMENDED TRAINING ACROSS THE IDT (Recommended refresher courses are denoted with *)

CAPC Course Title	Drivers	Aides	Administrators	Social Work	Nursing	Providers	Therapists, Dietitians
An In-Depth Look at Palliative Care and Its Services	✓	✓	✓	✓	✓	✓	✓
A Palliative Approach to Care for Direct Care Workers*	✓	✓	✓				
Communication Skills							
Delivering Serious News			✓	✓	✓	✓	
Discussing Prognosis			✓	✓	✓	✓	
Clarifying Goals of Care*	✓	✓	✓	✓	✓	✓	✓
Conducting a Family Meeting			✓	✓	✓	✓	✓
Advance Care Planning Conversations*			✓	✓	✓	✓	
Building Skills in Basic Advance Care Planning							
Basic Advance Care Planning: Introduce and Motivate				✓	✓	✓	
Basic Advance Care Planning: Guide and Document				✓	✓	✓	
Beyond Conversation: Integrating Basic Advance Care Planning into Practice				✓	✓	✓	

CAPC Course Title	Drivers	Aides	Administrators	Social Work	Nursing	Providers	Therapists, Dietitians
Symptom Management, Preventing Crises, and Relief of Suffering Across the Disease Trajectory							
Comprehensive Pain Assessment*	✓	✓	✓	✓	✓	✓	✓
Reducing Risks for Older Adults	✓	✓	✓	✓	✓	✓	✓
Relieving Suffering in Patients with Dementia and Their Caregivers	✓	✓	✓	✓	✓	✓	✓
Critical Decisions in Advanced Dementia*				✓	✓	✓	
Relieving Suffering in Patients with COPD				✓	✓	✓	
Relieving Suffering in Patients with Heart Failure				✓	✓	✓	