

Recognizing Early Signs of Decline – Transition from Palliative Care to Hospice

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Palliative Care Providers

In your current practice, what most often triggers a hospice referral?

- A. Rapid functional decline
- B. Repeated hospitalizations
- C. Caregiver crisis
- D. Clinician intuition
- E. Other



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**When to Transition from Palliative Care to Hospice**

Recognizing disease trajectory, functional decline, emotional readiness, and the right time for hospice referral




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### Why timing matters

National metrics show both increased hospice use and persistent late transitions

**National metrics**

**Scale of hospice use**

CMS reports that more than 1.7 million Medicare beneficiaries received hospice care in 2023, with Medicare hospice spending of \$2.7 billion.

**Median length of stay remains short**

CMS monitoring data continue to show a much shorter median LOS than average LOS, reinforcing that many patients still arrive late.

**Quality measures reflect transition problems**

Hospice quality monitoring includes live discharges, gaps in skilled nursing visits, and burdensome transitions after live discharge.

The goal is not "earliest possible hospice." The goal is an earlier, better aligned transition before patients reach a crisis point of uncontrolled symptoms, repeated hospitalizations, or caregiver collapse.

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### Palliative care versus hospice: what changes?

The transition is driven by prognosis, goals, burdens of treatment, and care intensity needed at home

**Foundational framing**

Palliative care	Hospice	Common mistake
<p>Can occur alongside disease-directed therapy</p> <p>Focuses on symptom relief, goals, caregiver support, and quality of life</p> <p>Appropriate at any stage of serious illness</p> <p>Often longitudinal and layered into home health or outpatient care</p>	<p>Appropriate when the clinical picture supports a terminal prognosis of 6 months or less if the disease runs its normal course</p> <p>Focus shifts toward comfort-centered, goal-concordant end-of-life care</p> <p>Requires election of the hospice benefit for the terminal illness and related conditions</p> <p>Team intensity and caregiver support typically increase</p>	<p>Waiting for one dramatic event.</p> <p>Most appropriate transitions are identified by accumulating markers:</p> <ul style="list-style-type: none"> <li>- Decline in function</li> <li>- Rising symptom burden</li> <li>- Lower reserve</li> <li>- Recurrent exacerbations</li> <li>- Caregiver distress</li> <li>- Clearer preference for comfort over disease-directed escalation.</li> </ul>

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### Disease trajectories that should trigger hospice thinking

Use trajectory language to teach teams what "decline over time" looks like

**Disease trajectories**

**1. Rapid downward slope**

Often seen in advanced cancer.

Markers include:  
- Accelerating weight loss  
- Reduced intake  
- Escalating symptoms  
- Increasing time in bed/chair/D  
- Dependence in ADLs  
- Fewer treatment options with meaningful benefit.

**2. Long-term decline with intermittent crises**

Often seen in CHF, COPD, renal, or liver disease.

The patient may partially recover after exacerbations, but baseline function, reserve, and tolerance steadily worsen after each event.

**3. Prolonged dwindling / frailty pattern**

Often seen in dementia, neurologic illness, and debility/frailty.

Decline is gradual but cumulative:  
- weight loss  
- infections  
- dysphagia  
- falls  
- skin breakdown  
- speech/cognitive decline  
- increasing total dependence.

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### Functional decline markers

Functional change is often the clearest bridge between trajectory and prognosis


**Functional decline markers**

**High-yield markers**

- Declining ambulation: walks less, becomes housebound, requires wheelchair or bed-to-chair transfer
- Increasing dependence with bathing, dressing, toileting, transfers, feeding, or continence
- Reduced activity tolerance: rests after minimal exertion, cannot finish ADLs without dyspnea or fatigue
- Progressive sleeping / time in bed or chair

**Often overlooked markers**

- Reduced oral intake or hydration; weight loss or visible loss of muscle/fat stores
- Falls, recurrent infections, pressure injuries, or slower recovery from minor illness
- Speech decline, dysphagia, reduced attention, worsening confusion, or inability to participate in decisions
- Caregiver report that "everything takes more out of them now"



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### Physical signs and emotional readiness

The best of referral timing considers both clinical decline and the patient-family readiness to shift goals


**Readiness.**

**Physical signs suggesting the window is narrowing**

- Escalating symptoms despite adjustment of routine palliative measures
- Recurrent ED visits or hospitalizations
- Rising oxygen needs, dyspnea at rest, recurrent aspiration, or exhaustion after minimal exertion
- Weight loss, reduced intake, increasing somnolence, infections, skin failure, or overall frailty
- A visible pattern that the patient is not returning to prior baseline after each setback

**Emotional readiness cues**

- "I do not want to keep going back to the hospital."
- "I want to stay home."
- "The treatments are harder than they used to be."
- "We need more help."
- Family expresses fear of another crisis, uncertainty about when to call 911, or inability to keep up with caregiving demands
- Team senses that hopes are shifting from prolonging life at all cost to comfort, time at home, and predictability



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### CMS hospice criteria: practical framing

Teach clinicians to use criteria as a structured support for judgment, not a checklist detached from the

**CMS hospice criteria**

**Anchor question**

Does the physician certify that the patient is terminally ill with a life expectancy of 6 months or less if the disease runs its normal course?

**How teams should use criteria**


Use LCDs and disease-specific tools to organize evidence:

- Objective decline
- Functional loss
- Nutritional change
- Recurrent complications
- Symptom escalation
- Worsening tolerance of treatment.

**Common documentation error**

Documenting only diagnoses without the trajectory.

Criteria are strongest when the note explains what has changed, how quickly, and what it means for prognosis and goals of care.



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### PPS trends

Use the trend, not just the single score

**PPS**

**How to teach PPS in this session**


A declining PPS helps translate observable change into a shared language.

Look for downward movement over time rather than overinterpreting one isolated score.

Particularly meaningful when lower PPS aligns with reduced intake, increased sleep, worsening dependence, and reduced tolerance for activity.

PPS becomes more persuasive when paired with disease-specific decline and caregiver burden.

70%	Reduced work / some disease evidence
50%	Considerable assistance; mainly sit/lie
40%	Mainly in bed; extensive assistance
30%	Totally bedbound or near-bedbound; total care



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### FAST scale in dementia

The score matters, but the accompanying decline narrative matters just as much

**FAST**

**High-yield teaching points**

FAST is commonly used to support hospice thinking in advanced dementia.

Teams should not rely on stage alone; they should pair FAST with complications and overall decline.

Important supporting markers include recurrent infections, aspiration risk, dysphagia, weight loss, pressure injuries, reduced speech, and total dependence.

**Common transition pattern in dementia**


Loss of meaningful ambulation

Dependent for dressing, bathing, toileting, transfers, and feeding cues/assistance

Minimal or fewer intelligible words

Dysphagia, aspiration events, weight loss, dehydration, or infections

Family goal shifts toward comfort, routine, and avoiding another hospitalization



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### NYHA scale in heart failure

Use symptom burden, reserve, and repeated exacerbations to tell the real story

**NYHA**

**What points toward hospice?**

Persistent symptoms at rest or with minimal activity

Recurrent decompensations, hospitalizations, or need for escalating diuretics/oxygen

Declining tolerance of ADLs and increasing fatigue

Coexisting cachexia, renal decline, hypotension, or inability to tolerate guideline-directed therapy


**How to talk about NYHA**

NYHA class helps structure severity, but the transition decision is stronger when clinicians show that the patient is increasingly symptomatic, increasingly limited, and recovering less after each episode.

**Bridge statement for teams**

This is no longer a patient who simply has CHF.

This is a patient with advanced heart failure, repeated instability, lower reserve, and goals that may now be better served by hospice support at home."



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### LCDs: how to use them without becoming checkbox-driven

LCDs help organize disease-specific evidence, but the narrative still has to describe decline

**LCDs**

Use LCDs to identify...	Examples
<b>Objective decline</b>	Weight loss, lower intake, lower PPS, lower tolerance for activity, cognitive decline
<b>Complications</b>	Recurrent infections, aspiration, skin breakdown, hospitalizations, falls, exacerbations
<b>Disease progression</b>	Advancing cancer burden, worsening HF symptoms, advanced dementia losses, worsening pulmonary reserve
<b>What it means</b>	Patient is less resilient, more symptomatic, more dependent, and more aligned with comfort-focused support



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### Case-based decision pathways

Use structured pathways to help teams move from uncertainty to action

**Case-based decision pathways**

**Case 1: Advanced cancer**

Recent 15-lb weight loss, PPS falling, increased sleeping, breakthrough pain, less tolerance of treatment, wants to stay home.

**Decision pathway:**  
Trajectory + function + goals all align -> discuss hospice now.

**Case 2: CHF/COPD with crises**


Three hospitalizations in 5 months, more dyspnea with ADLs, oxygen needs rising, walker to wheelchair, family exhausted.

**Decision pathway:**  
Repeated exacerbations + lower baseline + caregiver strain -> strong hospice conversation.

**Case 3: Advanced dementia**

FAST progression, dysphagia, aspiration concern, recurrent infections, total dependence, little meaningful speech.

**Decision pathway:**  
Advanced frailty pattern + complications + comfort-focused goals -> hospice appropriate.



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### Simple decision pathway teams can use

A practical framework for palliative teams, home health clinicians, and referring providers

**Decision tool**

- 1 Would I be surprised if this patient died in the next 6-12 months?
- 2 Is there documented disease progression or repeated serious setbacks?
- 3 Is function dropping: PPS, ADLs, mobility, intake, cognition, time in bed/chair?
- 4 Are symptoms, caregiver burden, or hospitalization risk increasing?
- 5 Have goals shifted toward comfort, time at home, and less burdensome treatment?

If the answer is repeatedly "yes," move from "watchful palliative follow-up" to an active hospice referral conversation.



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### End-of-life quality impact

Earlier, better aligned transitions support comfort, fewer crises, and more goal-concordant care

**EOL quality impact**

<p><b>For patients</b></p> <ul style="list-style-type: none"> <li>Better symptom control at home</li> <li>Less crisis-driven decision-making</li> <li>More time to build trust with the hospice team</li> <li>Greater chance of dying in the preferred setting</li> </ul>	<p><b>For caregivers</b></p> <ul style="list-style-type: none"> <li>More support and predictability</li> <li>Better teaching on what to expect</li> <li>Less fear around nights/weekends/crises</li> <li>More time for practical and emotional preparation</li> </ul>	<p><b>For systems</b></p> <ul style="list-style-type: none"> <li>Potential reduction in avoidable hospitalization near end of life</li> <li>Fewer disruptive transitions</li> <li>Better alignment of care setting with patient goals</li> <li>Better team coordination across settings</li> </ul>
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### Scripts for the transition conversation

Simple, repeatable language helps clinicians move from avoidance to clarity

**Scripts**

<p><b>Opening script</b></p> <p>I want to pause and talk about the bigger picture of what we are seeing.</p> <p>Even with good palliative support, your illness is changing in ways that tell us time may be shorter and needs may be increasing.</p> <p>I think it may be time to talk about whether hospice support would fit your goals."</p>	<p><b>If the family says "not yet"</b></p> <p>That is okay. We do not have to decide everything today.</p> <p>Can we talk about what matters most if things worsen, and what would make you feel more supported at home?"</p>	<p><b>Bridge to goals</b></p> <p>Given the hospital trips, lower strength, and harder recovery each time, what feels most important now:</p> <p>Trying to prolong life at any cost, or focusing on comfort, time at home, and avoiding another crisis if possible?"</p>
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### ACP tools that support better timing

Advance care planning should start before the hospice election conversation becomes urgent

**ACP tools**

<p><b>Useful ACP elements</b></p> <ul style="list-style-type: none"> <li>Surrogate decision maker confirmation</li> <li>Code status review</li> <li>Hospitalization preferences</li> <li>Preferred place of care / death</li> <li>What tradeoffs are acceptable or unacceptable</li> <li>Caregiver capacity and backup plan</li> </ul>	<p><b>Helpful tools / approaches</b></p> <ul style="list-style-type: none"> <li>Goals-of-care discussion template</li> <li>Serious illness conversation prompts</li> <li>Disease-specific preparedness teaching</li> <li>Emergency symptom plan for nights/weekends</li> <li>What would matter most if time were short?</li> </ul>	<p><b>Best practice message</b></p> <p>ACP is not a separate task from hospice timing.</p> <p>Good ACP often reveals when the patient's values now align better with hospice-level support than with continued crisis-based care.</p>
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**Team communication**  
 Consistent interdisciplinary language reduces mixed messages and delayed referrals

**Team communication**

**What strong team communication sounds like**

We are all seeing the same trend: more dependence, less reserve, and higher support needs.

Let's make sure nursing, social work, provider, and therapy are describing the same trajectory.

We need one message about what hospice is, why now, and how it supports the family.

Document not only the diagnosis, but what changed since last month.

**Operational habits that help**


Use case conference triggers for repeated hospitalization, falling PPS, FAST progression, or caregiver strain

Standardize the hospice referral handoff

Keep scripts in the EMR / team resource folder

Close the loop on family questions after the initial conversation

Revisit readiness rather than assuming one "no" means not appropriate



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**Common pitfalls that delay hospice**

These are the patterns that keep teams stuck too long in "watch and wait" mode

- Focusing on isolated stable findings while missing the longer decline trend.
- Waiting for absolute certainty instead of acting on accumulating evidence.
- Discussing hospice only after a crisis admission, severe symptom flare, or caregiver collapse.

Hospice timing improves when teams trust pattern recognition and revisit readiness early, often, and consistently



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**Take-home checklist**  
 A practical summary clinicians can use the next day in case review or patient visits

**Takeaways**

- 1 Look for disease trajectory, not isolated events.
- 2 Use functional decline markers as a bridge from observation to prognosis.
- 3 Support clinical judgment with PPS, FAST, NYHA, and LCD-based evidence bundles.
- 4 Name both physical decline and emotional readiness.
- 5 Use a decision pathway so "possible hospice" becomes "active conversation now."
- 6 Standardize scripts, ACP prompts, and interdisciplinary communication.



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**Questions and discussion**

Which patient populations create the most uncertainty in your palliative-to-hospice transition decisions?



Home Care & Hospice

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