



Helping care go well: A caregiver's role in the hospice experience

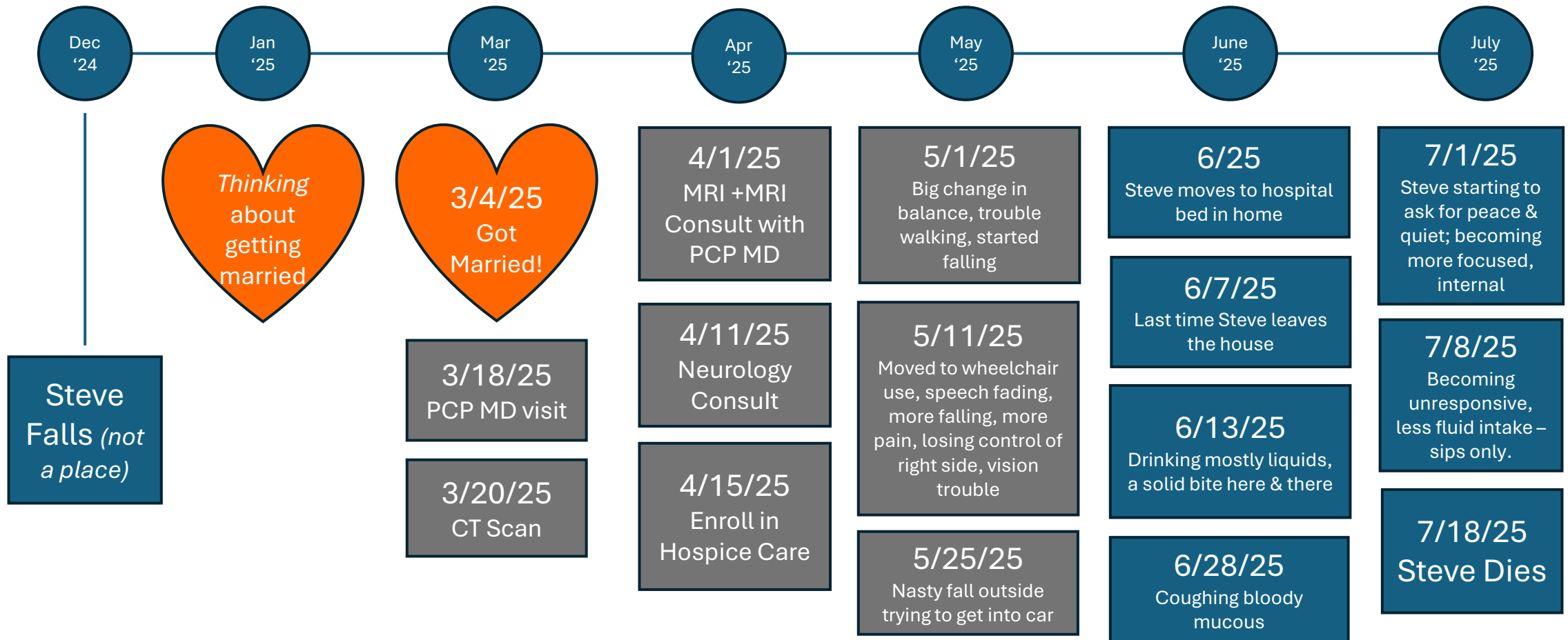
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Learning objectives

- Identify the factors that influence and positively support how a non-clinical caregiver manages the care needs of their loved one.
- Recognize how hospice teams can invite caregiver engagement by creating space for questions caregivers may not yet know to ask.
- Reflect on how communication, teaching, and logistical support (such as symptom management and equipment use) influence caregiver confidence and the day-to-day hospice experience at home.

Timeline





What caregivers don't know (but need to)

- What dying actually looks like
- When reality doesn't match expectations
- Clear guidance reduces fear and confusion
- Unexpected visitors and social dynamics can add stress



What happens after death?

- Caregivers often wonder—but don't always ask:
 - How long can we stay with our loved one?
 - What happens when the funeral home arrives?
 - Will the body be bathed—and can we be part of that?
 - Can there be a ritual or ceremony as they leave the home?
- **What helps:**
 - Introducing these conversations early
 - Offering options and flexibility
 - Creating space for meaning and ritual

Caregivers need
confidence in
themselves



Your hospice team helps build that confidence



Based on her portrayal in *1923*, Cara Dutton (Helen Mirren) is widely considered both **emboldened** and a **pioneer woman**, serving as the "hardened Irish" matriarch of the Dutton family who brings "unstoppable strength" to the Montana frontier. She is viewed as a "ride or die" figure who is arguably the bravest, boldest, and most loyal character in that era of the *Yellowstone* universe, often serving as the strategic, level-headed backbone of the family.

Caregivers need support—not just instructions

- Caregivers arrive with assumptions and secondhand stories
- The caregiving role is often unclear at the start
- Expectations about support vary widely across families
- Ask:
 - *“What are you expecting?”*
 - *“What would feel most supportive?”*
- Support includes teaching, presence, and real-time guidance

Broken dolls: A story of falling and hurting

Real life decisions aren't always safe ones - meaning, risk, and timing often collide





I wish we had started sooner

- A common reflection from families
- Hospice is often introduced very late
- Earlier support allows time to learn, adjust, and prepare
- Even a few months can make a meaningful difference



Choosing hospice: More options than families realize

- Families often don't realize they have a choice
- Hospice providers can be compared and “interviewed”
- Early conversations help build trust and clarity
- First impressions shape the caregiving experience



Asking the right questions

- The questions we ask shape the conversation
- Families often don't know what to ask
- Specific questions create clarity
- Follow-up is where real questions emerge



Building confidence through teaching and support

- **Caregiving Is Learned—Not Assumed**
 - Most skills are learned in real time
 - Caregivers need hands-on teaching and practice
 - Access to support builds confidence
 - Many don't know what's available—until they're shown

Life continued—at home

This is what all that effort made possible



Where did my living room go?



YAY! Who doesn't like a picture of diapers in a waste can?!



- Supplies take up more space than expected
- Daily care creates ongoing waste
- Small adjustments can make a big difference
- Practical tips can reduce stress for caregivers





When “simple instructions” aren’t so simple

- Medication disposal can be confusing
- Instructions may not match real-life situations
- Caregivers worry about doing something wrong
- Clear guidance and follow-up matter



When support is inconsistent

- Not all support is equal
- Small disruptions create big stress
- Confidence depends on consistency
- Systems matter—not just individuals

The final hours: Care can still go well

- Time, space, and support matter
- Small choices create meaningful moments
- Care continues after death
- Families remember how this part feels





Care continues: Bereavement support matters

- Grief is not linear or predictable
- Support after death is just as important
- Check-ins provide connection—even when unanswered
- Care doesn't end with the patient



With gratitude

