



Your Company

Family Caregiver Resources

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Suppose they don't get better...



Are frequent visits to the ER a significant part of the past six to twelve months? Does your loved one seem more fatigued? Not eating? Perhaps withdrawn?

Many of these are hallmarks of a serious illness that may yet be overcome. But it's reasonable to recognize that maybe your relative isn't going to beat their condition. It happens to all of us. None of us "gets out of here

alive." Still, it's hard to grasp the thought that your loved one may be at that juncture.

While each of us has our own journey, there are signs one is entering those last chapters. The medical term is "frailty syndrome." Here are some indications of frailty:

- Frequent hospitalizations or trips to the ER
- Frequent infections
- Reduced appetite, weight loss
- Sleeping more, especially during the day
- Trouble with balance (falls), walking, and getting around
- Assistance required for bathing, dressing, eating, or toileting
- Withdrawing from activities and social gatherings
- Nostalgic reflection on the past, life review
- Mental fuzziness or confusion

If you recognize some of these signs, it doesn't mean your loved one is at death's door. To gain perspective, consider asking the doctor, "Would you be surprised if [patient name] were to pass away in the next year?" Difficult as the answer may be, it also offers opportunities for choices about medical care and about how to spend one's last months.

It's wisest to follow your loved one's lead and let them determine how much they feel like eating and how active and out in the world they wish to be. Whether they want to pursue aggressive treatments. Or maybe the time has come to focus on quality of life—what makes life enjoyable and worth living—rather than quantity. At this stage it's quite common to decide no more hospital visits. No more chemo. To stop fighting the inevitable and let nature take its course, with support so their passing is as comfortable and pain free as possible.

Whatever they decide, your job as family members is to support their choice so they get to live these last chapters as much in their own style as possible.



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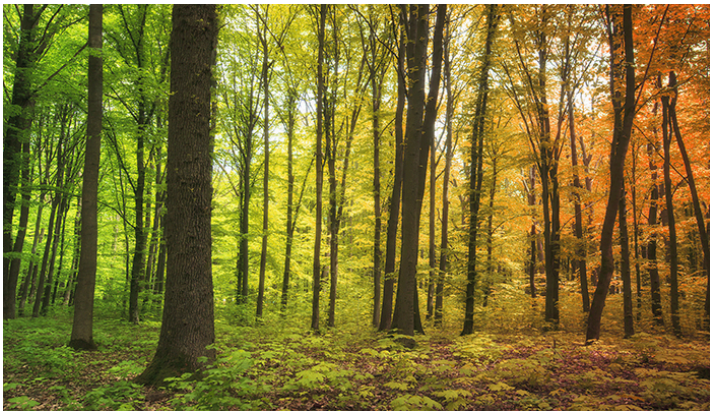
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Transitioning from curative care



At some point, the burdens of treatment may become just too much. Your relative may wish instead to enjoy the time they have left—months or weeks—without futile procedures. To prioritize peace and comfort.

Imagine time and energy to visit with those they love. The opportunity to eat what they want—ice cream, anyone? Or to simplify their meds—no more cholesterol pills. No more side effects.

Supporting your loved one's quality of life can be profoundly rewarding. Both you and your relative may find it emotionally liberating to let go of complexity. Instead of spending energy on unproductive cures, you can create fond memories.

If this sounds appealing, you don't have to go it alone. Transitioning from curative care does not mean no care at all. Hospice can provide your loved one with many different types of support. And the services are paid for completely by Medicare and Medicaid.

- Weekly visits from a nurse to help manage pain and other difficult symptoms
- Equipment needed for comfort, such as a hospital bed
- Bathing and grooming several times a week by a nurse's aide
- A social worker or chaplain to support emotional or spiritual needs
- All the medications your family member needs to stay comfortable (pain, trouble breathing, etc.)
- Instead of 911 calls and grueling trips to the ER, you can call hospice—anytime, 24/7. A nurse can provide guidance and have any needed medications or supplies delivered. Hospice care won't stop the inevitable, but it can make for a softer landing.

If this sounds appealing, talk to the doctor about your desire for these services.

Writing the last chapter

If your loved one has health challenges, they may be feeling a loss of control. Add to that a terminal diagnosis and a sense of doom may prevail.

But acknowledgment that life is coming to a close does not have to mean one waits glumly for the end. Following are some of the many ways hospice patients have chosen to take action and purposefully write their own "last chapter." Perhaps one of them might appeal to your loved one:

- **Write or record a life review.** Somewhere between a memoir and "lessons learned," in a life review your relative can share pivotal moments and why they were important. Take dictation for typing later. Or go to StoryCorps.org for an app that helps families video-interview relatives.
- **Finish a cherished project.** Perhaps it's a quilt that is not completed. Maybe it's a piece of furniture still unfinished in the shop. Or perhaps your loved one would enjoy a show-like exhibition of their artwork. Is there a way to publicly acknowledge their creativity?
- **Reconnect with estranged relatives or friends.** Asking and bestowing forgiveness is a deeply meaningful activity. Old grudges usually melt away in the context of limited time.
- **Write cards to family members.** One way to be present even after death is to write cards or letters to be given at particular life passages.
- **Have a celebration of life.** Perhaps your relative is of the temperament to invite friends to gather and share stories *before* their passing rather than after.
- **Leave a legacy to help others.** It doesn't have to be anything grand like a scholarship. It can be as simple as books for a library, or sports gear to a young team. Perhaps donate organs for transplant.
- **Actively enjoy the simple pleasures.** If ever there was a time to slow down and smell the roses, this is it. Many find deep contentment in the gift of each day.

Contact us at 707.477.0700



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