

Helping Care Go Well: A Caregiver's Role in the Hospice Experience - HANDOUT

Meg McCauley, Director of Association Management and IT Manager, OHPCA & WSHPCO

Google AI Search Question: "In the US, what caregivers of family members in hospice wished their care team would have told them?"

Item 1: In the United States, research on family caregivers in home hospice reveals that many feel ill-prepared for the physical and emotional realities of end-of-life care. While many appreciate the support provided, approximately half of hospice family caregivers report unmet communication and information needs.

- [Home Hospice Caregivers' Perceived Information Needs - PMC](#)
- [Close But Not Close Enough: How Distance Caregiving is Associated With Hospice Family Caregiver Hospice Communication Experiences - PMC](#)
- [Distance Caregivers Struggle With Communication - Penn LDI](#)

Item 2: Commonly cited areas where caregivers wished for more guidance from their care teams include:

Clinical and End-of-Life Expectations

The Dying Process: Caregivers often want more detailed information on signs of impending death and the specific symptoms to expect as their loved one's condition declines.

- [Home Hospice Caregivers' Perceived Information Needs - PMC](#)
- [How hospice staff members prepare family caregivers for the patient's final days of life: An exploratory study - PMC](#)

Symptom Management: Many report feeling unprepared to manage distressing symptoms like pain, delirium, and difficulty swallowing, which can lead to feelings of fear and helplessness.

- [Associations between hospice care and "scary" family caregiver experiences - PMC](#)
- [Close But Not Close Enough: How Distance Caregiving is Associated With Hospice Family Caregiver Hospice Communication Experiences - PMC](#)

Life Expectancy: Only about one-fourth of family caregivers report being informed of the patient's actual life expectancy.

- [Challenges and facilitators of hospice decision-making: a retrospective review of family caregivers of home hospice patients in a rural US–Mexico border region—a qualitative study - PMC](#)

In-Home Emergencies: Caregivers frequently desire clearer instructions on what to do during a crisis or emergency at home.

- [National Institutes of Health \(.gov\)](#)

Item 3: Logistics and Support Services

Hospice Benefits and Services: There is often confusion about the full scope of services, such as the duration of care, available medical supplies (e.g., hospital beds or "menus" of supplies), and how hospice affects access to other treatments.

- [Home Hospice Caregivers' Perceived Information Needs - PMC](#)
- [Home Hospice Caregivers' Perceived Information Needs - PMC](#)

Timely Referral: A recurring "biggest lament" from families is that they wish they had been told about and started hospice services much sooner rather than waiting for the final days of life.

Practical Training: Many caregivers wished they had received more hands-on training for daily tasks like feeding, bathing, and safely moving the patient.

- [What experts wish more people knew about hospice and other end-of-life care | Michigan Medicine](#)
- [Family Caregivers and Their Role in Hospice Care](#)

Item 4: Emotional and Post-Death Support

Bereavement Preparation: Caregivers often feel hospice teams focus heavily on the patient's immediate needs while neglecting to prepare the family for the emotional aftermath and life after the loved one passes.

- [Missed Opportunity: Hospice Care and the Family - PMC](#)
- ['Regrets become a lasting source of pain': A qualitative study on family caregivers' experiences leading up to a relative's death - PMC](#)

After-Death Procedures: There is often uncertainty regarding the immediate steps to take once a death occurs, including funeral planning and returning medical equipment.

- [Home Hospice Caregivers' Perceived Information Needs - PMC](#)

Item 5: Barriers to Communication

Effective communication is often hampered by:

- **Distance:** Caregivers who do not live with the patient report lower satisfaction with communication.
- **Health Literacy:** Differences in understanding medical terminology can make it difficult for families to navigate the care system.
- **Lack of a Point Person:** Frequent shift changes and multiple team members can lead to inconsistent messaging or gaps in information.
 - [Close But Not Close Enough: How Distance Caregiving is Associated With Hospice Family Caregiver Hospice Communication Experiences - PMC](#)
 - [Distance Caregivers Struggle With Communication - Penn LDI](#)
 - [Close but Not Close Enough: How Distance Caregiving is Associated with Hospice Family Caregiver Hospice Communication Experiences: Health Communication: Vol 39, No 3](#)
 - [Family caregiver participation in hospice interdisciplinary team meetings: How does it affect the nature and content of communication? - PMC](#)