



Transform the End-of-Life Care Experience

Four strategies to support hospice patients and their families

PUBLISHED BY

Post-Acute Care Collaborative

advisory.com/pacc

postacute@advisory.com

Executive summary

End-of-life can be one of the most challenging and significant times for patients and families, as well as for the staff who care for them. As such, ensuring a positive care experience at this time requires a unique approach—one that puts patient needs and preferences first, supports family members, and helps staff manage the emotional stress that comes with the job.

This report will equip you with four strategies that meet these goals, helping you to transform the end-of-life experience.

Table of Contents

Introduction: The end-of-life care difference	3
Four strategies to transform the end-of-life care experience	7
Integrate palliative care early to ease the transition to hospice	8
Empower patients to express their care preferences	10
Proactively identify after-hours needs	12
Equip staff to manage emotionally challenging situations	14

▶ The end-of-life care difference

A unique opportunity to make a long-lasting impact

End-of-life care focuses on family support and individualized preferences

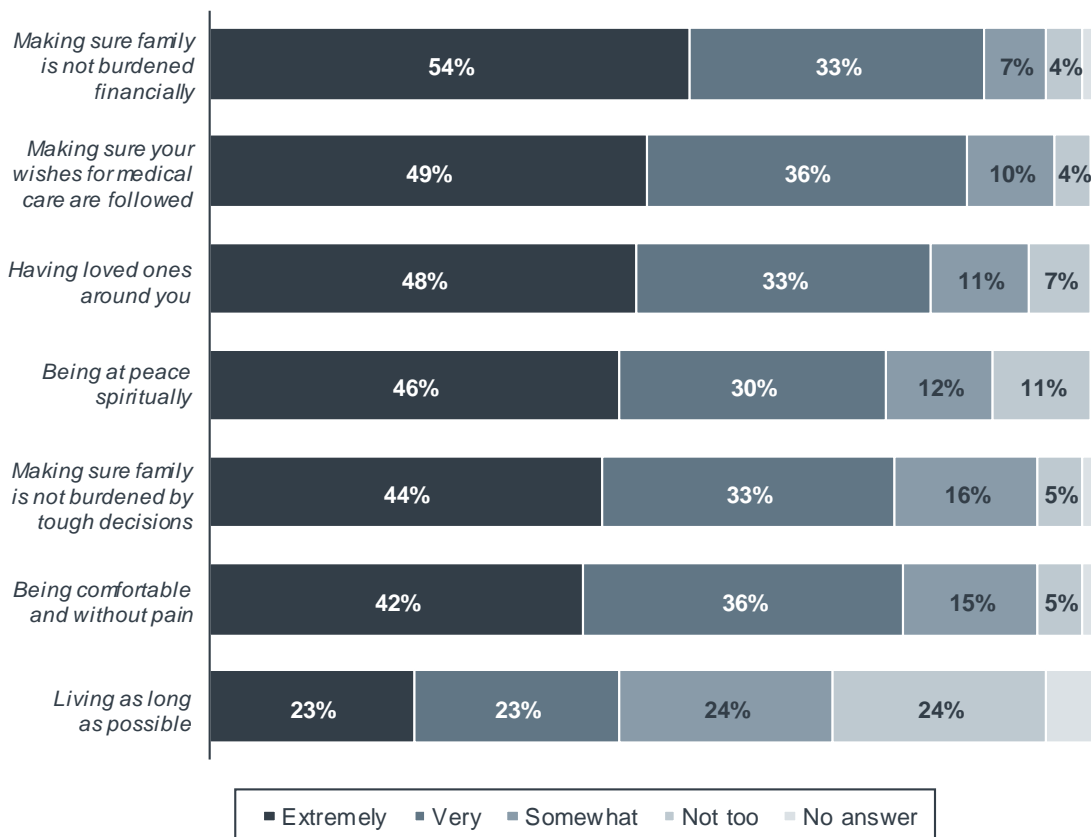
End-of-life care is a unique opportunity for providers to improve the lives of patients and families at one of their most vulnerable times. Unlike other types of care, the goal at end-of-life is not to cure—it's to make sure that patients are comfortable, family members are supported, and patients can live out their lives in whatever ways they find most valuable.

A joint survey of adults in the U.S. by the Kaiser Family Foundation and *The Economist* found that individual preferences at end-of-life do indeed align with these goals. During their last several months, patients care most about ensuring that their wishes are fulfilled and that their families and loved ones are supported, and least about living as long as possible.

Relative importance at end-of-life

Kaiser Family Foundation/The Economist 2016 survey

n=1,006



These results speak to the need to pursue a different approach to improving the end-of-life care experience.

Four strategies to transform the end-of-life care experience

How to manage patient, family, and provider needs

To improve the end-of-life care experience, providers across the continuum need to ensure that patients and families know their options for end-of-life care and have support for their unique needs and preferences once they begin services. A comprehensive approach requires that not only patients, but their family members and staff, are supported throughout the process.

Four strategies to transform the end-of-life care experience



Integrate palliative care early to ease the transition to hospice

Early referrals to hospice have been shown to improve both patient and family satisfaction with end-of-life care. Smooth the transition by integrating palliative services into care plans early on, so patients and families are prepared when it's time to transition.



Empower patients to express their care preferences

One of the primary goals of end-of-life care is to help patients live out their lives the way they want to—and even throughout their time with hospice, these preferences often shift. To meet these changing goals, providers must equip patients with a way to express their needs and adapt quickly to them.





Proactively identify after-hours needs

Because the majority of hospice care is provided in home-based settings, the care team can't always spend extended time with patients or visit on short notice. As such, providers must predict and manage after-hours needs so patients and families feel supported even when staff aren't present.



Equip staff to manage emotionally challenging situations

Hospice staff face difficult and emotional tasks every day. And they can sometimes struggle to deliver the best experience possible because of resulting burnout or ethical dilemmas. Providers must implement support systems for their staff so they can put their best foot forward for patients and families every day.



▶ Four strategies to transform the end-of-life care experience

- Integrate palliative care early to ease the transition to hospice
- Empower patients to express their care preferences
- Proactively identify after-hours needs
- Equip staff to manage emotionally challenging situations

Most patients do not receive the full benefit of hospice

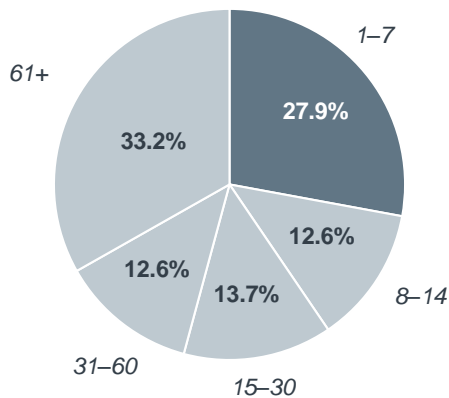
Late referrals to hospice care limit effectiveness of service

Hospice care provides diverse clinical and support services to patients and their families. Although the Medicare hospice benefit covers terminally ill patients who have six months or less to live, approximately **28% of patients are not referred to hospice until the last week of life**. As a result, patients and their loved ones miss out on crucial benefits available to them.

Total days of care on hospice benefit

2016 calendar year

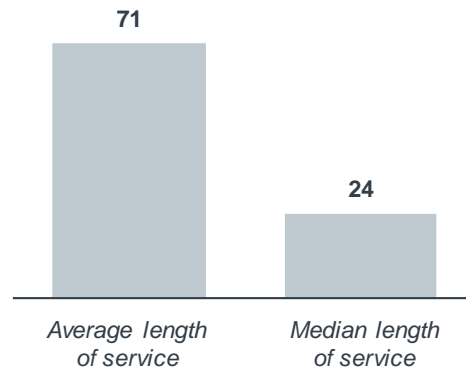
n=101 million days



Average and median length of service

2016 calendar year

n=101 million days



Shorter length of hospice service is associated with reduced quality and satisfaction

Numerous studies have indicated that hospice stays of 30 days or longer lead to better quality and satisfaction outcomes. When compared with a control group of patients near end-of-life who did not elect hospice services, or who received services for shorter periods of time, patients and families with over 30 days of hospice care reported:



Fewer unidentified or unmet needs



Less pain and discomfort



Higher satisfaction scores



More individualized goals and preferences met

Source: Facts and Figures: Hospice Care in America, National Hospice and Palliative Care Organization, 2017, accessed at https://www.nhpc.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf; Family Perspectives on Hospice Care Experiences of Patients with Cancer, *Journal of Clinical Oncology*, 35, no. 4 (February 1 2017) 432-439; Post-Acute Care Collaborative interviews and analysis.

Use palliative care to ease the hospice transition

Hospice of Northwest Ohio's partnership model has improved referral timeliness

One of the most predominant factors driving these late hospice referrals is discomfort around the idea of end-of-life care. Many physicians are reluctant to “give up” on their patients and therefore don't want to submit a hospice referral. Similarly, patients and families are hesitant to commit to hospice, knowing that it means they are forfeiting the opportunity to receive curative care.



CASE
EXAMPLE

Hospice of Northwest Ohio

Inpatient and community-based hospice provider • Perrysburg, OH

Hospice of Northwest Ohio has partnered with a local cancer center to normalize the transition to hospice by introducing palliative services to patient care plans early on.

Palliative care is embedded into the treatment model



Palliative care liaison, staffed by Hospice of Northwest Ohio's palliative program, Sincera™, joins care team at partner cancer center



Care team model eases stress, increases early referrals



At admission

Palliative care, through Sincera, is introduced as a natural part of treatment. All patients are automatically enrolled.



Throughout time at center

Patients and families grow familiar with palliative care and Hospice of Northwest Ohio. Patient receives more services from the liaison as illness progresses.



At hospice transition

Patients feel ready to move on to hospice care earlier than those who do not receive palliative care.

Benefits

- ✓ Built-in access to palliative support
- ✓ Earlier end-of-life decision-making
- ✓ Less stressful hospice transition
- ✓ More time with hospice services

Additional resources on improving access to hospice

Access our existing research library to learn more ways to help patients choose hospice earlier in their care trajectories. All resources are available on [advisory.com](https://www.advisory.com).

- [A New Strategy to Promote Hospice Access in SNE](#)
- [Expanding the Scope of End-of-Life Care](#)
- [Resources for End-of-Life Decision-Making](#)

Patient preference booklet captures changing goals

Booklet process helps staff identify what is most important to patients

One of the primary goals of end-of-life care is to ensure patients spend time in a way that they value. As such, providers need to carefully assess what is most important to patients at admission and determine how to help them reach these goals. Doing so can provide several benefits:

- Patients and families feel welcome and supported
- Providers can develop more targeted care plans
- Staff can proactively identify unrealistic patient and family expectations

As needs and preferences change over time, staff should continue to monitor these goals and adjust their care plans as necessary.



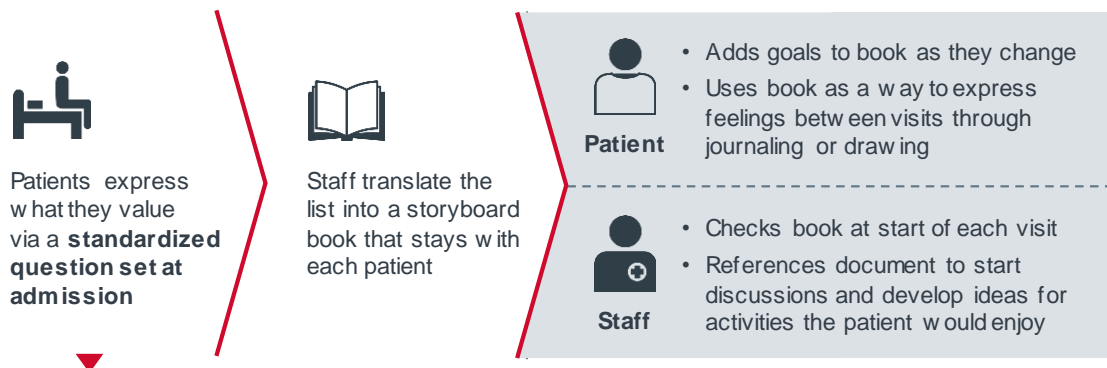
CASE
EXAMPLE

Jamesway Health¹

Network of community-based hospice, palliative, and home health care services • Southern U.S.

Jamesway Health, a pseudonymed organization, uses a patient preference storybook to identify unique preferences throughout a patient's time receiving hospice services. The booklet captures a standardized set of questions asked at admission, as well as patients' thoughts and feelings between visits.

Patient preference booklet process



Questions asked at admission

- What activities that you are currently able to do bring you the most joy?
- What is something you used to enjoy doing but are no longer able to?
- Who is it most important that you stay in touch with at this time?

This process has helped staff identify unique ways to improve each patient's experience. It's also given patients and families an outlet through which to express their goals and feelings. The next page shows how you could design a booklet of your own.

1) Pseudonym.

Sample patient preference book pages

Page 1

Name: _____

Age: _____

Hometown: _____

Activities I enjoy:

Things I want to accomplish:

Friends and family members who are important to me:

Page 1 summarizes basic information about the patient and what is important to her

Page 2

Pages 2+ give the patient and family space to journal, draw, and share additional information

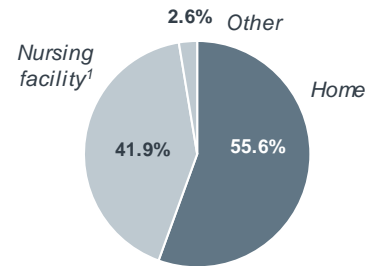
Thursday phone call system identifies high-need patients

Volunteers at Hospice of Northwest Ohio check on patients prior to the weekend

Over 97% of hospice care days are provided either in private residences or in nursing facilities—meaning that the majority of a patient’s time on hospice is spent outside the direct care of the hospice team. This creates another challenge for providers: ensuring that patients and families are safe and comfortable, even if they see the patient and his or her family only a few times a week. Given that many hospice organizations have limited staff available during the evenings or on weekends, it’s important to determine how to manage patient and family needs over this time.

Location of care

By percentage of days of care, 2016



CASE
EXAMPLE

Hospice of Northwest Ohio

Inpatient and community-based hospice provider • Perrysburg, OH

Hospice of Northwest Ohio addresses this challenge by enlisting a volunteer to reach out to high-need patients each Thursday morning. This helps patients and families feel more confident about the services they are receiving, and also reduces the need for after-hours visits.



A volunteer meets with team leaders each week to discuss which patients would benefit from a check-in before the weekend.

Team leads flag patients who:

- Won't receive a visit before the weekend
- Are new to hospice or have had recent symptoms
- Have complex needs, such as wounds or parenteral feedings



Volunteers call the main contact number for each of these patients and reads a standardized set of questions. If the volunteer identifies the need for a visit, a team member will adjust their schedule to see the patient that Thursday or Friday.

See the form each volunteer uses on the next page.



Call system proactively identifies after-hours needs

838 calls
made in CY 2018



25 Patients indicated discomfort and needed an additional visit

62 Patients had other needs that hospice could address

1) Includes nursing, skilled nursing, and assisted-living facilities.

Source: Hospice of Northwest Ohio, Perrysburg, OH; Facts and Figures: Hospice Care in America, 2017 report, National Hospice and Palliative Care Organization, https://www.nhpc.org/sites/default/files/public/Statistics_Research2017_Facts_Figures.pdf; Post-Acute Care Collaborative interviews and analysis.

Hospice of Northwest Ohio's check-in form

Hospice of Northwest Ohio Weekend Check-In Volunteer Program Call Script and Tracking Log

Patient Name _____ Patient's phone # _____

Spoke To _____ Date _____ Time _____

Relationship to Patient _____ No Answer _____ Left Msg _____

1. Hello, my name is _____. I'm a **volunteer** with Hospice of Northwest Ohio. I'm calling **on behalf of your nurse** to check on you (or patient's name). **The hospice team** wants to make sure you have everything you need before the upcoming weekend. May I ask to whom I am speaking? (Speak to either the patient or primary caregiver, if possible.)
2. We want to make sure you **feel confident** that you have all the medications and supplies that you will need to get you through the weekend? (Or, to take care of your loved one over the weekend?) Do you feel confident? **YES or NO**

(If no) Please tell me what you need and we'll let your team know so that it can be taken care of before Friday evening. (If patient needs meds or supplies ask: Has your nurse ordered those for you this week? If yes, when?)

Document response:

3. Are you (or the patient) resting comfortably? **YES or NO**
4. Is there anything else that Hospice of Northwest Ohio provides that you are in need of at this time? **YES or NO**

Document response:

5. Are you satisfied with the services hospice is providing including contracted services such as equipment, supplies and pharmacy? **YES or NO**
6. I'll get this information to your Hospice of Northwest Ohio team. If you find you need anything, please don't hesitate to call us. We are always available for you.

Volunteer Name (PRINT) _____

Notified Team Leader/Team Member **YES or NO**

Team Leader/Member Name _____

Use staff-run committees to support frontline team members

Ohio's Hospice of Dayton staff committees reduce burnout, improve experience

The ability to connect with and feel cared for by staff is one of the defining pieces of many people's experience with hospice. But throughout the time staff work in end-of-life care, they will face countless challenging emotional and ethical situations that can contribute to burnout and reduce their ability to provide a positive experience to patients and families.









CASE
EXAMPLE

Ohio's Hospice of Dayton

Inpatient and community-based hospice provider • Dayton, OH

Ohio's Hospice of Dayton operates two different committees to help staff manage challenging patient scenarios both on a personal and a professional level.

	Betty Schmolle Care Connections	Ethics Committee
What it is	A meeting for frontline staff to debrief about difficult case scenarios and express any personal impact they may have felt from bearing witness to a challenging situation	A meeting to help staff who face an ethical dilemma in the workplace determine how best to manage the situation with the patient and family members
Goal	To prevent burnout by giving staff an opportunity to be honest about their discomfort; to equip staff to put their "best foot forward" for patients and families	To help staff determine next steps when they're unsure how to help a patient or family member
Attendees	Any patient-facing staff member is welcome to join, but attendance is not mandatory	A physician, nurse, social worker, chaplain, and bereavement counselor representative; a bioethics professor from the local school of medicine
Meetings	<ul style="list-style-type: none"> • Standing meetings are held monthly • Staff have the opportunity to call for individual or group debriefs as needed 	<ul style="list-style-type: none"> • Quarterly two-hour meetings • Subcommittees are called as needed
Example scenario	 Heart failure patient expresses wish for LVAD to be discontinued  Staff feel uncomfortable about the patient's request to go off of support  Staff are honest about their discomfort at committee meeting; learn tactics for managing stress	 Husband and wife live next door in inpatient facility; wife suddenly dies  Children ask staff not to tell husband, but don't visit facility for several weeks  Staff discuss in ethics committee, determine it is best for the patient if staff tell him about his wife instead of waiting for family to do so

See a sample ethics committee request form on the next page

Ohio's Hospice ethics committee consultation request

Ohio's Hospice Ethics Committee Consultation Request

Goals of Ethics Consultation:

- Promote an ethical resolution of the case at hand
- Establish comfortable and respectful communication
- Help those involved work through ethical uncertainties
- Assist the Ethics Committee in recognizing patterns that need attention
- Does NOT make decisions for stakeholders NOR give legal advice
- Champions respectful discourse among all stakeholders (ethical dilemmas are often made worse when there is poor or disrespectful communications)

Definition of Ethics Consultation:

- Services provided by a subcommittee (often those who are able to gather quickly) in response to **questions** by patients, families, surrogates, healthcare professionals, or other involved parties who seek to **resolve uncertainty** or **conflict regarding value-laden concerns** that emerge in healthcare. (Hester D and Schonfeld T, *Guidance for Healthcare Ethics Committees*, Cambridge University Press, 2012)

Stakeholders: Who are the involved parties?

Situation summary:

Value conflicts/primary ethical question:

Are all stakeholders aware that a consult is being requested?

Patient preferences, current/anticipated quality of life:

Other contextual information (legal constraints/issues):

Post-Acute Care Collaborative

Project Director

Carolyn Buys

buysc@advisory.com

202-266-6591

Practice Manager

Monica Westhead

Managing Director

Jared Landis

Design Consultant

Kim Dixon

LEGAL CAVEAT

Advisory Board has made efforts to verify the accuracy of the information it provides to members. This report relies on data obtained from many sources, however, and Advisory Board cannot guarantee the accuracy of the information provided or any analysis based thereon. In addition, Advisory Board is not in the business of giving legal, medical, accounting, or other professional advice, and its reports should not be construed as professional advice. In particular, members should not rely on any legal commentary in this report as a basis for action, or assume that any tactics described herein would be permitted by applicable law or appropriate for a given member's situation. Members are advised to consult with appropriate professionals concerning legal, medical, tax, or accounting issues, before implementing any of these tactics. Neither Advisory Board nor its officers, directors, trustees, employees, and agents shall be liable for any claims, liabilities, or expenses relating to (a) any errors or omissions in this report, whether caused by Advisory Board or any of its employees or agents, or sources or other third parties, (b) any recommendation or graded ranking by Advisory Board, or (c) failure of member and its employees and agents to abide by the terms set forth herein.

Advisory Board and the "A" logo are registered trademarks of The Advisory Board Company in the United States and other countries. Members are not permitted to use these trademarks, or any other trademark, product name, service name, trade name, and logo of Advisory Board without prior written consent of Advisory Board. All other trademarks, product names, service names, trade names, and logos used within these pages are the property of their respective holders. Use of other company trademarks, product names, service names, trade names, and logos or images of the same does not necessarily constitute (a) an endorsement by such company of Advisory Board and its products and services, or (b) an endorsement of the company or its products or services by Advisory Board. Advisory Board is not affiliated with any such company.

IMPORTANT: Please read the following.

Advisory Board has prepared this report for the exclusive use of its members. Each member acknowledges and agrees that this report and the information contained herein (collectively, the "Report") are confidential and proprietary to Advisory Board. By accepting delivery of this Report, each member agrees to abide by the terms as stated herein, including the following:

1. Advisory Board owns all right, title, and interest in and to this Report. Except as stated herein, no right, license, permission, or interest of any kind in this Report is intended to be given, transferred to, or acquired by a member. Each member is authorized to use this Report only to the extent expressly authorized herein.
2. Each member shall not sell, license, republish, or post online or otherwise this Report, in part or in whole. Each member shall not disseminate or permit the use of, and shall take reasonable precautions to prevent such dissemination or use of, this Report by (a) any of its employees and agents (except as stated below), or (b) any third party.
3. Each member may make this Report available solely to those of its employees and agents who (a) are registered for the workshop or membership program of which this Report is a part, (b) require access to this Report in order to learn from the information described herein, and (c) agree not to disclose this Report to other employees or agents or any third party. Each member shall use, and shall ensure that its employees and agents use, this Report for its internal use only. Each member may make a limited number of copies, solely as adequate for use by its employees and agents in accordance with the terms herein.
4. Each member shall not remove from this Report any confidential markings, copyright notices, and/or other similar indicia herein.
5. Each member is responsible for any breach of its obligations as stated herein by any of its employees or agents.
6. If a member is unwilling to abide by any of the foregoing obligations, then such member shall promptly return this Report and all copies thereof to Advisory Board.