Hospice & Palliative Care

One funeral director stresses the importance of sharing your final wishes with your family.

Learn why Aging Life Care Professionals are good options for families caring for those with ongoing health issues.

Discover what experts are saying about the importance of transparency and telemedicine.

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HOSPICE PHARMACY. INNOVATION. PARTNERSHIP.
Don’t Let End-of-Life Care Decisions Take You by Surprise

While facing our own mortality can be difficult, being as informed as possible now about end-of-life care is important for you and your loved ones.

Every day we are confronted with a countless number of choices. All too frequently, many challenging yet important decisions are set aside for the future. Unfortunately, one of the most significant decisions of one’s life is too often put off, or made for us by others, leaving us little or no opportunity to make our own choice based on our personal priorities and wishes.

Hospice and palliative care professionals see this play out on a daily basis — families in the corridor of a hospital or emergency room trying to figure out what their loved one would have wanted at the end of their life. The outcome is rarely what the individual at the center of care would have chosen.

Facing your mortality
It’s safe to say that most people would probably not choose to face their own mortality. I get it; I don’t choose to face mine. Yet the choice of having a serious or life-limiting illness is seldom in our power. While hard to face, the best time to learn about palliative care and hospice is long before you need it.

Far too many people receive hospice care for only a handful of days at the end of life. When individuals forgo hospice care, they may suffer needlessly while struggling with pain from symptoms of a serious illness that could be alleviated by palliative care services. Delaying or not choosing to access palliative care or hospice care can deprive you and your family from the full clinical, emotional and spiritual benefits these services offer.

Having the talk
Patients say they are waiting for their doctors to recommend hospice; physicians say they are waiting for patients to ask whether hospice care would be a good option. Perhaps it seems less “real” to not think about it. However, the choice of how we wish to live out our lives should only be ours.

As Americans, we pride ourselves on being well-informed consumers. In planning a vacation or buying a new car, we tend to explore all options. Why don’t we put the same effort into planning for our end-of-life care needs?

“The best time to learn about palliative care and hospice is long before you need it.”

Moving toward understanding
If you or a loved one are facing a serious or life-limiting illness and need help in understanding your options, think of your local hospice or palliative care provider as an important resource for information. Don’t wait until you’re facing a medical crisis to learn about your options for hospice and palliative care.

Most of us would prefer the end of our lives to be a peaceful transition. It’s possible. We just need to make that choice when the time comes.
Getting Holistic, Client-Centered Help When Caring for Aging Adults

Aging Life Care Professionals engage with clients and their families to help make difficult decisions, suggest possible options and assist with end-of-life care transitions.

Aging Life Care™, also known as geriatric care management, is a holistic, client-centered approach to caring for older adults or others facing ongoing health challenges.

Members of the Aging Life Care Association*, called Aging Life Care Professionals (ALCPs) partner with clients, families and other providers to help clients make the best decisions and find personalized solutions. Respecting the client’s values, preferences and resources are the guiding practice. ALCPs are practitioners with extensive knowledge about costs, quality and availability of resources in their communities.

Because ALCPs adhere to a strict code of ethics and standards of practice and are generally not affiliated with, or representatives of, any health care entities, they can be completely objective in recommendations while providing a safe place for clients and their loved ones to express their concerns and fears.

ALCPs are engaged with clients for the long haul and are uniquely positioned to engage in the difficult discussions about health care and end-of-life goals. ALCPs often are the ones to suggest hospice to clients and assist with the transition to palliative care or hospice care when appropriate.

**What they do**

The following case example illustrates how ALCPs, hospice teams and clients work together: "When Joe’s son hired me as his father’s Aging Life Care Manager six years ago, it was to provide a weekly check-in. They didn’t know then that they would journey through hospice care, but I was able to help them navigate multiple hospice admittances while relieving some of the burden.

“On the first admittance, I served as the bridge between Joe, his family, and the hospice staff. I helped with solving medication management and communication challenges, and with coordinating Joe’s changing levels of care. I had the difficult conversations with Joe concerning end of life planning and made sure his choices would be honored. Once it became clear that Joe’s health had stopped declining, I helped the family transition away from hospice care.

“When Joe was diagnosed with cancer at 97, we made the decision to re-engage hospice care. I helped the family customize his care plan and coordinated his eventual move to an inpatient unit. Because I handled the day-to-day realities of hospice and end-of-life care, Joe, his father and family were able to focus on their remaining time together.

ALCPs are able to assist clients and their families at any stage in the aging process, from the initial assessment to final decisions.

Deborah Liss Fins LICSW, ACSW, CMC and Lisa Laney, MSW, CMC

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**Palliative care as an option**

He urges patients who’ve received a tough diagnosis to contact a palliative care doctor. When patients often reject the idea as embracing death, he says the opposite is true. “Palliative care can help you live better and longer, because in expertly treating pain and making sure patients are eating and sleeping better and getting around more, plus addressing unspoken fears and concerns for their family, people simply do better.”

He also urges everyone to choose a representative who can speak for them should they become incapacitated, and says there are four things everyone should say to their loved ones before they die. “Please forgive me, I forgive you, thank you and I love you. For many of us, that’s just stating the obvious, but it has so much value.”

Liane Bonin Starr
How Talking About Death Can Enrich Life

A funeral director shares his biggest lesson: When it comes to remembering the deceased, it can be most fulfilling if you spend some time uncovering your loved ones' life history.

Death is something we don't like to talk about in our culture, for understandable reasons. For many, it can seem like an overwhelming experience, full of emotion and the stressors of legal obligations. But if there's one thing a funeral director can tell you, it's that by putting off thinking about it, you miss out on opportunities to make a memorial into a far more enriching experience.

Remember to celebrate life
"As a funeral director, when we sit down with families to make arrangements, we find that they haven't really discussed much ahead of time in terms of how they want to memorialize their loved one," explains Jack Mitchell, president-elect of the Funeral and Memorial Information Council.

"Funerals aren't about the deceased; they are about the living."

"You've known your parents your whole life so you might think you know everything about them," Mitchell explains. "Then we make arrangements and we can see this family that isn't thinking about the nuances of mom or dad or how to incorporate them into some kind of tribute."

It's an emotionally trying time for families. We tend to associate funerals so much with doom and gloom; we may forget the joy that can come from a beautiful celebration of a person's life. "You can have a totally different kind of send-off," says Mitchell. "If you have conversations about memorable experiences in life, you may learn about things that you never knew, things that you're going to remember when the time comes to think about a final tribute."

Encouraging families to open up
Mitchell's organization is made up of funeral professionals who've all witnessed families who missed the opportunity to turn their loved one's memorial into a true celebration of their life, and they're providing materials in their Talk of a Lifetime campaign to spread the word and offer tools for families to have these conversations.

"You can have a community event and offer conversation cards with questions like, 'What person influenced you most in life?' or, 'What was the most trouble you ever got into as a child? It's for people of any age.'"

This isn't just a practical concern — it's an opportunity to change our culture, to have the right kinds of conversations about death, and thus about life as well.

"We're trying to get the word out across the country," says Mitchell. "By encouraging people to talk about how they want to memorialize a loved one, we can recognize the importance of the people whose lives they touched. Funerals aren't about the deceased, they are about the living."

Dash Lunde

Dr. Ira Byock leads Providence St. Joseph Health's Institute for Human Caring.

The Providence St. Joseph Health Institute for Human Caring, led by Dr. Ira Byock, is guiding a transformation of health services called "whole person care." Patients are more involved in decisions about their care. Families receive help supporting loved ones who are seriously ill. And caregivers receive help coping with the strains of caregiving. At Providence St. Joseph Health, our goal is to offer clinicians the resources, training and support they need to have more meaningful conversations with patients and families in developing the best approach to care.

We're delivering the future of health—today.

Ira Byock M.D., FAAHPM
Founder and Chief Medical Officer
Providence St. Joseph Health Institute for Human Caring

High quality health care with compassion and integrity.
Remembering a Life Well-Lived: Honoring and Mourning Through Funerals and Services

Planning a funeral for loved ones to come together to grieve and celebrate the passing of an individual is a beautiful way to honor a lost life.

Our lives are full of special moments and wonderful memories. When a loved one dies, sharing those moments and memories through a tribute that beautifully memorializes a life lived provides the opportunity to reflect and remember.

“A funeral or memorial service provides a social support system for grieving family and friends.”

Honoring a loved one’s life after death recognizes the impact he or she had on the lives of others through family, work and community involvement. Through gathering to share stories and memories that helped define who our loved one was, we learn about the ways in which he or she shaped the lives of others and ensure they live on.

A social support system
For surviving family and friends, honoring a life also creates a bridge between the loved one’s death and the beginning of the grieving process. A funeral or memorial service provides a social support system for grieving family and friends, eases the transition to a new life after a loved one’s death, and reaffirms one’s relationship with the person who died. It also provides a time to say good-bye, surrounded by the comfort of others who are also grieving.

The average person makes funeral arrangements for a loved one only once or twice in their lifetime, so it’s natural to feel overwhelmed or perhaps have a fear of the unknown. The main role of a funeral director is to make this difficult time as easy as possible — from helping to create a meaningful funeral that beautifully reflects the life of your loved one to assisting with paperwork and beginning your journey through the grieving process.

Planning the perfect service
The National Funeral Directors Association ensures that their members operate their funeral homes under the highest principles in funeral service and are committed to serving families in their community. You can be confident your local NFDA member funeral home will serve your family with the utmost care, dignity and respect, and help plan a service that captures the essence of your loved one’s life.

National Funeral Directors Association

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How Telemedicine Is Changing the Way Patients and Providers Communicate

When using telemedicine technology that allows providers and patients to communicate quicker and easier, patients, caregivers and providers repor improved quality and efficiency of care.

The use of telecommunication technologies in patient care, also known as teledmedicine, offers a potential solution to improve access and quality of care, especially for those in rural settings. Teledmedicine has grown dramatically over the last decade among many specialties, with demonstrated improvements in chronic care management and promising trends in improving access to care in rural areas. A home-based palliative care telemedicine program utilizing video-conferencing demonstrated that patients receiving telemedicine had reduced hospitalizations and increased hospice utilization and length of stay compared to usual care.

In 2016, Four Seasons Compassion for Life in Western North Carolina initiated a pilot teledmedicine project as part of the Centers for Medicare & Medicaid Services Healthcare Innovation Award, utilizing a combined approach of remote patient monitoring (via the TapCloud application) and video conferencing.

Using TapCloud, the palliative care team monitors data as patients or caregivers, “check-in/tap-in” to inform providers of symptoms, concerns and well-being. Information is transmitted directly to a dashboard and to the team’s smartphones. When problems are identified, clinicians send secure push messages via the application to the patient/caregiver to attempt to remedy the situation. If unsuccessful, telephone calls and video-conferencing are used to further resolve the issue and, if needed, a home visit occurs.

By capturing real-time patient symptom data, TapCloud alerts providers to emerging patient health issues, which can be acted upon immediately, preventing unnecessary suffering and potential emergency room visits or hospitalizations.

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Emerging Discussions: Telehealth Excitement and Calling for More Hospice Pharmacy Pricing Transparency

As concerns about the price of prescription drugs sweep the nation, those within the hospice and palliative care industry discuss the increased difficulty of navigating pharmaceutical purchasing contracts and the opportunities that exist for patient care with the rise of innovative telehealth technologies.

Do you feel like telehealth could have a positive impact within palliative care?

Edo Banach: Yes, telehealth is beneficial for proactively managing and supporting seriously ill individuals and their families. For example, traditional telemonitoring can keep track of biometric data and identify trends that need further attention (e.g., increased weight gain, high blood pressure, elevated temperature). Telehealth also includes virtual and telephonic visits allowing individuals and their families to interact with the palliative care team on a more frequent scheduled basis or on an as needed basis.

Telehealth allows for timely intervention in the home. For example, some programs routinely call their patients every 7 to 14 days. The team member reviews symptom and medication management, addresses any questions or concerns, and determines whether any changes in the plan of care are needed. A team member in the home can also connect virtually with the primary care provider to determine if any adjustments to medication are necessary.

Drew Mihalyo: Absolutely! Many of our colleagues throughout the country are struggling to come up with a solution to make sense of what can be a complex business model to deliver. Palliative care organizations are really being asked to provide the highest quality of patient centered care under what remains a current fee-for-service reimbursement mechanism. It's different than how hospices are paid. Unless you're able to drive operational efficiency via time and expense saving technologies or innovations, it just doesn't work out as intended.

Telehealth and remote patient monitoring can pave the way for providers, care teams and pharmacists to rethink everything when it comes to caring for those with advanced disease illness.

In my opinion, patients residing in rural areas stand to benefit most from this technology. There was a great article released this past summer in the Journal of Pain and Symptom Management that evaluated the feasibility and acceptability of a telehealth program in a rural palliative care population in North Carolina. It's a spectacular read for anyone further interested in this topic.

Do pharmacy vendors provide enough transparency when it comes to purchasing options for hospices expected to pay for medication treatments related to patients’ terminal disease states?

Patrick White: I think transparency is clearly lacking. It is very concerning when I hear about episodes where commonly used medications at end-of-life are marked up as high as 10,000 percent over their real acquisition cost. These highly inflated generic drug costs have the potential to lead to patients not receiving optimal therapies that could help better relieve their symptoms. This process appears to be increasing among my hospice colleagues with vendors often chosen for niche service levels. My organization has had the benefit of working with a transparent pharmacy benefit manager who has been a great partner. However, as a chief medical officer these days you have to be a smart shopper and really dig through the details to obtain a pass-through purchasing model that keeps you from paying vendors “spread money” off the products dispensed, or you can incur massive fees that are hard buried in the notes. I feel like a forensic accountant at times and much prefer to pay a low administrative fee and not have to continually watch every medication. This is especially true as opiate supplies tighten—putting pressure on prices.

Mary Mihalyo: There are not sufficient levels of business transparency among all vendors serving the hospice industry today. We have worked tirelessly over the past decade to promote a fair playing field for hospices clients of ours or not with respect to achieving purchasing power equal to what non-hospice health care payers enjoy. We absolutely embrace, practice and promote real business transparency. The lack of transparency resides within relationships between hospices and either traditional Hospice Pharmacy Benefit Managers or large prescription mail order providers.

Hospices need to watch pricing spreads where they are charged one amount for a prescription, only to find out that the dispensing pharmacy was paid far less than what the hospice was charged. If you use a mail order pharmacy provider, things to look out for are penalties imposed for formulary non-adherence, rogue administrative fees, and other hidden costs buried within what can be very carefully crafted purchasing agreements.
When’s the last time you REALLY looked at all of your hospice pharmacy options?

Transparent and Pass-Through Pharmacy Benefit Management (PBM)

Mail Order Pharmacy

DME and Medical Supply Mgmt.

Easy Cost Reporting

Telemedicine Options

EMR Integrations

On-Demand Pharmacist Services (ODPS)

Hospice Tailored e-Prescribing

Inpatient Innovations™

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AVERAGE Rx SAVINGS ESTIMATES WHEN YOU SWITCH TO DELTA’S HOSPICE TAPER

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Maybe it’s time you take a closer look. You just might be surprised.

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